

INVESTIGATING SOCIAL SUPPORT IN THE BREAST CANCER CONTEXT

Prema Nirgude, BSc (Hons), MSc

Thesis submitted to the University of Nottingham for
the degree of Doctor of Philosophy

September 2014

ACKNOWLEDGEMENTS

I would like to thank Dr Nigel Hunt and Dr Shirley Thomas for their expert guidance and advice throughout my PhD and their friendliness which I felt went beyond their roles as supervisors. I am incredibly grateful for all their support and patience, without which this thesis would not be possible.

I would also like to acknowledge my family, friends and colleagues within the Institute of Work, Health and Organisations who have helped and supported me for the past three years, in particular I would like to extend my thanks to:

Mum, with her no-nonsense attitude who always pushed me to work as hard as I could.

Richard, for always being there, for believing in me and putting up with my bad moods and tantrums.

Raj, Angela, Miriam, Neetu, Yinyin, Ashraf and Mohammed from IWHO for the good times, help and encouragement.

I am also grateful to the breast cancer survivors and their family and friends who kindly gave up their time to participate in this research.

For Mum and Dad.

PUBLICATIONS AND CONFERENCES

- Nirgude, P., Hunt, N. and Thomas, S. (2013). Ecomaps as a tool for understanding the support networks of breast cancer patients. Oral presentation, BPS Qualitative Methods in Psychology Conference in Huddersfield, UK.
- Nirgude, P., Hunt, N. and Thomas, S. (2013). Exploring the support networks of breast cancer patients. Poster presentation, 13th European Society for Traumatic Stress Studies Conference in Bologna, Italy.
- Nirgude, P., Hunt, N. & Thomas, S. (2013). Exploring the support networks of breast cancer survivors. 13th European Conference on Traumatic Stress - Trauma and its clinical pathways: PTSD and beyond. *European Journal Of Psychotraumatology*, 4. doi:10.3402/ejpt.v4i0.21502
- Nirgude, P., Hunt, N. and Thomas, S. (2013). Exploring the support networks of breast cancer patients. Oral presentation, 3rd Global Conference - The Patient: Therapeutic Approaches, Inter-disciplinary Net, Lisbon, Portugal.
- Nirgude, P., Hunt, N. & Thomas, S. (2013). Exploring the support networks of breast cancer survivors. In B.B. Editor (Ed.), *People Being Patients*. Retrieved from <https://www.interdisciplinarypress.net/online-store/ebooks/diversity-and-recognition/people-being-patients>
- Nirgude, P., Hunt, N. and Thomas, S. (2011). Breast Cancer and the Marital Dyad. Oral presentation, Institute of Work, Health and Organisations Postgraduate Research Conference, University of Nottingham, UK.
- Nirgude, P., Hunt, N. and Thomas, S. (2010). Coping with Breast Cancer: A Dyadic Approach. Poster presentation, Institute of Work, Health and Organisations Postgraduate Research Conference, University of Nottingham, UK.

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GLOSSARY OF TERMS AND ABBREVIATIONS

BC	Breast Cancer
BMI	Body Mass Index
BRCA1	Breast Cancer Type 1 Susceptibility Protein
BRCA2	Breast Cancer Type 2 Susceptibility Protein
DCIS	Ductal Carcinoma in Situ
DoH	Department of Health
EF	Emotion-Focussed Coping
GP	General Practitioner
NHS	National Health Service
NHSBSP	National Health Service Breast Screening Programme
PF	Problem-Focussed Coping
PTG	Posttraumatic Growth
PTSD	Posttraumatic stress disorder
QoL	Quality of Life
UK	United Kingdom
USA	United States of America
WI	Women's Institute
Breast cancer survivor	An individual who has been diagnosed with breast cancer but is no longer undergoing treatment. They are "in remission".
Cancer trajectory	The course of the breast cancer illness.
Significant other	A person who is considered to be a main source of support to the woman with breast cancer or breast cancer survivor. They may be a family member, friend, etc.
Woman with breast cancer	A female who has been diagnosed with breast cancer.

ABSTRACT

The overall aim of this thesis was to examine the role of social support networks and the significant other in breast cancer survivors.

This thesis begins with a scoping review of current scientific literature to assess social support in the breast cancer context. The findings from this review showed that studies which have investigated social support networks in women with breast cancer do not often consider whether the actual support needs of the patient are met. In addition, there is little evidence from the support sources about the support that they may attempt to provide. Past research has attempted to measure social support and coping but is limited when attempting to understand interactions between the woman with breast cancer and their significant other as a dyadic process. Furthermore, the review indicated the lack of relevant research based in the UK.

In Study 1, the perceptions held regarding the male partner were explored in five in-depth interviews with breast cancer survivors to answer the research question of “What support do male partners provide?”. Data were thematically analysed and findings indicated that male partners were perceived to provide instrumental support, whereas female support sources were perceived to provide more emotional support. In addition, the male partner was not always perceived to be the significant other as previous literature has suggested. This finding led to Studies 2A and 2B which aimed to find out more about different social support sources, the types of support provided and identify the significant other.

Studies 2A and 2B mark one of the first examples of using ecomaps in this research area 1) as an elicitation tool in semi-structured interviews to

collect data regarding an individual's social support network and 2) as a method of visually presenting social support networks. Studies 2A and 2B illustrate the variety of sources and support provided. The final study, Study 3, presents three case studies of dyads, consisting of a breast cancer survivor and their nominated significant other, who they perceived to have provided them with the most support along the illness trajectory.

This thesis contributes to the research literature in several ways. First, it outlines the research gaps in the current scientific research. Second, it provides a novel methodology for investigating the social support networks of breast cancer survivors through the use of ecomapping. Third, it contributes to the emerging knowledge on dyadic coping. The new knowledge generated is of importance when considering the post-treatment phase of the breast cancer trajectory. Finally the limitations and strengths of this work are discussed.

1. BREAST CANCER, COPING AND SOCIAL SUPPORT: AN OVERVIEW

1.1 Introduction

Incidences of cancers are increasing across the global population (Cancer Research UK, 2008). Breast cancer, in particular, is the most common cancer diagnosed in the UK (Macmillan Cancer Support, 2008). Breast cancer is a chronic illness that has life-changing effects, not only on the individual with the illness, but also their family and friends. The effects of breast cancer are medical, emotional and social. In particular, the stress of diagnosis and treatment will affect the way an individual will cope with their illness and this is further mediated by the role of family members and friends and the support that they may provide. This chapter outlines the incidence, survival rates, causes and treatment options of breast cancer. It also discusses how women with breast cancer may cope with their illness and how social support may play a role in improving psychological health. Therefore the theoretical frameworks relating to coping and social support are presented.

1.2 Breast Cancer

1.2.1 What is Breast Cancer?

Breast cancer is a malignant tumour that starts in the cells of the breast. A malignant tumour is a group of cancerous cells (cells which begin to grow and multiply uncontrollably) that can grow into surrounding tissues or metastasise (or spread) to distant areas in the body (American Cancer Society, 2013). The disease occurs almost entirely in women, with breast cancer accounting for 22.9% of all female cancers, but it can affect men – breast cancer accounts for less than 1% of male cancers (Cancer Research UK, 2010).

There are several different types of breast cancer which can develop in different parts of the breast. These are often categorised into non-invasive and invasive type (American Cancer Society, 2013).

1. Non-invasive breast cancer. This is normally known as cancer or carcinoma in situ or pre-cancerous cells. It is found in the ducts of the breast and has not developed the ability to spread beyond the breast. This type of cancer rarely produces a lump and is more likely to be found on a mammogram. The most common type of non-invasive cancer is ductal carcinoma in situ (DCIS).

2. Invasive breast cancer. Invasive cancers have the ability to spread outside the breast, although this does not necessarily mean that it will have already spread by the time of diagnosis. The most common type of breast cancer accounting for 80% of all cases is invasive ductal breast cancer.

3. Other types of breast cancer. These are less common breast cancers, such as those which develop in the cells that line the milk-producing lobules, inflammatory breast cancer and Paget's disease. It is possible for these cancers to spread to other parts of the body, most commonly through the lymph nodes or bloodstream. If this happens, it is known as secondary/metastatic breast cancer.

1.2.2 Incidence and Survival Rates

According to Macmillan Cancer Support (2008), breast cancer is now the most common cancer in the United Kingdom (UK), with the lifetime risk for women being a 1 in 8 chance. 80% of cases occur in women who are over 50 years old (National Office for Statistics, 2010). In 2010 in the UK alone, more than 49,500 women were diagnosed with breast cancer. In the last ten years,

breast cancer incidence has increased by 6% (see Figure 1-1). According to Cancer Research UK (2011), this may be due to factors including introduction of a breast screening programme in the UK, lifestyle, hormone replacement therapy (HRT), diet and exposure to chemicals in the environment.

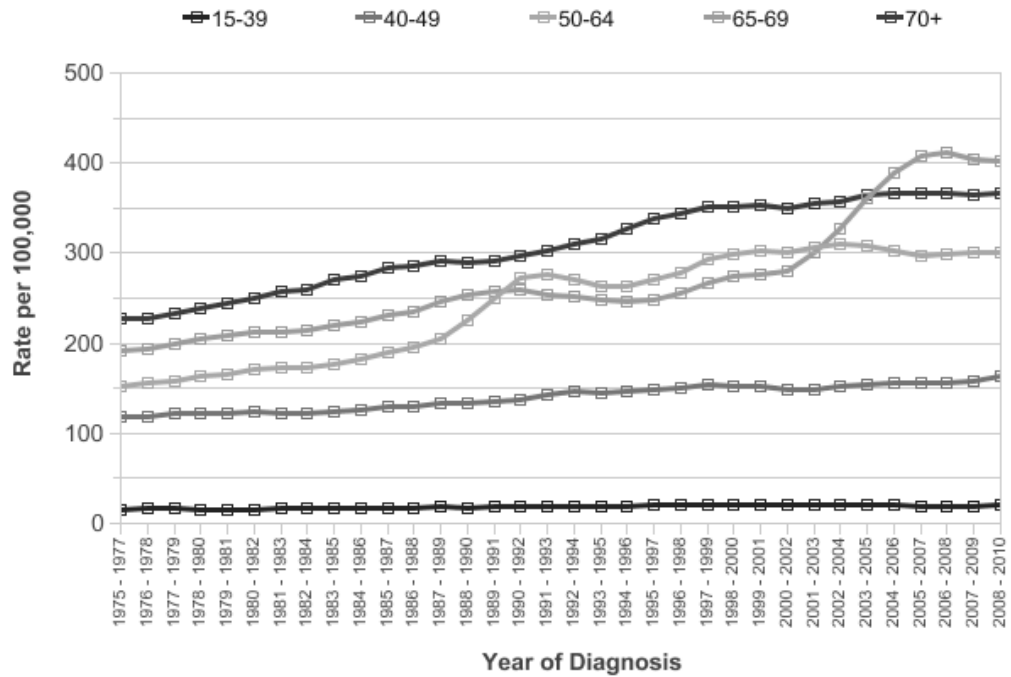


Figure 1-1. Age standardised incidence rates of female breast cancer in Great Britain 1975-2010 (Cancer Research UK, 2010)

In 2010 in the UK, around 11,600 women died from breast cancer with 1,200 of these deaths occurring in women aged 50 or younger. More than half of the breast cancer deaths in the UK are in women aged over 70. Breast cancer is now the second most common cause of death from cancer in women after lung cancer (NHS Choices, 2012).

Survival chances have also increased with more women surviving breast cancer than ever before, but this does depend on the type of breast cancer and the stage of the disease. Women diagnosed with breast cancer

are now twice as likely to survive the disease for at least ten years compared to those diagnosed forty years ago. 75% of women will survive their disease for at least ten years. Breast cancer survival rates are better the earlier the cancer is detected (Harnett et al., 2009).

1.2.3 Causes of Breast Cancer

The cause of breast cancer is not fully understood and literature in this area has demonstrated that is difficult to speculate why one individual may get breast cancer when another may not. A single cause has not been identified, but a number of risk factors have been suggested:

1. Genetic component. There is a genetic component to breast cancer. Mutations in the *BRCA1* and *BRCA2* genes increase breast cancer risk, although these gene mutations are rare and account for a small proportion of cases (Venkitaraman, 2002; Szabo & King, 1997). Women with a mother, sister or daughter diagnosed with breast cancer have almost double the risk of being diagnosed with breast cancer themselves (Denayer et al., 2009). This risk increases with the number of first-degree relatives who have been diagnosed with breast cancer but even so, eight out of nine cases of breast cancer occur in women without any family history of breast cancer whatsoever (Ford et al., 1998).
2. Lifestyle choices. Women who use hormone replacement therapy have a 66% increased risk of breast cancer and around 3% of breast cancer cases are linked to its use (Cancer Research UK, 2012). The risk of breast cancer in current users of oral contraceptives has increased by around 25% but only 1% of breast cancer cases are linked to their use (NHS Choices, 2012), presumably because younger

women are at less risk of breast cancer. Drinking moderate amounts of alcohol increases the risk of breast cancer, with the risk increasing the more the individual drinks (Ferraroni & La Vecchia, 2002). Around 3,100 cases of breast cancer are linked to alcohol consumption. Finally, 1,700 cases are linked to lack of physical activity, so a more active lifestyle can reduce an individual's risk of being diagnosed with breast cancer. Some studies have shown that childbearing can reduce a woman's risk of developing breast cancer (MacMohan, 2005; Byers et al., 1985, Tryggvadóttir et al., 2001).

3. Body mass index. Being obese (having a body mass index (BMI) >30) can increase the risk of post-menopausal breast cancer by up to 30% and more than 4,000 cases of breast cancer in the UK are linked to excessive bodyweight (Cancer Research UK, 2012).

1.2.4 Breast Cancer Screening in the UK

In 1986, the Forrest Report (Forrest, 1986) recommended the introduction in the UK of a National Health Service Breast Screening Programme (NHSBSP), originally offering three-yearly mammography screening to women aged 50 to 64 who were registered with a General Practitioner (GP). Since 2004 this has been extended to include women aged 65 to 70. Women over age 70 are eligible for breast screening but are not automatically invited. At present in England, a trial is taking place to look at the possible benefits of extending breast screening so that women aged 47 to 50 and 70 to 73 are also invited (Department of Health, 2011).

A problem associated with a screening programme is the potential anxiety that may arise to those who attend (Raftery and Chorozoglou, 2011). There is also the issue of over-diagnosis (Welch, 2009), which is the diagnosis

of a disease which will never cause symptoms or death during the patient's lifetime. Over-diagnosis is a side-effect of the NHSBSP which may turn individuals into patients and lead to unnecessary treatments. In the next section relating to treatment of breast cancer, it is evident that treatment options can have some very severe side-effects. Mammography involves very low doses of radiation and there is the ethical issue of subjecting individuals to harmful x-rays unnecessarily. This is justified by the fact that the risk that such a low dose could result in cancer is far outweighed by the benefits of early detection of breast cancer. The level of x-rays is monitored closely so as to ensure it remains as low as possible while still providing a high quality image.

The Department of Health (DoH) (2013) recognised that cancer screening was an important way to detect cancer earlier and that around a third of breast cancers are not diagnosed through screening. Duffy et al. (2010) demonstrated that the benefit of mammographic screening in terms of lives saved was greater than the harm in terms of over-diagnosis. He states that between 2 and 2.5 lives are saved for every over-diagnosed case, However it is worth noting that the impact of false diagnosis can be devastating (Independent UK Panel on Breast Cancer Screening, 2012).

In addition to NHSBSP, the DoH's policy on breast awareness encourages women to regularly check their breasts for what is normal for them (DoH, 2013). There is no recommended set technique for routine self-examination but self-examination has strong support from medical professionals due to the fact that self-examination may result in earlier presentation for diagnosis (Huguley & Brown, 2006). However not all cancers are detected via the NHSBSP; the first symptom of breast cancer for many women is a lump in the breast. Although 90% of breast lumps are benign (Breast Cancer Care, 2014), NHS advice states that a GP should be visited so

the lump can be checked to rule out cancer (NHS Choices, 2012). They may provide referral to a breast specialist for further checks, including mammography or ultrasound.

1.2.5 Treatment Options

There is a variety of treatments available to women with breast cancer, including surgery, chemotherapy, radiation therapy and hormonal therapy. Unfortunately, all have undesirable side-effects, such as hair loss, vomiting, nausea, fatigue, menopausal symptoms, memory loss and pain (Breast Cancer Care, 2014). The range of treatments available to patients is largely dependent on the stage of their disease. This section will provide a brief overview of these options and the side-effects. Actual benefits and side-effects of treatment will differ from person to person and are also dependent on the stage of the cancer.

1.2.5.1 Surgery

The aim of surgery is to remove cancerous cells which have a border with normal tissue, with the intended outcomes of reducing the risk of cancer coming back to the breast and stopping any spread. It is usually the first treatment for breast cancer, although chemotherapy or hormone therapy may be offered first to treat the whole body or to shrink the cancer so that any surgical intervention may be less extensive. There are two types of surgical procedure offered to patients: lumpectomy or mastectomy. Lumpectomy involves the removal of cancerous cells which border normal breast tissue. Mastectomy involves removal of all the breast tissue and, in some cases, removal of the lymph nodes underneath the breast tissue. Following surgical intervention breast reconstruction is offered to patients, which can be done immediately after mastectomy or months or years later (Breast Cancer Care, 2014).

Although recovery from surgery can differ from person to person, most people recover well with few major side-effects. However there are a number of potential side-effects. The anaesthetic provided for surgery may result in feelings of nausea which commonly pass after a day or two post-surgery. Bruising and swelling is common and may affect the breast, chest wall, shoulder and arm. This will normally improve over a 6-8 week period. Some individuals experience pins and needles, burning and numbness in the chest area and down the arm on the operated side, which can go on for weeks or months post-surgery. Finally, regardless of the surgery that has been undertaken, there will be some form of permanent scarring (National Library of Medicine, 2013).

1.2.5.2 Radiotherapy

Radiotherapy involves the use of carefully measured and controlled high energy x-rays to destroy cancer cells. Treatment is given regularly over a period of time and will have a greater effect on cancerous cells whilst limiting the damage to normal cells (Shapiro & Recht, 2001). Radiotherapy is commonly used after surgery to treat any remaining cancer cells left in the breast area, thus reducing the risk of reoccurrence. Following lumpectomy, radiotherapy is usually delivered to the remaining breast tissue on the side of removal. Following mastectomy, radiotherapy may be given to the chest area. Radiotherapy may be used to treat the lymph nodes above the collarbone and in the armpit if they have not been removed surgically.

Immediate side-effects of radiotherapy include tiredness, skin reactions including darkening, redness, tenderness and itching of the skin and swelling and feeling uncomfortable in the area of treatment. Hair loss is a permanent side-effect in the area where radiotherapy is directly received, for example, there may be permanent loss of armpit hair. Longer-term side-effects can

include tissue hardening (fibrosis). In some cases, part of the lung behind the treatment area can become inflamed causing a cough or shortness of breath. Nerve damage in the arm may lead to weakness, pain, tingling and possibly cause loss of movement (NHS Choice, 2012).

1.2.5.3 Chemotherapy

Chemotherapy involves using cytotoxic drugs to destroy breast cancer cells.

Cancer cells grow by dividing in an uncontrolled way and cytotoxic drugs interfere with their ability to grow and divide. A variety of chemotherapy drugs are available which affect cancer cells dependent on their stage of growth, and normally a combination of drugs is used depending on the individual's situation. Chemotherapy is offered if cancer cells have been found in the lymph nodes in the armpit. It is often given to treat primary breast cancer, usually after surgery and before radiotherapy, a process known as adjuvant treatment.

Chemotherapy is usually given as a series of treatments every two to four weeks over a period of four to six months. The gap between treatment courses allows time for the body to recover from any short-term side-effects (Macmillan, 2011).

There are over 100 types of chemotherapy drugs available which have different side-effects on the patient. The nature and extent of the side-effects will depend on the combination of drugs used and may differ between individuals. The side-effects of chemotherapy can be debilitating. They include nausea and vomiting which can occur immediately after chemotherapy or up to several hours later (Shapiro and Recht, 2001). This can be treated with anti-emetic medication or complementary therapies such as relaxation therapy, hypnosis or acupunctures. The mouth and gums may become sore, impacting on dental care during treatment. In addition, patients' sense of taste may change, with some individuals noticing a metallic taste in their mouth. Some

studies have demonstrated that hair loss is one of the most distressing side-effects of chemotherapy (Fobair et al., 2006; Batchelor, 2001). It usually occurs gradually, beginning within two or three weeks of starting treatment. All body hair can be lost, including eyelashes and eyebrows, but hair often grows back post-treatment. Bone marrow can also be affected, meaning the body is less able to make new blood cells. As platelet production is affected, patients may bruise more easily, have nosebleeds or have bleeding gums. Tiredness is also a side-effect, generally attributed to anaemia as a result of a low red blood-cell count. However, tiredness may persist even if red blood-cell levels are normal and this fatigue can last for several months post-treatment (Broeckel et al., 1998). Concentration can also be affected as a result. Menstruation may become irregular or stop temporarily during chemotherapy. It may stop completely which may indicate primary infertility. Some women will also experience menopausal symptoms such as hot flushes, decreased sex drive and changes in mood.

1.2.6 The Long-term Impacts of Breast Cancer

Breast cancer treatment and subsequent months can be a stressful time for most women (Fann et al., 2007). Given that survival rates of women with breast cancer are increasing, there is a large cohort of women living with the aftermath of this disease. The consequences of cancer and treatment mean that some women may experience enduring physical and psychological problems and subsequently long-term morbidity, poor psychosocial adjustment and quality of life (Nesvold et al., 2011; Bouillan et al., 2010; Harrington et al., 2010). Emotional distress (e.g. symptoms of depression and anxiety) and intrusion and avoidance (e.g. intrusive thoughts and feelings; avoidance of situations, feelings and ideas) are most frequently reported by breast cancer survivors in relation to cancer and its treatment (Lebel et al.,

2008). Studies investigating the long-term effects of cancer on quality of life (QoL) have demonstrated no major differences between cancer survivors and healthy controls (Bower et al., 2000; Dorval et al., 1998). In contrast Helgeson et al. (2004) found, over a four year period post-treatment, the majority of breast cancer survivors showed improved mental and physical functioning over time, but there were subgroups who showed marked improvement or deterioration, which was mediated largely by age, personal resources and social support. The body of literature suggests that for some breast cancer survivors, the impact of the illness can be long-term. However this is not evident across all literature. One reason that some women will adjust to breast cancer beyond the treatment phase without long-term problems may be to do with *how* they cope during the illness trajectory. Coping efforts can be mediated by the social support that is available to them. The following sections provide theoretical frameworks relating to coping and social support which will be referred to throughout the thesis.

Some studies have reported that receiving a diagnosis of breast cancer is a traumatic experience (Talgehani et al., 2008; Cordova et al., 2007) and some of the feelings experienced relate to anxiety, chaos, despair and hopelessness (Shaha et al., 2008; Zabora et al., 2001; Al-Azri et al., 2009). The levels of anxiety and depression experienced at diagnosis were significantly associated with anxiety and depression 1-2 years later (Burgess et al., 2005) and may be sustained beyond this time period (Montazeri et al., 2008). Posttraumatic-stress disorder (PTSD) symptoms have been reported by some women (Kornblith et al., 2003) illustrating the long-term effects of breast cancer. As such, it would be important to investigate the long-term impact of breast cancer.

1.3 Coping

Coping has been defined as “*constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of a person*” (Lazarus & Folkman, 1984, p. 141). Transactional theories of stress and coping have suggested that stress arises from the interaction between an individual and their environment. Stress occurs when there is an imbalance between the demands placed on an individual and their ability to meet these demands (Gross, 2005). Appraisal refers to the mediating process that occurs when this person-environment interaction takes place (Lazarus & Folkman, 1984). Appraisal is influenced by the characteristics of a person, e.g. commitment and values, beliefs about the self and the environment along with personal resources such as energy, health and money. These individual differences help to explain why individuals may cope very differently when faced with the same stressor. One person may appraise a stressor (such as breast cancer) as a threat, whereas another individual may perceive it as a challenge that needs to be overcome. It is worth noting that there are different stressors associated with breast cancer depending on the stage of the illness trajectory. Personality traits have also been associated with types of coping, e.g. use of denial and avoidance and neuroticism (Ferguson, 2001).

Coping styles and coping strategies are distinctive. Coping styles refer to personality characteristics and more stable, dispositional features of an individual, whereas coping strategies are used in response to a stressor at a particular point in time (Carver & Scheier, 1994).

Pearlin (1989) suggested that stress research should consider sociological features, such as the systems and contexts in which individuals live and work, as these are often related to stressors which are experienced. An interactional model of stress and coping should also incorporate a variety of factors,

including environmental and personal systems, transitory events, appraisal and coping strategies, and health and wellbeing (Moos & Holahan, 2003). An individual may employ primary and secondary appraisal. Primary appraisal refers to an individuals' initial assessment of an event, deciding whether it is threatening or harmful. A perception of threat would then trigger secondary appraisal, where an individual would decide what coping behaviours or resources are available to deal with the stressor (Lazarus & Folkman, 1984). Coping has frequently been dichomiosed as either problem focussed (PF) or emotional focussed (EF), where PF coping involves direct action to manage a stressor and EF refers to efforts to regulate feelings associated with a stressor. One theoretical framework that is appropriate to the stressor of breast cancer is the Moos Crisis Theory (Moos & Schaefer, 1986). This model proposed that factors related to the crisis, background and personal issues, along with the social and physical environment influence how an individual copes with a crisis. Individuals cope by appraising the stress, undertaking problem solving related to it, and then completing other tasks relating to psychosocial functioning. Individuals then utilise specific coping strategies, for example seeking social support. These processes combine to determine the outcome of a crisis (Sarafino, 2005).

The literature suggests that some types of coping are more adaptive than others. PF coping has been associated with more adaptive outcomes compared to EF coping, e.g. disengagement has been associated with depression (Votta & Manion, 2004). Although studies have attempted to make associations between EF coping, PF coping and health related outcomes, it may be that the dichotomy of EF coping and PF coping has been oversimplified (Lazarus, 1999). Mental state is often used as an outcome related to the efficacy of types of coping. It may be that the associations

between EF coping and distress could be due to the confounding of the two concepts (Coyne & Racioppo, 2000). It has been suggested that the diversity of items included in EF coping makes it difficult to measure a single construct (Austenfeld & Stanton, 2004). EF coping and PF coping are interdependent and should be measured both separately and together (Lazarus, 2000).

Studies looking at samples of cancer patients have found that they mostly use EF coping (Ahadi et al., 2014; Zhiyang, 2008; Matososhita, 2005) and tend to seek more social support than healthy people (Filis et al., 2003; Sing, 2010). According to Lazarus and Folkman (1984) individuals with intense levels of perceived stress are more likely to use EF, but if an individual believes that the stressor can be controlled, they will use PF. In the context of breast cancer, potential mortality along with other potential negative consequences, may lead breast cancer patients to believe that the situation is out of their control, and hence use EF. What is important to note is the importance of context and that coping is situation-specific. Context does not only relate to an individual's situation but also the social environment in which they are operating, for example in the context of breast cancer, coping may be prohibited or mediated by the social environment of the patient. Therefore coping strategies should not be rated in terms of their adaptive qualities without considering the wider social context. Context should incorporate interactions between individuals and their environment but also attempt to link between different systems such as family, health policies etc., thus taking a more ecological approach incorporating socioeconomic factors. This is applicable to breast cancer as it involves government provision of healthcare.

Lazarus (2000) proposed that not all avoidant coping strategies are maladaptive and what is important for psychological wellbeing is the situation and the characteristics of an individual. Psychological wellbeing and individual characteristics may involve the use of different coping strategies that may

have different effects depending on the levels of distress experienced by women with breast cancer. In particular, the physiological stage of breast cancer disease, treatment options, stage of the illness trajectory, along with personal characteristics may influence the type of coping strategy used. Overall, different individuals will use a variety of coping styles and strategies throughout the process of coping with breast cancer (Brown et al., 2000).

EF coping is often discussed in the context of breast cancer and one of the coping strategies that falls under this is seeking social support. Indeed social support is considered to be a form of EF coping (Dragestset & Lindstrom, 2005). This suggests that social support is a resource which could promote adaptive coping. However it may also be that individuals who use more EF coping strategies happen to be good at building up their social networks because of their ability to cope (Drageset & Lindstrom, 2003). It is worth highlighting that although seeking social support is considered an EF coping strategy, it may not be the case that an individual is seeking emotional support or that the social support source will attempt to provide emotional support. Social support can be considered in two parts. The first relates to how individuals who are sought to provide social support may influence the patient's own psychological wellbeing, depending on their own coping strategies. This is known as dyadic coping, which will be discussed in the next section. Dyadic coping is linked to social support because it is likely that members of the dyad would provide social support to each other. The second consideration is how individuals seek social support as a coping strategy and the effect that this has on psychological wellbeing. This will be returned to later in this chapter.

1.4 Dyadic Coping

Breast cancer can be a devastating diagnosis, not only for the patient, but for family members and friends who may become supporters and carers following this negative life event (Fallowfield & Clarke, 1991) – breast cancer does not just affect the woman diagnosed but those around her. One factor that may affect the women with breast cancers' coping strategies is the coping strategies of their significant other, who could be a partner, spouse, friend, family member or work colleague. Research into dyadic coping in the breast cancer context has predominantly focussed on the breast cancer patient-husband/spouse/male partner dyad.

The construct of dyadic coping was pioneered using a systemic-transactional perspective (Bodenmann, 1995). This proposed that dyadic stress is elicited by a stressful event (such as the diagnosis of breast cancer and consequent stages of treatment) which will directly concern one of the members of the dyad, and will include efforts used by one of the members, or dyad collectively, to handle the stress elicited. Dyadic coping comprises of the stress signals of one partner, the verbal or non-verbal coping responses of the other partner and joint coping efforts, which can be positive and negative (Bodenmann, 2005). Positive dyadic coping occurs in three main ways:

1. Supportive dyadic coping. This involves one partner taking over daily tasks, communicating empathy and conveying solidarity.
2. Common dyadic coping. This occurs when couples engage in joint activities, involving problem-solving, information seeking and the sharing of feelings and mutual commitment.
3. Delegated dyadic coping. This occurs when one partner is explicitly asked by the other to provide support in an attempt to reduce stress levels.

In contrast, negative dyadic coping is characterised as follows:

1. Hostile dyadic coping. This involves one partner distancing themselves from the other, being mocking and/or using sarcasm.
2. Ambivalent dyadic coping. This involves one partner providing support but unwillingly.
3. Superficial dyadic coping. This involves one partner appearing to be detached or asking questions without any attempt to understand or appreciate the answers.

A more recent systemic framework of dyadic coping was proposed by Kayser et al. (2007), which views coping with breast cancer specifically as a multi-process progression, involving the appraisal of illness-related stress, the reaction of the individual to their partners' responses, managing stress using behaviour and cognitive strategies and understanding and making sense of the illness.

Dyadic coping has two main objectives. The first is to reduce distress for both members of the dyad. The second objective is to enhance or preserve relationship functioning (Bodenmann, 2005). Dyadic coping is considered to be more than just social support (Revenson & DeLongis, 2010). Dyadic coping involves both members of the dyad who are mutually involved in the stress coping process, including providing and receiving support from each other, shared emotional regulation and joint problem-solving (Bodenmann, 1995). With this in mind, members of a dyad may act as a unit when faced with breast cancer and the literature pertaining to this is presented in the next section. As mentioned previously, dyadic coping in the context of breast cancer is largely focused on the relationship of the woman with breast cancer and her male partner, with the assumption that the woman with breast cancer has one significant other only (who is her male partner).

1.4.1 Dyadic Coping and Breast Cancer

Hannum et al. (1991) found that the coping strategies of the husband predicted psychological distress in the patient. Therefore the influence of informal caregivers or significant others may influence symptom distress. With this in mind, patients with more severe symptoms of treatment may benefit from a significant other who uses more active coping strategies (Kershaw et al., 2004). Findings from Skerrett (1998) demonstrated that breast cancer dyads focussed on factors such as communication, health and illness beliefs, problem-solving techniques and feelings of loss as coping strategies. Couples were categorised as being “resilient” or “problematic”, with a large proportion being identified as the former. Their philosophy of coping was mutual and based on the demands of the illness. They believed that the experience was shared and they used each other to confide in, to discuss thoughts and seek advice. Though they discussed breast cancer, they did not feel that it dominated their day-to-day lives. In contrast, the “problematic” couples felt that breast cancer had a devastating effect on their lives, with every aspect of their lives being polluted by intrusive breast cancer-related thoughts. These couples found it difficult to develop a common philosophy that both members could relate to and their communication was withdrawn or non-existent. Compared to the “resilient” couples, they especially found it hard to make sense of the situation.

Longer term psychosocial outcomes of cancer in dyads have not been as widely investigated. In a sample of cancer survivors (including but not limited to breast cancer) and their partners between 1-11 years post-treatment, a positive relationship was found between psychological distress and supportive care needs both within and between the dyad (Hodgkinson et al., 2007). Dyad members reported both shared and unique needs which

persisted over time, despite showing characteristics demonstrative of posttraumatic growth.

Hostile dyad coping patterns predict poorer adjustment in male partners of women with breast cancer, with the impact of coping with their partners' breast cancer negatively impacting other aspects of their life, such as work and sleep, along with aspects of their relationship such as sex life (Felman & Brousaard, 2006). Badr et al. (2010) additionally found that dyad members who experienced more negative dyadic coping were likely to experience significantly more distress. Women with breast cancer using positive dyadic coping resulted in mutual benefit for both dyad members (Banthia et al., 2003). Dyadic coping is significantly associated with higher levels of relationship functioning and psychosocial adjustment in the breast cancer context (Kuijjer et al., 2000; Kayser, 2005; Acitelli & Badr, 2005; Manne et al., 2005). Although dyadic coping does improve adjustment at the time of stress, longitudinal studies have demonstrated that positive dyadic coping is significantly associated with relationship functioning (Bodenmann et al., 2006).

The issues that members of the dyad face have been described by Shands et al., (2006). Four core concerns of members of the breast cancer dyad have been addressed. They include dealing with tension in the relationship, needing to be together as a couple, wondering about the children and managing the threat of breast cancer. These issues in particular will elicit dyadic coping.

The frameworks of dyadic stress (Bodenmann, 2005; Kayser et al., 2007) previously discussed do have strengths, although having considered the research into dyadic coping in breast cancer their limitations must be discussed. The first limitation is the assumption that members of a dyad will

work through a stressful situation together, rather than employing their own individual coping strategies only (as discussed earlier in this chapter). The frameworks also fail to take into account the cultural context, family structure, personality traits of the dyad members and socio-economic status that not only have an influence on individual coping strategies but may also have an effect on dyadic coping. It also fails to acknowledge that if one individual in the dyad is faced with a diagnosis of breast cancer, they may not turn to the other member of the dyad for support, but may rely on external sources of support. This suggests that although the dyad may play an important role it is not mutually exclusive from other social support sources and may be part of a wider social network. The model also emphasises heterosexual couples and does not address same-sex couples and also assumes that an individual will have one main significant other. Finally, the framework assumes that the intimate relationship may be the most important when considering dyadic coping. This may not be the case and perhaps a relationship with a different significant other, such as another family member, friend, etc., may be perceived to be the primary dyad. There is minimal research which considers the support dyad beyond that of the relationship with the male partner.

To summarise, the intimate dyad may play an important role as the members will react to breast cancer as a unit rather than on an individual level. However social support may be sought beyond the dyad into an individual's wider social support network including other family members, so it would be relevant to not only investigate the dyad but also other individuals within the family and social support network. The next section in this chapter discusses Family Systems Theory and social support and its role in the breast cancer context.

1.5 Family Systems Theory

Family Systems Theory describes an active interplay between family members such as partners, parent-child and sibling relationships. According to this framework, families can be understood as complex integrated frameworks including individuals with various needs and perspectives (Cox & Paley, 1997). One of the characteristics of Family Systems Theory is that families function by composition law. This states that processes at a family level cannot be reduced to an individual family member level. From this perspective, it is important to study family level constructs rather than relying on a single family member to make inferences about family functioning.

A second principal of Family Systems Theory is that families are comprised of subsystems, for example marital, parent-child and sibling, and that every family subsystem contains a small group usually made up of two or three people (Cox & Paley, 1997). Each subgroup has its own unique characteristics. These family subgroups are known to be interrelated and function in an interdependent manner. This principal emphasises the need of using multiple informants to understand how a family operates.

A further characteristic of Family Systems theory is that families have the capacity to reorganise in response to external stressors (Minuchin, 1985). This is an important feature of this theory as it points to a need to consider how the family system responds to challenges, but also how particular subgroups respond. This suggests that there will be challenges to existing patterns of interaction at all levels in the family during a transition, for example, if the mother is diagnosed with breast cancer. Research has shown that middle-aged and older couples adapt to new caregiving roles in the face of illness which consequently affects marital interactions between them (Braun et al., 2007). The acquisition of new roles within the family system may affect the

type of social support that is provided by family members to the woman with breast cancer.

Although social support may be provided by family members, there is a possibility that individuals in the wider social support network of women with breast cancer may also play an important part in the provision of social support. This is considered in the next section.

1.6 Social Support

Social support has been defined as the "*provision of emotional, instrumental, informational and appraisal assistance that includes both the resources that meet individual needs as well as the social relationships through which these needs are met*" (Clarke et al., 2006, p67). Social support has been conceptualised in a number of ways, from the structure of one's available social network size (e.g., Sarason, Sarason, Potter & Antoni, 1985) to perceived satisfaction with functional aspects of support. This includes tangible, appraisal, self-esteem, belonging, emotional, affectionate, instrumental and informational support, along with positive social interaction (Cohen, Mermelstein, Kamarck, & Hoberman, 1985; Sherbourne & Stewart, 1991).

When considering social support, it is a key factor that the provider of support will always offer social support with the intention of it being received as a helpful gesture. However intended support may not be perceived to be helpful by the receiver and it is perceived social support which is important (Cortes et al., 2014). Providing social support is a conscious process and though it can be provided to influence behaviours in the recipient, such support is provided in a context of trust and respect for that individual's choice (Heaney & Isreal, 2002). This distinguishes social support from other types of social influence.

The way in which social support influences health and wellbeing can be explained using two theories: the direct effect theory and the buffering theory (Cohen & Wills, 1985). The direct effect theory states that support is beneficial to health and wellbeing regardless of the amount of stress that people are experiencing. The buffering theory maintains that social support buffers or protects against the adverse effects of stressors under conditions of high stress. Studies that have investigated the buffering effect of social support in the breast cancer context conclude that social support from family and friends is associated with better adjustment to the disease (Bloom et al., 2001; Kornblith et al., 2001).

1.6.1 Social support networks

Several terms relating to social support are widely used when discussing the health-enriching elements of social relationships (Berkman et al., 2000). In particular, social support network refers to links between individuals that may or may not provide social support, but may have a different role (Heaney & Isreal, 2002). Bourdieu (1972) coined the term social capital, which has been used to describe resources and norms that arise from social networks. Social networks may include family, friends, work colleagues, medical professionals etc.

The structure of social support networks can be described in two ways. First, it can be described in terms of the characteristics of the support network as a whole and second, it can be described in terms of dyadic characteristics, i.e. features of the relationship between the individual of interest and other individuals in their social support network (Isreal, 1982). Characteristics that describe a whole network include factors which show the extent to which the members of the network are similar in terms of demographical information, e.g. gender, age, ethnicity, the geographical proximity to the individual of

interest and the extent to which different members of the social support network know and interact with one another (Heaney & Isreal, 2002). Dyadic characteristics include the reciprocity of the relationship, that is, the extent to which resources and support are given and received, the strength of the relationship which is indicated by the emotional closeness of sources, how the relationship serves on a multi-functional level and the extent to which a relationship is embedded in an institutional structure or formal arrangement (e.g. though work or due to family ties) (Heaney & Isreal, 2002).

1.6.2 Breast cancer and social support

The importance of social support has been shown in previous studies involving cancer patients and it has been treated as a positive coping resource in the diagnostic phase of breast cancer (Northouse et al., 1997; O'Mahoney, 2001). It has been found to reduce anxiety (Woodward & Webb, 2001).

Studies have shown that perception of social support is a significant predictor of favourable prognosis (de Boer et al., 1999; Watson et al., 1999; Carlsson & Hamrin, 1994). Kroenke et al., (2006) found that a sample of 2,835 socially-isolated women had an elevated risk of 66% of all-cause mortality after being diagnosed with breast cancer, which is likely to do with little access to care, specifically beneficial caregiving from friends, relatives and adult children. The findings from this study are strong as many potentially confounding variables (such as age, BMI, etc.) are controlled for. Pineault (2007) found that in a sample of women recalled after abnormal screening results, 75% reported that they found the support provided by family and friends comforting, but this did not diminish the participants' levels of anxiety.

Studies have found that social support (as discussed in the previous section), the size of the social network and the integration of the women within their social network are important in adjustment during the breast cancer

trajectory (Michael et al., 2002; Falagas et al., 2007). Women with breast cancer with inadequate social support or a limited social network may be at risk from increased psychological distress and even increased cancer progression (Ganz et al., 2008; Nausheen et al., 2009).

A number of other studies have shown that women with breast cancer who are most vulnerable to psychological distress have minimal social support and experience highly negative events (Kornblith et al., 2001; Ell et al., 1989; Arora et al., 2007). Being widowed or having a broken marriage was also associated with severe distress in breast cancer patients (Kornblith et al., 2001). This may be attributed to the lack of a close, intimate relationship. Without an intimate relationship or a confidant, patients may be less able to maintain self-esteem, to obtain help or to seek advice or reassurance from any individuals who they felt cared deeply for them.

Maley et al. (2006) found that in a sample of women with breast cancer who had to choose between mastectomy and breast conservation, it was ultimately the family members who decided what type of surgery to perform: this was particularly significant in Latino populations. In addition, having children at home or living with other family members was associated with the decision to proceed with more aggressive treatment (Yellen & Cella, 1995).

The effectiveness of social support is affected by several factors. It could depend on the source that is providing the support (e.g. family, friends, work colleagues, health professionals or other women with breast cancer (Teleghani et al., 2008). The type of relationship and the setting in which social support is experienced is also important (Remmers et al., 2010). Finally, different types of social support are valuable at different stages of the disease and treatment (Liao et al., 2007). During the diagnosis period, information

support is most important (Liao et al., 2007, Demir et al., 2008), but in the period around treatment and recovery emotional support appears to be important (Arora et al., 2007; Remmers et al., 2010).

1.7 Methodological considerations in the coping and social support literature

Although existing literature does yield many important findings, it is important to be aware of their limitations and any issues that are not addressed; in particular, issues relating to the medical diagnosis of the stage of breast cancer, the stage in the illness trajectory where data collection took place, the treatments which took place and the length of the trajectory may all influence the findings of studies (Franks & Roesch, 2006). The diagnostic phase of the breast cancer trajectory has been identified as being the most stressful, due to increases in perceived stress, uncertainty, anxiety and mood disturbances (Northouse et al., 1995; Lebel et al., 2003; Montgomery & McCrone, 2010; Montgomery, 2010; Steffens et al., 2011). Higher levels of anxiety and/or depression are significant predictors of psychological distress after diagnosis (Van Esche et al., 2011). Similar levels of anxiety are found in women with benign breast lumps from the discovery of symptoms up until the point of diagnosis (Woodward & Webb, 2010). Anxiety levels have also been reported to be higher before diagnosis rather than after (Liao et al., 2008). In the period after diagnosis, levels of anxiety and emotional stress tend to fall quicker in women with benign disorders compared to those who received a breast cancer diagnosis, with emotional stress apparently intensifying or remaining constant for the latter group (Liao et al., 2011; Blow et al., 2011).

In addition, personal characteristics such as personality traits, age (Franks & Roesch, 2006), socioeconomic status and ethnicity may also influence the research findings. For example, higher levels of education have

been associated with lower experiences of stress (Andrykowski et al., 2002) and unrelated to anxiety (Macfarlane & Sony, 1992). Although there is limited evidence in the literature, illness-comorbidity, cancer recurrence and past cancer status may all influence which coping strategies individuals use and whether they seek social support (Franks & Roesche, 2006). Younger women with breast cancer are less successful at coping with treatment related side-effects, seeking support and maintaining a positive attitude, compared to older women (Baider et al., 2003).

There are several factors which may have an effect on coping and social support in the breast cancer context, for example, variation in illness severity, stage and treatment, and the personal characteristics of sample populations. As such, an idiographic approach to social support in the breast cancer context would be appropriate. With this approach, this thesis will not intend to generalise its findings to individuals who have been affected by breast cancer, but will use the findings and explain them in the context of participants.

1.8 Conclusion

This chapter outlined the prevalence, survival rates, causes and treatment options of breast cancer. The longer-term impact of breast cancer on the psychological well-being of patients was considered and the role of stress and coping in the context of breast cancer was explored. The importance of social support and its relationship to breast cancer adjustment was discussed along with the rationale for looking at social support networks as a whole and looking at the focal individual and support sources separately (dyadic characteristics). The next chapter uses this information to conduct a scoping review of the literature to explore the existing literature base relevant to social support networks and breast cancer. The focus on social support networks and their

resources will provide information regarding the various sources who are providing support to women with breast cancer, from diagnosis to long-term remission. In addition, the scoping review will highlight the gaps in the literature and identify the research questions for this thesis.

2. A SCOPING REVIEW OF THE LITERATURE: BREAST CANCER AND SOCIAL SUPPORT

2.1 Introduction

This chapter presents a scoping review of the literature relating to breast cancer and social support. Specifically the scoping review aims to determine the role of social support, the sources that may be included in the social support network and to establish current findings relating to (dyadic) social support links in the breast cancer context. A narrative synthesis of the findings is presented and these are discussed along with the methodological limitations of the included studies. The chapter closes with the rationale for the thesis is discussed and the research questions are presented.

2.2 Rationale for a scoping review

The purpose of this review was to evaluate the existing evidence base regarding breast cancer and social support. To achieve this, the scoping review method was chosen. Scoping reviews allow researchers to evaluate and interpret all available research evidence pertaining to a particular research question (Arksey & O'Malley, 2005). The scoping review was chosen over a systematic review as systematic reviews tend to focus on a well-defined question looking at particular study designs, whilst a scoping review tends to address broader topics where there may be different study designs (Arksey & O'Malley, 2005). In the previous chapter there was evidence of this. In addition, systematic reviews aim to provide answers from a relatively narrow range of quality assessed studies. In this scoping review, the aim is not to address a specific research question, nor will studies be included based on their quality (although the quality of included studies will be discussed towards the end of this chapter).

The question guiding this review was “What is known about social support and social support networks in the breast cancer context?” Having defined the research question, scoping reviews follow a set process for finding relevant studies, appraising and selecting studies and summarising and synthesising the findings from appropriate studies (Arksey & O’Malley, 2005). Procedural guidelines (Arksey & O’Malley, 2005) are followed for searching, selecting and appraising studies to ensure that the methods are transparent and that the findings can be reproduced. A key strength of the scoping review is that it enables researchers to draw together all knowledge on a topic where perhaps a narrow research question is not used. In addition, scoping reviews allow for the inclusion and dissemination of a variety of methods (Mays et al., 2005). Finally scoping reviews go beyond the research findings and allow gaps in existing literature to be identified. A scoping review is sufficient here because of the range of study designs that may be yielded as well as differences in illness stage, treatments and disease progression in participants.

2.3 Aims and objectives

The primary aim of this scoping review was to generate information regarding social support and breast cancer. The specific objectives of this scoping review were to:

- (i) Determine the role of social support and the impact that this may have on the woman with breast cancer.
- (ii) Establish current findings relating to features of social support networks in the breast cancer context.
- (iii) Understand perceptions of family members and friends of the support they provide and how this affects their relationship with the patient.

2.4 Methods

A scoping review is a knowledge synthesis technique that is commonly used when: it is difficult to identify a narrow review question; studies in the reviewed sources are likely to have employed a variety of methodological and analytical techniques; there has been no prior synthesis relating to the topic; and when a rigorous quality assessment is not going to be conducted (Arksey & O'Malley, 2005). In this study, a scoping review that meets all these criteria is presented. The review poses the broad question: What is known about breast cancer and social support? This study followed the scoping review protocol set out by Arksey and O'Malley (2005) and aimed to summarise previous findings relating to the broad research question and to identify any gaps in the literature. The remainder of this section outlines the five stages taken to complete this review, outlined in Table 2-1.

Table 2-1. Stages of scoping (Arskey & O'Malley, 2005).

Stage 1	Identification of the research question
Stage 2	Identifying relevant studies
Stage 3	Study selection
Stage 4	Charting the data
Stage 5	Collating, summarising and reporting

The following describes each of these five stages as applicable to the topic in question.

Stage 1: Identification of a research question.

The broad research question in this scoping review is: "What is known about breast cancer and social support and social support networks?"

Stage 2: Identifying relevant studies.

To identify studies on this topic, academic electronic databases were searched using the following key words: breast cancer, breast carcinoma, breast tumour, breast lump, social support, partners, husbands, couples,

marriage, family, caregiver, friend, dyad, dyadic coping and dyadic stress. The following databases were searched: PSYCH Info, Web of Science, Science Direct, PubMed, Medline and Wiley Online. Certain combinations of keywords yielded large and mostly irrelevant results and in such instances the results were narrowed by adding additional keywords (see below). This ultimately enhanced the focus and relevance of the findings. The primary search was conducted using the following search strings in combination with each other:

String 1: Breast cancer OR breast carcinoma OR breast tumour OR breast lump.

String 2: Social support OR social network OR support sources OR social resources.

String 3: Partner OR husband OR couples OR marriage OR family OR friend OR caregiver OR significant other.

String 4: Dyad OR dyadic coping OR dyadic stress

Stage 3: Study selection.

In order to select papers for inclusion in the review, the titles and abstracts were read and 'post hoc' inclusion criteria were developed and employed, where studies involving participants younger than 18 year old were excluded. This is important to the scoping review as it is unlikely that those undertaking this step will know what the exclusion criteria are at the outset which is a fundamental difference between a scoping review and a systematic review (Arksey & O'Malley, 2005).

What was deemed irrelevant or relevant was guided by the following inclusion and exclusion criteria:

- The studies addressed the research question.
- The research was published in a peer reviewed journal.

A total of 292 references were identified from the searches, excluding duplicates. Titles and abstracts were scanned for relevance according to the above criteria and 62 were read in more detail. A total of 19 articles were included in the scoping study. Papers were excluded where the paper did not contain relevant information considering the aims of the scoping review. Reference chaining yielded a further 5 articles. (see Figure 2-1: Search strategy).

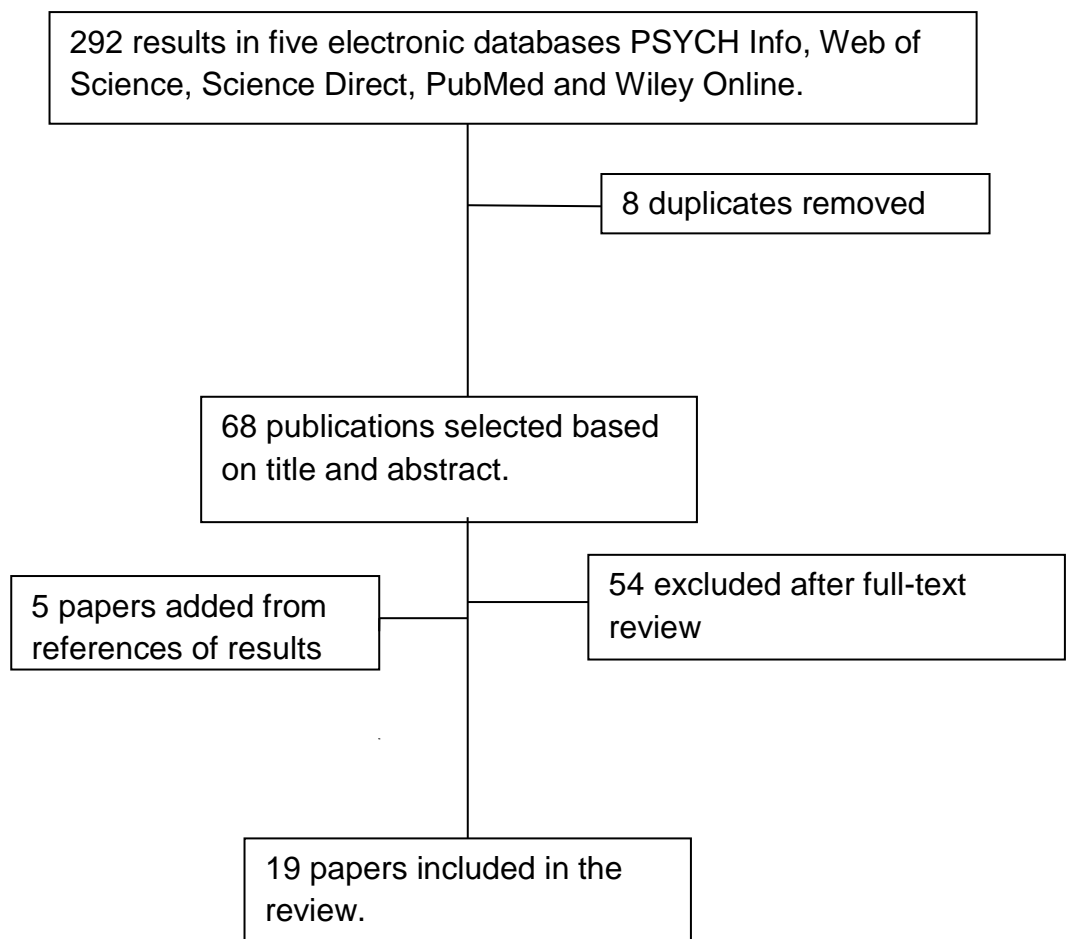


Figure 2-1. Search strategy

Stage 4: Charting the data.

Details regarding the included sources were recorded: publication information, study design and sample along with any other information relevant to the research question. The extracted information was considered in view of the research objectives resulting in the development of themes and key issues. Further characteristics of the studies included in the review are presented in Appendix 1.

Stage 5: Collating, summarising and reporting.

Due to the heterogeneity of methods used and the way findings were reported across the studies, a narrative synthesis was deemed most appropriate for reviewing the findings (Jackson & Waters, 2005). According to Pope et al. (2007), this constitutes an interpretive/integrative process of constructing a textual summary to explain findings of multiple studies. This narrative synthesis of data includes descriptive characteristics and key findings. Gaps in the evidence were also identified. Findings are reported below in the results section.

2.5 Results

A narrative synthesis of the literature identified two broad subject areas into which literature could be grouped. These were:

Table 2-2. Subject areas (themes) outlined in the scoping review.

1. Social Support	<ul style="list-style-type: none"> a) Support network size b) Primary sources c) Types of support
2. Impact on family members	<ul style="list-style-type: none"> a) Information seeking b) Physical and psychological health c) Relationship with the patient d) Changing roles

Theme 1: Social Support

The theme Social Support addresses the size of the support network, the primary sources, the types of support provided and the coping outcome for women with breast cancer.

a) Support network size

Bloom et al. (2001) suggest that larger social support networks are important because they provide more emotional and instrumental resources. However they argue that the integration of the women with breast cancer is also important.

b) Primary Sources of Support

The second theme discusses who the primary support sources of the women with breast cancer were. Gass et al. (2007) asked women with breast cancer to identify their primary support source, emergency contact and health care proxy. For married/partnered women, the partner was named 78%, 69% and 68% of the time respectively, and 58% named the same person to all three roles. For those without partners, an adult child was named most often to these same roles. A qualitative study of six breast cancer survivors found that all women were supported by family and friends (Wilkes et al., 2002) and another emphasised the role of family members (Coyne et al., 2012). However the participants in this study stressed that they did not receive enough support, specifically related to the lack of support from health professionals in the period related to making treatment decisions. Family members and husbands or partners in particular are consistently mentioned in the articles and some address that women with breast cancer are aware of the difficulties that these individuals face (Lindhöj & Cannon, 2001). The same study also highlights the importance of children as a source of support, giving the woman with breast cancer a reason to “keep going”, and also that support needs differed

along the illness trajectory (e.g. professional help was more valued at pre-treatment).

c) Types of support

When asked what primary support meant to them, 52% of women with breast cancer characterised it as emotional and 23% defined it as a combination of roles, normally emotional and structural and less than 10% described it as purely structural or informational in nature (Gass et al., 2007). Another study found that too much sympathy was inappropriate (Lindhop & Cannon, 2001). In addition, the greater perceived availability of instrumental support, the poorer the women's physical health. In another study, most participants felt that they were emotionally supported by their family, friends and doctor, but overall the support that they received was not the right kind, with more emotional support being desired (Wilkes et al., 2002). Bloom et al (2001) found that 34% of participants received psychosocial support in the previous year, through support groups, individual or family counselling from a mental health professional, from a minister or social worker or through other counselling opportunities. In addition, it was found that women who were married received more emotional and instrumental support than those who were unmarried (Bloom et al., 2001). Family members also report providing instrumental support, but also an emotional buffer, especially during treatment, and also each family member provided a different supportive role (Coyne et al., 2012).

The type of treatment received also affected the levels of support received: women receiving radiotherapy reported less emotional and instrumental support than those not receiving radiotherapy. Women received more emotional support if they were undergoing chemotherapy and more instrumental support was reported if undergoing mastectomy (Bloom et al.,

2001). Den Oudsten et al, (2010) found that perceived social support decreased over time, from diagnosis to 24 months after surgical treatment.

Theme 2: Impact on family members

The second theme discusses how male partners and family members are affected by the breast cancer diagnosis. Specifically information relating to information seeking, physical and mental health, the relationship with the patient and changing roles are discussed.

a) Information seeking

A diagnosis of cancer has a significant impact on the partners and family members of patients who perceive a need for information on a wide range of topics (Adams et al., 2009). Unsurprisingly Adams et al.'s systematic review found that information needs of spouses or partners of patients related to sexual intimacy specifically to breast cancer. Spouses or partners of women with breast cancer wanted more information on complimentary therapies, understanding drug trials, prognosis, risk factors and impact on day to day life.

b) Physical and mental health

Wells-Di Gregorio et al. (2012) found that caring for women with breast cancer through providing instrumental support had an impact on the physical health and immune function of spouses. They further state that subjective experiences of stress are associated with greater physical symptoms such as backache, headache, indigestion and shortness of breath. In a sample of couples dealing with breast cancer, those who experienced high psychological distress reported lower levels of perceived family support than spouses who both reported normal levels of psychological distress (Baider et al., 2003).

c) Relationship with the patient

For the male partner to maintain the relationship with the woman with breast cancer, processes of adaption and appraisal were often employed. Many men

considered their relationship to be their primary concern during the breast cancer experience and a commonly used strategy was to maintain a positive stance which actually covered their true feelings (Harrow et al., 2008). Examples of this included trying to convince the woman with breast cancer to believe something which they could not, covering feelings relating to treatment progress and being positive (often misconstrued by the patient as “fighting spirit”). Having a positive stance often made the male partners feel uncomfortable but they felt that it was of benefit to their wives.

Post-treatment, male partners deemed it necessary to move on from the breast cancer experience but it was difficult to find a balance between doing this and dealing with their emotions. Some men admitted that things never returned to how they were pre-diagnosis, with daily reminders of cancer making this particularly difficult (Harrow et al., 2008). In addition, husbands have reported receiving social support from their wives (Kadmon et al., 2004).

d) Changing roles

One finding related to the negotiation of the role of the male partner when faced with breast cancer. Harrow et al. (2008) found that male partners attempted to maintain a level of equilibrium with regards to normality but often felt uncertainty or ambiguity in their experiences. They also described feeling “in limbo” when experiences of expecting to move on post-treatment were not fulfilled. Women with breast cancer and their family members have reported moving between “supporting” and “being supported” at different points in the breast cancer trajectory (Coyne et al.; 2012).

2.6 Discussion

The larger a support network and the more integrated a woman with breast cancer is within it, the more she can make use of the emotional and instrumental support is available to her (Bloom et al., 2001). Individuals who

have smaller social support networks, regardless of the quality of the social ties they have, have less emotional and instrumental support available to them. This is consistent with previous studies (Wellman & Wortley, 1990). Whilst it is logical that a larger support network will have more emotional and instrument support available, it is whether or not the woman with breast cancer chooses to engage with these sources to seek this support which is important. The quality and type of support is also important: more available support does not necessarily mean that it is what the individual is seeking.

Whether women with breast cancer are in a relationship or not, there is variability in whom they describe as their primary source of support. As Gass et al. (2007) demonstrated, this extended to other clinical considerations such as emergency contacts and advance care planning. Understanding this variability in primary social support sources and any factors associated with changes over the course of the illness trajectory has implications for the comprehensive care of patients. By further defining the roles that the primary source of social support plays, along with other social support sources and the social support network, strategies can be identified in including these support providers in care models of women living with breast cancer. Additional assistance may be needed for women who are socially isolated or have a smaller support network, but the finding of the scoping review have not indicated that larger social support network means that the support needs of women with breast cancer are adequately met. The literature has not provided details on whether a woman with breast cancer feels that her support needs are met by support sources which are available to her.

In the study by Bloom et al. (2001) some women received psychological counselling, in particular the ones who reported poorer mental wellbeing. Perhaps poor psychological health has a negative effect on the ability to utilise the social support links available to improve one's mental

health and wellbeing. In particular, if counselling occurs in a group setting, it may be the case that the group provides social support, with the foundation for such groups being the sharing of common experiences, as well as providing emotional support.

Social support is regarded as an important contribution to the health and wellbeing of women with breast cancer and this is a view reflected by this population (Lindop & Cannon, 2001). The support network of women with breast cancer is largely made up of friends and family, but it is important to note the important role of health professionals, particularly when women embark on treatment. However an important theme in the social support papers discussed in this review is that the amount of social and emotional support required varies from person to person, with some drawing on their own emotional strength, rather than turning to others. The amount of social support desired by an individual will differ and the studies included in this review have not made this distinction.

Few studies identified the male partner as the main source of emotional support, particularly when restoring confidence in their changing appearance. However this may lead to difficulties when partners were perceived to be coping badly themselves – the role of health professionals in considering the impact of breast cancer on the male partner is relevant here. Indeed, existing NHS services do not perhaps adequately address the supportive care needs for women with breast cancer and their families post-treatment (Harrow et al., 2008). Previous research has focussed on the partner or spouse of the woman with breast cancer rather than on other family members, so further investigation is warranted on a wider variety of significant others. Family members are frequently not included in research studies, often due to recruitment and retention (Northouse et al., 2006).

The scoping review discovered that the greater perceived availability of instrumental support, the poorer the women's physical health (Bloom et al., 2001). This is not unsurprising that those with greater physical needs (e.g. those who had mastectomy) perceived and used more instrumental resources compared to an individual who underwent chemotherapy.

Wilkes et al. (2002) found that some participants felt that they did not rely on others for emotional support but felt that they wanted to be in control. Individuality in the style of decision making in women with breast cancer has been highlighted previously (Bilodeau & Degner, 1996).

Wells-Di Gregorio et al. (2012) found that caring for women with breast cancer had a negative impact on the physical health and immune function of spouses. The burdens that may face the healthy partner include providing care and support to the sick partner, financial difficulties, coping with their own and their unwell partners' emotional difficulties and disruption in social and recreational life (Baider et al., 2003). These stressors may put the healthy spouse at risk of greater psychological distress or physical disease (Cliffe et al., 2000). This is important as these informal caregivers may be more vulnerable to infections which may limit their ability to provide support to the patient, along with implications for their own health. This finding is consistent with another spouse immune response study in the context of breast cancer (Mortimer et al., 2005).

Breast cancer has also been highlighted to be a continuous factor in the lives of male partners (Harrow et al., 2008) post-treatment and for an unknown period of time. It appears that male partners are constantly engaged in reappraisal and have to find strategies to address any ongoing demands. This process affects the perceived role of the male partner which changes, for example, the role of protecting the patient may be difficult in certain settings, e.g. hospital visits, so uncertainty and ambiguity manifests in the male partner.

This may be particularly difficult due to the differences between men and women's caregiving – patterns of care are often attributed to gender role norms, where care is considered to be an extension of the woman's role, whereas for men, it could often be the beginning of a new and unknown role (Miller & Kaufman, 1996).

2.7 Methodological Issues

In conducting the scoping study, a range of methodological issues became apparent. Cross-sectional design of certain studies (Bloom et al., 2001) meant that causal inferences cannot be drawn. The quantitative studies included in this scoping review have used questionnaires that are validated in the breast cancer context (Bloom et al., 2001; Budin, 1998; Den Outsten, 2009; Kadmon et al., 2004; Kroenke et al., 2006; 2013; Manning-Walsh, 2005; Oztunc et al., 2013) with the exception of one study (Pinkert et al., 2013). The one limitation of previous quantitative and qualitative research is the diversity of sample populations. For example, samples have consisted of participants where their age, ethnicity, marital status, treatment options and time since diagnosis have differed quite dramatically. The ability to generalise the findings of these various studies to populations beyond the research samples is questionable and indeed, it is difficult to draw concrete conclusion due to the diversity of samples. However, according to Arksey and O'Malley (2005), the aim of the scoping review is not to assess the quality of evidence or aggregate findings from different studies. The aim is to provide an overview of all the material reviewed, identifying the breadth of available literature and the key issues and themes (Green & Thorogood, 2004). Through this process, dominant areas of research and interest on this topic were identified, along with inconsistent findings, for example who the primary source of support is and types of support provided by different individuals.

The qualitative studies in this review have revealed rich information regarding the issues faced by women with breast cancer and their family caregivers, and provide a deeper understanding of the processes associated with seeking social support (from the perspective of women with breast cancer) and providing social support (from the perspectives of family caregivers) (Coyne et al., 2012; Harrow et al., 2007; Lindop & Cannon, 2001; Makabe & Hull, 2000; Sandham & Harcourt, 2007; Tighe et al., 2011 ; Wilkes et al., 2002).

One systematic review paper was included in this scoping review. The results of this need to be interpreted with caution due to differences in methods in the papers included and also that the majority of included studies focused on the partner or spouse of the cancer patient rather than other family members.

A longitudinal survey had 92 respondents at the final stage of data collection compared to the 233 to begin with. The same study looked at perceived social support but did not investigate other quantitative aspects of social support, e.g. size of social support networks. Information regarding the type of support (e.g. emotional and instrumental) received and needed from individuals was lacking (Den Oudsten et al., 2010). Therefore future research warrants investigation into potential factors which play a role in social support.

2.8 Concluding Comments

The narrative synthesis of the scoping review revealed two themes of Social Support and Impact on Family Members. A large network size suggested that there would be more emotional and instrumental resources. This is a tautological finding and does not reflect if the emotional and instrumental resources available are what is required by the woman with breast cancer. The primary source of the woman with breast cancer was also different, with male partners, adult children and other family members discussed. These

individuals provided emotional and instrumental support. Healthcare professionals were also revealed to provide emotional support in some cases and friends were also mentioned to a lesser extent in terms of support. Samples have consisted of participants where their age, ethnicity, marital status, treatment options, time since diagnosis and stage of breast cancer trajectory have differed quite dramatically and it not clear how this will affect a) who is providing social support, b) the type of support provided by the social network and c) the support needs of the women with breast cancer.

2.9 Rationale for thesis

Although breast cancer can occur in women under the age of 50, the incidence increases with age and doubles every 10 years until the menopause, after which the rate of increase slows. At the age of 50+, it is more likely that many patients will be in a long-term, cohabiting relationship or marriage – this may not necessarily be the individuals' first marriage (Office for National Statistics, 2009). In addition, the survival rates for breast cancer have been improving, with cancer sometimes going into remission on a long-term basis. It has been widely documented that breast cancer affects the whole family, not just the patient alone, and the effect that cancer has on a family could potentially have an impact on the way the patient adjusts to their illness (Ben-Zur et al., 2001). It is therefore important to consider and investigate the effects that breast cancer has, not only on the patient, but on their partner and other family members and friends. The literature presented in the scoping review has revealed that social support may play an important role in buffering the effects of breast cancer and may influence how women with breast cancer and their social support sources and networks cope with the illness.

Social support is an interpersonal process (Fingeld-Connett (2005) which is centred on the reciprocal exchange of information and is context

specific (Coffman & Ray, 2002). In particular emotional, instrumental, informational and appraisal support may be sought and provided. Preceding the provision of social support is the need for this and a social network that will be able to provide this.

One's social support network is a critical factor in the physical and emotional recovery from breast cancer treatment. Previous research has focused on the partner or spouse of the woman with breast cancer rather than on other family members, so further investigation is warranted on a wider variety of significant others. The social support process is dynamic and changes in response to challenging circumstances (Makabe & Hull, 2000) so the social support needs of the women with breast cancer may change at different points in the illness trajectory. As treatment for breast cancer improves and individuals live much longer following diagnosis, more research is required on the needs of partners and family members and, as the scoping review has demonstrated, experiences of breast cancer are not limited to the patient only.

It is important that practitioners recognise these needs alongside those of the patient. In addition, stress associated with cancer may extend for several years post-diagnosis (Nijboer et al., 1998). It has also been established that in some cases one of the main sources of social support is the spouse of a woman with breast cancer and that spousal social support has an association with how an individual copes with their illness. The findings in the scoping review have also noted that the spouse may not be perceived as the main source of support. If this is the case, then it is relevant to identify who this source is. The theoretical framework on dyadic coping is limited to the intimate relationship, but it may be possible for this framework to be applied other dyads. Along with the main dyad, there may be other individuals who

form part of a larger social support network for the women with breast cancer and this social network may influence the dyadic relationship.

Finally, the literature that has been discussed in Chapters 1 and 2 includes both qualitative, quantitative and mixed-methods approaches. This thesis is exploratory, concerned more with description and explanation, rather than quantifying the phenomenon of social support in the breast cancer context. Indeed the quantitative studies investigating social support have already attempted this. Therefore a qualitative approach was considered appropriate as it allows for a deep understanding of social phenomena (Silverman, 2000).

2.10 Research Questions

This thesis aimed to understand the role of the male partner in supporting the woman with breast cancer. It also aimed to understand the social networks of women with breast cancer in terms of the perceived sources of support and types of support provided. Finally this thesis aimed to explore the dyad with respect to social support and coping in the context of breast cancer. It aimed to investigate the dyadic relationship between the patient and a significant other including, but not limited to, their male partner. In addition, this research sought to understand the wider support networks of women with breast cancer and the extent to which they had an impact on the coping of the woman with breast cancer. Research questions pertaining to this are:

1. What role does the male partner play in supporting the woman with breast cancer?
2. Who are the sources of support that help women with breast cancer and what type of support do they provide?

3. Does social support provision and needs change along the illness trajectory?
4. Who is considered to be the main source of social support in the breast cancer context?

2.11 Summary

This chapter presented a scoping review of the literature related to breast cancer and social support, specifically to determine the role of social support and the impact this may have on the women with breast cancer involved in an intimate relationship, establish current findings relating to (dyadic) social support links in the breast cancer context and understand perceptions of family members of the support they provide, their needs and their own levels of psychological distress. A narrative synthesis of the findings identified social support and impact on family members as main themes in the analysis. The rationale for the thesis has been presented and the research questions stated.

3. METHODOLOGY & METHODS

3.1 Introduction

This chapter provides details regarding the research process. First the researcher's philosophical position which underlies this research is discussed. This determines the choices of research methods and the decision to use semi-structured interviews as the main process of data collection with breast cancer survivors in Studies 1, 2A and 2B and in Study 3, with an individual who was perceived to provide the most support to them. The participants and recruitment process are discussed. Details of how the interviews were conducted followed by a description of data analysis follows and the issue of reflexivity will also be discussed. The chapter finishes with the ethical considerations relevant to this research.

3.2 A Critical Approach and Interviewing Participants

Ontologically, the foundation for this research is embedded in the belief that social reality is an ongoing construction by individuals. Discourses created as a result of variation of people's roles and the world shape social reality and the study of it.

Epistemologically underpinning this research is a post-modern paradigm. Social knowledge is actively constructed and people make meaning of their experiences – this involves interpretation of what happened to them, evaluation using their current perspective and conclusion of what those experiences mean to them. Their construction will depend on current assumptions about the self and the world,

conflicting assumptions that they may encounter and the context in which the experience occurs.

The traditional approaches to research in the 19th century favoured quantitative research methods, where objectivity and deduction were key concepts in defining and understanding reality. A post-modern paradigm acknowledges that reality can be constructed through knowledge. This knowledge is subjective and can be constructed through human interaction (Gergen, 1991). There is clearly an underlying reality, but post-modernism assumes that knowledge and truth that is acquired will never be complete, that it is relative and that no single method can capture the variety and variability of human experience (Hoffman, 2005).

Whilst there is an underlying reality, interviews such as the ones that will take place as part of this research are about constructing versions of that reality through conversation between the researcher and participant (the rationale for using a qualitative approach is explained in the next section).

Potter and Hepburn (2005) highlight some important issues relating to qualitative research that will be considered throughout this research:

The deletion of the interviewer - The participants talk may be taken out of context (Smith, 2003). The researcher (who attends the interview with pre-existing ideas about the topic, based on theoretical literature) will inevitably affect the interview questions asked and the direction of discussion. The participant will respond to those particular questions in

a certain way which may or may not be replicated on another occasion. In this research, particularly in the analysis chapters, the researcher will be mindful to present quotes in a contextually accurate way. During the data collection stages the researcher will ensure that interruption of the verbal construction of knowledge (through asking for clarification/following up statements) is minimal but that conversation is focussed on the topic of social support in the breast cancer context.

This epistemological basis illustrates the dyadic approach to interviews where there is a fluid, interactive process, negotiated by the researcher and participant, both of which are considered to have their own areas of expertise. This framework could be used to pre-empt the use of more indirect questions where more direct questions may bias responses or alienate the participant. The researcher can also help the participant consider different aspects and consider the social processes that the researcher aims to understand. In this research, the position of the researcher is to help guide the participant through the interview, with the aim being to explore topics as outlined in the research questions. Although the researcher has expertise with regards to conducting interviews, particularly with asking open-ended questions and probing participants for relevant information, it is the participants who have experience of the topic of breast cancer. To minimise the influence of the researcher's knowledge on the participant, a jargon-free interview schedule will be developed to ensure that participants are constructing their version of reality, and not what they are expecting the researcher to hear.

The conceptions of representation of interaction – Jefferson (1985) proposed the presentation of interview transcripts using various conventions to represent features of speech, e.g. changes in intonation, pauses, etc. Potter and Hepburn (2005) argue that standard orthographic versions of transcripts miss conversationally live features. Although the full Jeffersonian representation of discussion addresses the socially engaged and jointly constructed dialogue, given the time constraints in this research, it would not be plausible to create transcripts beyond the standard orthographic version. In addition, as the researcher was actively involved in all stages of data collected i.e. the researcher interviewed all participants and transcribed all interviews, there was a high level of familiarisation with the data where it was not deemed necessary to include conventions of speech.

3.3 The qualitative approach

3.3.1 Rationale for the qualitative approach

The four studies presented in this thesis were designed to answer the research questions: what impact does breast cancer have on social relationships, what role does the male partner play in supporting the woman with breast cancer, who are the sources of support that help women with breast cancer and what type of support do they provide, and who is perceived to provide the most support? The overall aim of the thesis was to conceptualise the social support provided to women with breast cancer and their perceptions of this. Therefore the objectives of the four studies in this thesis were exploratory, concerned more with description and explanation, rather than quantifying this phenomenon. The qualitative approach was considered appropriate as it allows for a deep understanding of social

phenomena (Silverman, 2000). The qualitative approach is also useful for generating theory (Brown & Linford, 2008) through the organisation of individuals' accounts of their experience. The research in the field of breast cancer and social support would benefit from a qualitative approach as quantitative data represents a single dimension of knowledge (Mason, 2002). In addition the advantage of qualitative data is that the researcher can gain an understanding of reasons for actions and motivations. It can be used to provide insight into a problem, generating ideas or hypotheses for later quantitative research. Questionnaires that have been used frequently in breast cancer research would not provide the breath of detail required to answer the research questions proposed.

When considering the research questions, the use of quantitative methods would not be appropriate for this thesis. To answer the research questions, participants were asked to describe aspects of their lives in detail as part of a semi-structured interview which would not be possible through a survey or questionnaire. One-to-one interviewing was used because the topic may have been too personal to discuss in a focus group, particularly if participants did not know each other beforehand. Therefore one-to-one interviews were used in Studies 1, 2A and 2B. In investigating the breast cancer dyad in Study 3, the decision to interview two people at the same time was based on the fact that these individuals would be known to each other and of course, allowing the dyad to be explored.

3.3.2 Rationale for using semi-structured interviewing as a research tool

Unstructured interviews are popular in qualitative fields of research. It allows the participant to talk at length without the interruption of an interviewer. As this research aimed to understand social support in the context of breast

cancer, this was not considered to be a suitable method. In this respect, the participant would talk freely about social support sources that they deemed worthy for discussion without any external influence from the researcher's own agenda. This is particularly advantageous as the interview may inadvertently interrupt the participant's flow of speech which may result in the loss of information. However as this method of interviewing is unrestricted, there may not be a particular focus to the discussion and therefore the interview transcripts may not provide any data that adequately answers the research questions. Following this, the transcription process and analysis of data takes time and there is the problem of having too much irrelevant data with regards to the research questions. In addition, there are specific research questions and so it was of particular importance that these could be answered in the timeframe allowed for each interview. As such, unstructured interviews were rejected due to the fact that they are inappropriate to use in this thesis in this research. In contrast, structured interviews consist of a set of pre-determined questions to be asked in a set order with little flexibility (Burgess, 1984).

Using focus groups allows the researcher to carry out group interviews of up to 5-6 people (Sparkes & Smith, 2013). It allows individuals to share common experiences, which in some cases can be positive for the participant. It could potentially allow participants to speak more freely, allowing rich data. However there is the issue that certain individuals may dominate the session. In addition, core focus of the group session can be lost due to the number of individuals contributing to the discussion (Silverman, 2007). Due to the sensitive nature of the topic, it may be unrealistic and even unfair to ask participants to disclose personal details about themselves to several strangers. In addition the research questions are interested in individual, personal

experiences which would be more appropriately discussed in a one-to-one setting. Focus group methods were rejected on the grounds of this reason.

Semi-structured interviews were chosen as the interview method for this study. An interview guide was developed prior to conducting interviews, containing set themes and predefined questions, so that relevant questions were asked which pertained directly to the research questions. The order of questions and exact terminology can vary between interviews to allow more of an informal, conversation feel (Patton, 1990). If the conversation digressed from the focus of the discussion, a new question could be introduced. The flexibility of semi-structured interviews allowed the researcher to explore themes or issues that were suggested by the participant, which may not have been considered when developing the initial interview schedule (Patton, 1990), provided that they are relevant to the research aims. This allowed for unpredicted themes to emerge. Finally a semi-structured style of interviewing was chosen because it was important that certain core questions were answered by participants and therefore an interview guide was needed.

3.4 Methodological Triangulation in Data Collection and Analysis

Triangulation in social science is defined as “the mixing of data or methods so that diverse viewpoints or standpoints cast light upon a topic” (Olsen, 2004, p3). Commonly used in the field of social science is the use of quantitative and qualitative methods in the same study. Denzin (2009) identifies four different types of triangulation (Data, Theoretical, Investigator and Methodological) and Guion et al. (2011) proposed Environmental Triangulation. In this research, methodological triangulation is implemented as the four studies presented use different methods of data collection in an attempt to answer the research questions.

Methodological triangulation involves using two or more qualitative and/or quantitative methods to either gather data (e.g. interviews, focus groups, questionnaires etc.) or analyse data (e.g. statistical analysis, qualitative analysis, etc.). Methodological triangulation can be further distinguished (Denzin, 2009) into two groups; between methods triangulation and within methods triangulation. Between-Methods Triangulation refers to the use of both qualitative and quantitative methods in the same study, used for the aim of testing the degree of external validity and achieving convergent validity (Hussein, 2009). In contrast, Within-Methods Triangulation involves the use of two or more complementary qualitative OR quantitative methods in the same study, for example using two different statistical analyses on the same data set, or two different types of qualitative data collection, e.g. interviews and focus groups. This involves an increase in internal validity of the research findings. If more than one type of triangulation is used (e.g. both data and methodological triangulation), these are referred to as multiple triangulation studies. This study specifically uses Within-Methods Triangulation, in that three diverse but complimentary qualitative methods are used to collect data on the subject of social support and breast cancer.

Triangulation in research is a heavily debated topic. On one hand, it can be argued that triangulation can increase the depth of understanding of a specific phenomenon (Olsen, 2004). On the other hand, others have argued that triangulation is used to increase study accuracy and, in fact, triangulation is used as a validity measure (Golafshani, 2003). It is important to note that triangulation is not the only criterion for good qualitative research and it does not ensure that findings are interesting and give appropriate answers to research problems (Decrop, 1997).

There are instances where qualitative researchers have used triangulation to check and establish validity in their studies by investigating research questions from a number of perspectives (Guion et al., 2011). However there is a misconception that the goal of triangulation is to have consistency across data sources: Patton (2002) argues that inconsistencies, in fact, are likely due to the strengths of different approaches and these inconsistencies do not weaken evidence but rather provide the opportunity to explore deeper meanings. This thesis will use a variety of qualitative methodologies to understand the research questions, which are presented as four separate chapters. The researcher is using Within-Methods Triangulation specifically to gain a deeper understanding and meaning of the subject area. Having different methods of data collection will also increase the credibility of the findings.

3.4.1 Triangulation Procedure

Table 3-1. Overview of the Triangulation Procedure (Developed from Meijer et al., 2002).

Step	Study	Research Theme	Method	Analysis	Outcomes
1	1	Perception of male partner	Interview with BC survivor	Thematic	Themes
2	2a	Social support network	Interview with BC survivor + Ecomap	Thematic	Themes
3	2b	Social support network	Interview with BC survivor + Ecomap	Case Study	Ecomap to depict relationships
4	3	Dyadic coping	Interview with BC survivor and nominated support source	Case Study	Development of new themes related to dyadic coping

Step 1: Analysing semi-structured interviews from Study 1.

The first step in the triangulation procedure consisted of understanding the role of the male partner when supporting the woman with breast cancer.

Interviews took place with a breast cancer survivor. The data collected consisted of five transcripts of the interviews which were thematically analysed.

Step 2: Analysing semi-structured interviews from Study 2A.

The second step involved understanding the wider support network of the woman with breast cancer. Interviews took place with a breast cancer survivor.

The data collected consisted of ten interview transcripts and ten ecomaps. All individuals who took part in the ten interviews were asked for their consent to be included as an individual case study, of which three agreed. Of these ten interviews, seven were used in a thematic analysis and the remaining three were used as case studies in Study 2B (see next paragraph). In this study, the ecomaps were used purely as an elicitation cue or prompt to help facilitate thorough discussion of the topic. The interview transcripts were thematically analysed. The themes that emerged were compared with those found in Study 1, resulting in a validation of some of the themes but primary development of new themes and subthemes.

Step 3: Producing Case Studies – Exploring the social support networks (Study 2B)

The third step involved using a series of three case studies to illustrate the themes that were found in analyses from Studies 1 and 2A. In addition to this, ecomaps which were used as an elicitation tool in the interview were also used as a visual representation of the social support network.

Step 4: Understanding the Dyad (Study 3)

The final step involved interviewing breast cancer survivors with an individual who they considered to be a main source of support. These three interviews are presented as case studies.

3.5 Research design

The data collection method for all three studies involved semi-structured interviews. Study 1 included interviews with breast cancer survivors. Studies 2A and 2B used ecomapping (discussed in the next section) as an elicitation tool in one-to-one interviews with breast cancer survivors and finally, Study 3 involved joint interviews with breast cancer survivors and an individual that they considered to be a main source of support to them.

3.6 Methods

3.6.1 Participants

Participants invited to take part in the study were either breast cancer survivors or individuals who has been appointed by a breast cancer survivor as their main source of social support or significant other. The sampling approach in this thesis was purposive, as the researcher actively selected the most product sample to answer the research question (Marshall, 1996). Characteristics of these two groups of participants are given below:

1. Participants - Breast cancer survivors (Studies 1-3)

Eligibility

Individuals were eligible to take part in the study if they had previously been diagnosed with breast cancer and were no longer receiving hospital-based treatment.

Inclusion Criteria

1. The participant was required to be older than 18 years old. There was no upper age limit, providing that the individual was not affected by Alzheimer's disease or other forms of dementia.
2. The participants had been cohabiting with their partner for more than six months prior to diagnosis. The thesis aimed to look at the shared coping of the woman with breast cancer and their partner, couples who live together are more likely to share the experience than those who live in different residences. In addition, if couples have lived together for more than six months before diagnosis, then any changes that occur will be more prominent.
3. More than one year since the diagnosis of breast cancer. Individuals who are recently diagnosed/whose partners are recently diagnosed may find their experiences are too distressing to discuss in detail as part of this study. As the joint narrative which is developed over time is of interest, newly diagnosed couples are unlikely to have developed their narratives at this stage.
4. The breast cancer must be in remission for more than three months.
5. The individuals must be fluent in spoken English. This is so potential participants can fully understand the aims and objectives of the study before they choose to take part and are able to give full, informed consent.

Exclusion Criteria

1. If the patient or partner suffered with any other health problems at the time of interview which involved regular hospitalisation. All studies focussed on breast cancer and should any member of the dyad be experiencing other enduring health problems, it will be difficult to differentiate the effect of breast cancer on the dyad from current health problems that they may be experiencing.

2. Participants - Nominated source of support (Study 3 only).

Eligibility

Individuals were eligible to take part if they were identified as a main source of social support to the participant, by the participant.

Inclusion Criteria

1. The participant was required to be older than 18 years old. There was no upper age limit, providing that the individual was not affected by Alzheimer's disease or other forms of dementia.
2. The participant had known the breast cancer survivor for more than one year prior to diagnosis.
3. More than one year since the diagnosis of breast cancer.
4. The women with breast cancer must be in remission for more than three months.
5. The individuals must be fluent in spoken English .

Exclusion Criteria

1. If the partner or the breast cancer survivor suffered with any other health problems at the time of interview which involved regular hospitalisation.

3.6.2 Recruitment

Recruitment was a continuous, ongoing process once ethical approval was obtained, from December 2010 until June 2013. Breast cancer survivors and significant others of breast cancer survivors were recruited via a variety of methods outlined below.

3.6.2.1 Recruitment from face-to-face cancer support groups

Participants were recruited from face-to-face self-help groups for women with breast cancer and their families, based in the East Midlands area. The groups were limited to this geographical area as it was desirable to keep the distance for the researcher and the participant to travel to attend interviews to a minimum. These groups were identified by using an Internet search, from which eight local groups were identified. The researcher contacted the moderator or facilitator of the self help group first. This is because the perception of such self-help groups as a “safe place” for its users was very important, and the researcher did not want to jeopardise or infringe on this in an inappropriate way. It was important that potential participants did not feel that they were being approached purely for the sake of the research. The researcher initially contacted the facilitator of the face-to-face breast cancer support groups to discuss the aims and objectives of the research. The facilitator then passed on this information (via information sheets that were emailed to them) to members of the self-help group. If appropriate for the face-to-face self-help groups, the researcher delivered a short presentation to the potential participants and allowed them to ask any questions. A short presentation was given at one Breast Cancer Support group and details of the study were passed on to members for seven Breast Cancer Support groups. Participant information sheets were provided so that the potential participants were fully aware of the aims, risks, benefits and consequences of taking part in the research. In addition, the email address of the researcher was included in this leaflet. Individuals were asked to contact the researcher directly if they were interested in taking part or if they required any further details. On completion of all studies, the researcher planned to give a short presentation to all participating face-to-face self-help groups to describe the findings of the

research and their implications, should they be interested in hearing the findings.

3.6.2.2 Recruitment from online cancer support groups

Online support groups were identified using an Internet search. In particular, three breast cancer-specific forum and five non-specific cancer groups were found. For online recruitment, the moderator or gatekeeper of the discussion boards on various cancer internet forums was contacted first and informed the researcher of the appropriate way to present the recruitment information on the website (and any permissions required). For both breast cancer forums, the moderator posted on behalf of the researcher, detailing the study and contact details of the researcher. One non-specific cancer group consented to study details being published on the forum. The moderator of this forum gave details to the researcher on the most appropriate location for a study recruitment post. This was then posted by the researcher, giving details of the study including an email address to contact the researcher if interested in taking part. On completion of all studies, a summary of findings was provided to all participants.

3.6.2.3 Recruitment from community-based organisations

Posters and leaflets were distributed at various community-based organisations within Nottingham. Examples of locations that consented to having the posters and leaflets displayed included charity shops, places of worship, staff rooms at various business, community centres, council buildings and local libraries (as before, managers were consulted and approved of the posters and leaflets being on display). All posters and leaflets had the contact details of the researcher so that interested people could get in touch with the researcher.

3.6.2.4 *Other recruitment efforts*

A meeting with another PhD student (DT) based in the School of Sociology at the University of Nottingham was arranged. Her PhD was also looking at a sample of breast cancer survivors and she and the researcher discussed some of the difficulties of recruitment as at that time, very few individuals had agreed to be interviewed. Some potential recruitment strategies were discussed, including organisation of the University to publish a press release. This student also agreed to email participants of her study with contact details for the researcher to see if any would want be willing to take part in the current research.

The press release which provided details of this research resulted in a ten minute interview on BBC Radio Nottingham to discuss the current research, along with a breast cancer survivor. This radio appearance resulted in individuals contacting the researcher, wishing to take part.

In addition to the above recruitment efforts, the researcher asked family, friends and colleagues if they knew of anyone who may be eligible and encouraged individuals to pass on the contact details of the researcher to any individuals.

Finally, the researcher used social media platforms Facebook, Twitter and Linked in to create interest in the study. This was done by:

1. Asking friends to share the researchers' status on Facebook with details of the study along with contact details of the researcher.
2. Asking for retweets from appropriate users on Twitter e.g. @PhDForum, @BPSDHP and also using the hashtag #breastcancer and #breastcancerresearch so that the tweet was visible to anyone who searched those words.

3. Posting about the study in relevant groups on LinkedIn which were visible, open groups e.g. Breast Cancer Survivors.

A flowchart detailing participant recruitment can be found in Figure 3-

1.

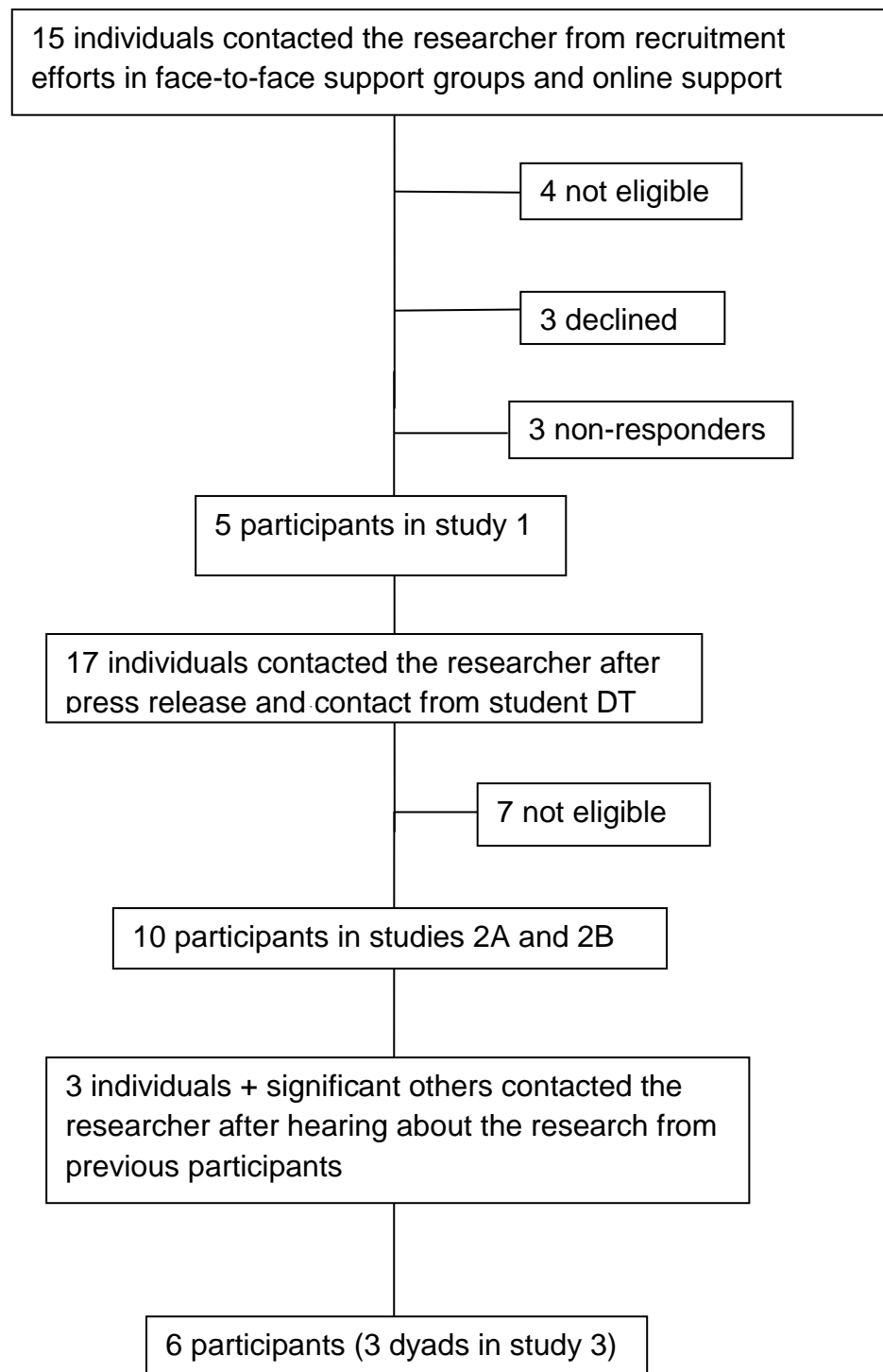


Figure 3-1. Recruitment uptake in this research.

3.6.2.5 Issues with recruiting male partners

The recruitment stages outlined above did not yield any interest from male partners of breast cancer survivors though breast cancer survivors did express an interest. Those who contacted the researcher were asked whether it would be possible for their partners' contact details to be passed on to the researcher so that she could contact them directly about participation. If they did not agree, the researcher asked the female participants to pass their contact details to their partner so they could contact the researcher directly if they were interested in participating.

To target men specifically, the researcher visited pubs in the local area and left leaflets if the manager/landlord of the pub consented to it. In total, 31 pubs consented to leaflets being left. None of the approaches outlined in this section or the previous section were particularly successful and only one male partner is included in this thesis.

3.6.2.6 The consent process

When individuals contacted the researcher to express an interest in taking part in the study, the researcher took several steps before confirming that they could take part. First the aims of the study was explained via email in all cases and the potential participant was given the opportunity to ask questions.

Second the researcher checked the eligibility of the participant by asking their age, if they had a male partner and if so, how long they had been co-habiting, how long since they finished their treatment and also if they were undergoing hospital based treatment involving another chronic disease. If the participant was eligible, the researcher then explained factors such as confidentiality and anonymity to the participant as well as showing potential participants the information sheet for the study. Those who were not eligible were not

interviewed, but were asked by the researcher if their details could be kept if a more appropriate study took place in the future, carried out as part of this thesis. If they were happy to proceed, an interview was arranged where they were given written information about the study and a consent form to sign.

3.6.2.7 Justification of Sample Size

The term “saturation” is widely used in qualitative research, which can simply be defined as “data accuracy” – the point where no new information is obtained using additional data (Morse, 1995). There are no standard tests for estimating or proving an adequate sample size in qualitative research (Kerr et al., 2010). It has been argued that it is a matter of judgement and experience on the part of the researcher to recognise the stage of saturation (Sandelowski, 1995; Bowen, 2008).

This thesis argues the case for saturation according to the above definition. The exact number of participants required to reach saturation in a study cannot accurately be estimated in advance, as this will depend on a number of factors (Marshall, 1996). These factors include the scope of the study, the nature of the topic and the amount of useful information obtained from each participant (Morse, 1995; 2000; Sandelowski, 1995). This study intended to recruit 6 participants for Study 1, 10 participants for Studies 2A and 2B and initially planned to recruit at least three different dyads for Study 3. For the Study 1, five participants took part rather than six as the researcher felt that due to lack of male participant uptake, saturation had been reached. Finally, it is believed that the number of participants who took part in the studies was sufficient to answer the research questions present in Chapter 2 and that the sample for each study consisted of participants who best represent the research topic (Morse, 2002).

3.7 The Interviews

3.7.1 Arranging interviews

Interested individuals who contacted the researcher were asked questions that related to their eligibility to take part in the research. For individuals who did fit the participant criteria for these studies, the next step was to arrange an interview.

1. Face to face interviews.

Individuals who lived in the East Midlands area were invited to take part in a face-to-face interview at a time and place convenient for them. Three interviews in Study 1 and all interviews 2A, 2B and 3 took place in person.

2. Skype interviews.

Individuals who were recruited from online support groups were located in various locations around the United Kingdom. In all cases, it was not feasible to arrange a face-to-face interview in person, so arrangements were made to conduct the interview over Skype. This was arranged at a time of mutual convenience. Two participants were interviewed over Skype.

3.7.2 Interviews Setting

Each participant was interviewed at a time and venue of convenience, including their own home or at the Institute of Work, Health and Organisations based at Jubilee Campus, University of Nottingham.

3.7.3 Interview Procedure

The setting of each interview followed a predetermined routine. An information sheet was given to the participant and this was also read aloud by

the researcher, who invited the participant to ask any questions or raise any concerns. The participant then signed a consent form which contained details which were again read aloud by the researcher. In all cases prior to the actual interview, the researcher spent approximately 5 minutes having a conversation with each participant which did not mention the research project but related to either the researcher's or participant's ease at finding the location of the interview. The reason for this was to help the participants feel more relaxed and so able to speak more freely about their experiences and to start building a trusting rapport (Douglas, 1985). However the researcher wanted to ensure that the participants did not misinterpret the relationship as being that beyond an interviewer and interviewee which would be considered somewhat exploitative in an attempt to encourage the participant to share more, hence why the topic of travel to the interview location was discussed. The digital recorder was then switched on and the interview would commence. Each interview concluded with the researcher inviting further comments from the participant. The participant was given a Post-Information leaflet and thanked for their time.

Each interview was recorded using a Samsung Digital Audio Recorder..

Following interview, the audio files were stored at the University for seven years in line with the Data Protection Act.

3.7.4 Using Ecomaps as an elicitation tool in Studies 2A and 2B

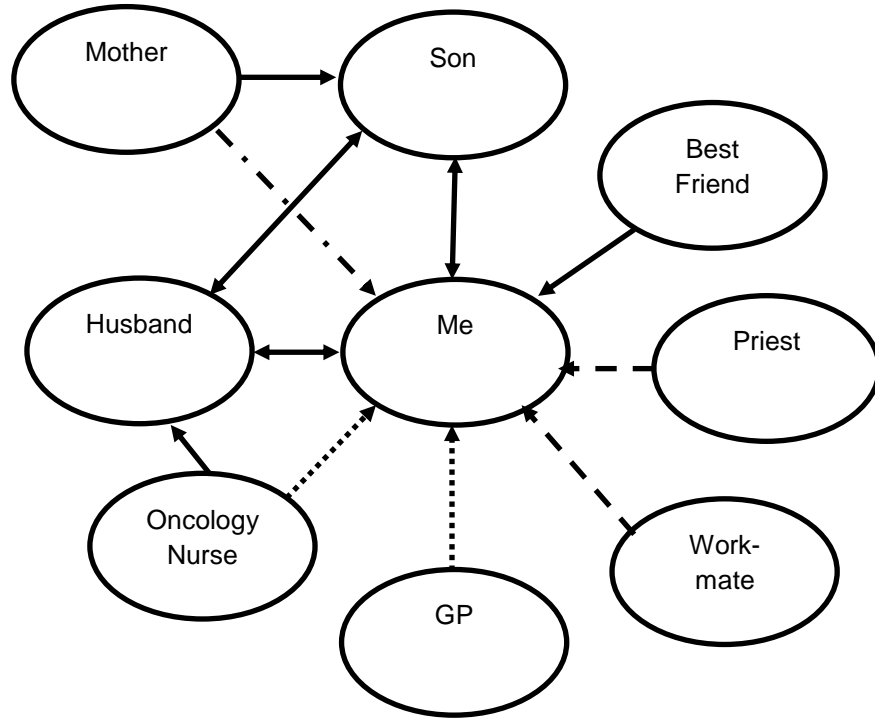
As discussed in chapters 1 and 2, the need for social support with regards to maintaining good health and coping with illness has been widely documented (Berkman, 1995). Ecomaps have been used as a clinical tool in social work and this has been shown to create a valuable tool for data collection. First created by Hartman (1995), the word "ecomap" is derived from the word

“ecology” – the study of the connection between a living thing and its environment and how the connection in question is maintained and enhanced. It depicts the structure and strength of family and social relationships. It has been adapted by nurse researchers investigating the social networks of informal carers of people living with motor neurone disease (Ray and Street, 2005). Hartman’s ecomaps encompass the human elements of ecology or the social relationships and systems that people have developed to help them interact with the physical and social environment which they live in. Therefore people develop relationships which allow them to provide resources, such as information, practical assistance and emotional support to assist with their everyday lives. An ecomap provides a visual representation of the relationships by means of a depiction of the network that exists between members of a social group and their connections with larger social networks (Wright & Leahey, 2000), which give researchers evidence relating to the size, structure and function of that network. (Tracy et al.1994). They can also be used as opportunities for patients to confirm or refute what they have said in the interviews (Lugton, 1997).

Three main ideas that are fundamental to the development of ecomaps are relationships, social support networks and support. A relationship refers to any personal interaction or sense of connection that arises from mutual feelings (dictionary definition) and these relationships will adapt and change over time (Hartman, 1995). In this research, an individual’s social network is defined as “*a cooperating group of significant others with whom the person interacts in their daily life*” (Ray & Street, 2005, p546). The concept of social networks implied both social interactions, actions and communications amongst groups of people, and social connections or bonds that exist between people in the context of their day-to-day lives (Giddens, 1990). Supportive networks are those who the individual says has a beneficial effect on their life.

Members of the support network could be from personal relationships, including family and community ties, or they could be from institutional connections, such as work connections or interactions with the health care services.

Ecomaps consist of an inner circle that contains the person of interest (in this case, it will be the breast cancer survivor), surrounded by other circles which represent other individuals within their social network. Relationship lines are drawn between the inner circle and outer circles which depict the strength of the relationship and flow of resources. Although the strength of relationship can be represented in many ways, strong relationships are represented by thick lines, weak relationships are represented by dotted lines and unstable or problematic relationships are represented by wavy lines. In addition to the lines, comments can be written alongside for clarification. Arrowheads can be used to indicate the flow of resources (Hartman, 1995; Wright & Leahey, 2000). An example of an ecomap is shown in Figure 3-2. The ecomap shows the individual of interest in the centre of the ecomap and various social support sources are displayed in circles. The relationship between sources is represented by the lines and the flow of resources indicated by the arrowheads, e.g. The person of interest has a weak relationship with the priest who provides them with support.



- Indicates direction of support →
- Strong relationship ———
- Problematic relationship - - - - -
- Weak relationship - - - - -
- Acquaintance relationship ·····

Figure 3-2. Example of an ecomap.

There are three potential ways of mapping. The first is for the researcher to construct the map (as an outsider), which means that the participant would have no influence over the finished ecomap, which is often used in shorter interviews. This would decreased the validity of the final ecomap as the participants would not have had an opportunity to interact with the ecomap or

explore their social network either by themselves or with the researcher. The second approach would be to allow the participant to construct the ecomap themselves without any influence from the researcher. Again, the validity for this approach may also be limited as the participant may forget to include elements of importance (Tracy et al. 1994). The third approach involves developing an ecomap as part of a collaborative discussion. Methodologically, this is the most appropriate approach for ecomapping as it is more interactive and reflexive. It allows the participants to consider their social networks and allows the researcher to prompt them to consider elements that they may have forgotten. It is important to ensure that the ecomap itself is constantly being negotiated with the participant, so as to not influence the outcome so that the data is the accurate perception of the participant, and not what is perceived or led by the researcher. As the ecomap is being constructed, the research can also use the emerging ecomap data to ask questions which are relevant to the research topic.

Ecomaps provide a graphical representation of an individual's social network, therefore discussions will be easily facilitated based on the structure and the strength of the network. According to Ray and Street (2005), having a visual representation allows people to identify each member in their own network, examine the strength of the relationship and establish the course of the relationship over time. It is a helpful research tool, particularly when looking at social support networks as it incorporates the use of consistent symbols that are standardised amongst all recipient responses, allowing data comparisons. It is a useful research tool to help provide a visual representation to an individual's narrative.

Construction of ecomaps took place in Study 2A and 2B. After spending a few minutes getting to know the participant, an overview of the

study was reiterated and the outline of the interview was clarified. The first stage involved an explanation of an ecomap and the relationship mapping process was explained with the aid of an example (the data within the example ecomap was fabricated) by the researcher. This was a simple diagram of an ecomap where examples of different relationships were shown (see Figure 3-2 above). Using a simple representation to explain the concept of an ecomap allowed the participant to understand the process of mapping without getting distracted by unnecessary details. It allowed participants to understand how different relationships could be depicted and gave them the opportunity to begin to think about who might be included in their own ecomap.

3.8 Analysis of Results

3.8.1 Thematic Analysis

The results from the studies were derived using thematic analysis (Braun & Clarke, 2006), using an inductive, data driven approach where no a priori themes were identified, resulting in all themes produced being derived directly from the datasets themselves (Patton, 1990). Thematic approach was chosen an appropriate method for analysis as to does not privy to a strict epistemological position. As such, it does fit in with the researcher epistemological positioning of Critical Realism. The flexibility of thematic analysis is also considered to be one of its weaknesses, where it could be considered to be too subjective. It is also acknowledged that the researcher's interests and background knowledge may also influence the rigour with which thematic analyses were conducted. To address this issue of flexibility, guidelines produced by Braune and Clarke (2006) were followed strictly and issues related to reflexivity are also discussed.

There were several steps which took place when conducting thematic analyses of the datasets:

1. Familiarisation with data.

As transcripts were transcribed by the researcher, there was already a level of familiarity with the data prior to the actual analysis processes. Transcripts were double-checked against the audio-recordings for accuracy and then read at least three times for the researcher to continue to familiarise herself with the data.

2. Initial coding of data.

The next stage of analysis involved coding the data with basic labels, essentially on a semantic level. All data sets were subject to this initial step, with the codes produced being the very basic level of analysis with little deviation from what was present in the text. This produced a large number of codes and so the next stage of coding revisited this.

3. Revisiting the codes.

Revision of codes occurred by grouping together basic codes which addressed the same phenomena. In doing this, the revised codes (nodes) allowed the data to become more manageable and condense original codes related to the same phenomena into smaller chunks of meaningful information. This was done by extensive and constant comparison with the raw data to ensure that the revised codes still reflected the essence of the basic codes within it. These revisions meant that these codes were now the lowest level of data analysis and will now be referred to as “subthemes”. The next stage of the analysis was to develop themes to describe the subthemes and any patterns that emerged.

4. Development of themes

Themes were developed by clustering sub-themes together in groups based on shared characteristics. The boundaries of the themes were revised by limiting or extending their description (Braun & Clarke, 2006). This was an iterative process, with the final themes dependent on continuously revisiting

the raw data, as well as the sub-themes, to ensure that the final themes reflected what was present in the raw data. At this stage, there were three levels of categorisation: first the nodes which were clustered together to make up a subtheme and subthemes which were clustered together to make a theme.

5. Refining the themes.

This stage involved looking at links between themes and assessing the appropriate level of themes and sub-themes. This stage required input from the supervisors of the project and as with the previous stage, required continuous reappraisal of the themes and subthemes until a consensus was reached by all members of the research team.

3.8.2 Reflexivity

One of the main challenges of qualitative research is that the researcher's background and position will affect what they choose to investigate, the angle of investigation which they take, the methods they choose to employ, the findings that they consider appropriate and the way in which this is communicated. Haraway (1991) defines objectivity as the recognition that knowledge is partial and situated and therefore the effects of the positioned researcher need to be addressed. Finlay (2002) describes reflexivity as a personal accounting of sorts considering how the researcher impacts on the research. Reflexivity involves continual assessment of the researcher at every stage of the study and Haraway (1991) suggests that these assessment outcomes be shared. Giorgi (1986) states that a researcher will always enter a field of research with certain opinions about it. Reflexivity begins by identifying these preconceptions and drawing on previous personal and professional experiences, pre-study beliefs about what is to be investigated and motivations for this.

To address the issue of reflexivity, the following information is disclosed regarding the researcher.

3.8.2.1 The Researcher's Story

I am a British female of Indian ethnic background, born to professional parents in the south of England. When data collection began I was 24 years old and I was 26 when it ended. Growing up, my father worked as a GP and my mother worked alongside him as the Practice Manager. My two older sisters completed medical school before I moved out of the family home to attend university. Consequently, the occupations of my close family meant that health and illness were naturally of interest and as a consequence, I studied for a degree in Psychology and an MSc in Health Psychology. A personal experience of breast cancer fuelled my interest in the topic. A close family friend, was diagnosed with breast cancer and underwent chemotherapy. She was married to her husband for over 30 years and unfortunately, he passed away shortly before she had completed treatment and her cancer was diagnosed as being "in remission". This reliance that this woman with breast cancer had on her husband became apparent after his death, however she found comfort in other family members, neighbours, friends and colleagues.

3.9 Ethical considerations

Ethical approval for all studies was obtained from the Institute of Work, Health and Organisations, University of Nottingham Ethics Committee. However, with regards to all studies, there are some points that require consideration. These are explained in further detail below, with focus on how harm and distress was minimised, so that the experience was considered to be a positive one by everyone involved in all of the studies. Specifically the studies adhered to the British Psychological Society Ethics Code of Conduct (BPS, 2009).

3.9.1.1 Participant Withdrawal

It was explained to the participants that entry into the research was entirely voluntary. It was also explained that they were able to withdraw at anytime providing that their data had not already been analysed.

3.9.1.2 Informed consent

All participants provided either written or verbal consent. The consent form was signed and dated by the participant before they entered into the study. Verbal consent was given in the instances where interview was conducted by Skype. The researcher explained the details of the study and provided a Participant's Information Sheet and ensured that the participant had sufficient time to read through this and consider whether they wish to participate or not. The researcher answered any questions that the participant had regarding study participation. In the instances where interview was conducted by Skype, the participant was emailed the participation sheet at least 3 days prior to interview.

3.9.1.3 Discussion of sensitive topics

Participants in all studies were required to recall life events that related to either themselves or the breast cancer survivor being diagnosed with breast cancer as well as their life experiences post-diagnosis. This may have been an upsetting and stressful experience for some of the participants. Exploring such a painful time may have caused the participants to feel a range of emotions, unfortunately some of which may have been negative. The researcher had previous experience of working within a mental health setting, where they were in contact vulnerable people. The researcher was empathetic and sensitive towards the participants. If the researcher felt that a particular topic was causing unnecessarily high levels of distress to the participant, the topic was moved away from. The researcher made it clear from the onset of

each interview that the participant could ask to stop the interview or take a break at any point. All participants were made aware of the risks, as well as the benefits of taking part in the research, and so full informed consent was obtained from all participants in each study. The fact that informed consent was given ensured that participants were made aware of the aims, risks, benefits and consequences of taking part in the research.

It was a possibility that participation in this study may have induced psychological stress or anxiety, but this was unlikely to be beyond that encountered in everyday life. Most individuals will have shared their experiences informally with family, friends and peers, so this means that the psychological stress and anxiety that they experienced whilst taking part in the study was unlikely to be greater than what they would normally experience. The researcher was confident that they would be able to interview the participants, while remaining empathetic and respectful. The participants were never made to feel humiliated, embarrassed or ridiculed by the researcher. As mentioned previously, if the researcher sensed that particular topics appeared to be causing high levels of distress, then that particular topic would not be probed further. All participants were fully debriefed post-interview. Here, participants were asked if they had anything else that they wished to share, prior to the termination of the interview. The researcher then asked participants briefly how they found the interview and whether they wished to discuss the experience. Should the interview have induced psychological stress or anxiety, then there are many professional teams that are trained to provide support to these individuals. Contact details of these specialised support groups were provided to all participants on a leaflet which they can take away with them. Therefore, all participants had the knowledge of how to access these services should they experience any distress. Participants were

reminded (if necessary) of the social support available to them. None of the interview did induce psychological stress or anxiety as far as the researcher was aware.

3.9.1.4 Audio-recording of interviews

All the interviews were recorded using a digital audio recorder. This was made clear to the participants before they consented to the interview, so there was no deception. As participants were required to provide informed consent, it was made clear to them that if required, they were free to withdraw at any time without giving reason. They were reassured that the data collected would be kept on a password-protected computer, which only the researcher had access to. Coding the data provided anonymity, so it would be difficult to trace their participation. Following data collection, participants were fully debriefed, and issues relating to confidentiality, anonymity and access to the data were explained to them once again. They were given the opportunity to discuss any issues with the researcher and provide feedback. It was also explained to participants that material would be written up for publication and presented at appropriate conferences to academic, clinical and service user audiences. The purpose of the interview was to ensure that participants were comfortable enough to discuss their experiences freely and openly. The recording device was unobtrusive, so it was not obvious that it was recording. To get participants used to the research setting (and to ensure the recording device was working), an informal discussion initially took place prior to the start of the actual interview. The transcribed interviews were saved onto a password-protected computer that only the researcher had access to. Identifiable information was not transcribed and all participants were given a pseudonym.

3.9.1.5 Risks to the researcher

The interviews may have involved discussion of traumatic or upsetting information. This may have had a psychological effect on myself, causing me to become upset or worried. I was aware of the negative psychological impact that this research may have, but was also aware of the methods of dealing with this: peer support with other researchers conducting similar research, to debrief and feel supported, academic supervision/support from supervisors Dr Nigel Hunt and Dr Shirley Thomas, professional support from a general practitioner and 24/7 anonymous help lines. E.g. Samaritans, Breast Cancer Care.

As I met alone with all participants the University Lone-Working Policy was followed. If I was travelling to meet with a participant, I informed my supervisor of who I was going to meet and where. After the end of the interview, I contacted my supervisor to inform them that the interview had finished.

3.10 Conclusion

This chapter has discussed various topics pertaining to the methodology and methods in this thesis. First the researcher's philosophical position of critical realism was discussed, followed by the justification of using interviews as a means of data collection. Recruitment efforts were stated and issues with this were highlighted. The thematic analysis process was discussed along with the issue of reflexivity. Finally the ethical considerations of this research were considered.

4. STUDY 1 – BREAST CANCER AND THE MARITAL DYAD

4.1 Introduction

The literature review showed that there is limited research which discusses the experience of women with breast cancer with regard to their male partner and social support. In particular, the experience of the partner is largely ignored with research focusing on the experience of the woman with breast cancer. To understand dyadic coping and the intimate dyad, this study sought to interview breast cancer survivors and their male partners but it was difficult to secure the male partners for interview (as discussed in Chapter 3). As such the aims of the study were modified, specifically to understand the perception of support provided by male partners and the study itself was ended sooner than expected, due to the lack of male participants. Specifically this study aimed to find out whether the male partner was perceived to be the main role of support, to ascertain the ways that they supported the woman with breast cancer and to understand whether there were other individuals who provided support.

4.2 Methods

4.2.1 Participants

The mean age of participants was 55.2 years (range 49 to 64). Participants had undergone a variety of treatments, including total mastectomy, lumpectomy, chemotherapy and radiotherapy. The time spent cohabiting with their partner ranged from 18 – 39 years, with a mean period of 27 years. The names used in this study are aliases given to the participants. A summary of the five participants can be found in Table 4-1.

4.2.2 The interviews

The interviews took place either in the homes of the participants or a location mutually decided by the participant and researcher between January-February 2011. An interview guide was developed and this was followed (see Appendix 2). Participants were encouraged to answer all questions. The mean length of the interviews was 67 minutes.

The interviews were transcribed verbatim by the researcher and the content was thematically analysed by developing themes and subthemes from the transcripts. Thematic analysis allowed for the comparison of data between participants. Due to the lack of male partners in this study, the perceptions of the care that they provided is from the perspectives of female breast cancer survivors who took part in this study. This is clarified in the discussion section of this chapter.

Table 4-1. Demographic characteristics of participants in Study 1.

<u>Participant (Alias)</u>	<u>Age (Years)</u>	<u>Date of diagnosis</u>	<u>Treatment</u>	<u>Date of remission</u>	<u>Years living with partner</u>
Cindy	53	April 2008	Lumpectomy Chemotherapy	October 2008	18
Mel	57	December 2004	Lumpectomy Chemotherapy Radiotherapy	October 2009	32
Catherine	53	November 2003	Lumpectomy Chemotherapy Radiotherapy	November 2010	30
Karen	64	June 2010	Mastectomy	August 2010	39
Joyce	49	December 2008	Mastectomy Chemotherapy	April 2009	16

4.3 Results

The thematic analysis of the five transcripts suggested a number of themes that were evident between all participants. These are outlined in Table 4-2. Three overall themes were developed: Responses, Maintain Equilibrium and Resolution. Responses describes the behaviours of individuals following the breast cancer diagnosis, Maintaining Equilibrium relates to the efforts employed by patients to restore normality in their lives post-diagnosis and Resolution describes the period post-treatment and outlines some of the changes experienced as a breast cancer survivor.

Table 4-2. Themes and Subthemes developed from Study 1 data.

Theme	Subtheme
1. Responses	a) Mechanical Help vs. Emotional Help b) A Safe Home c) Appearance Shock
2. Maintaining Equilibrium	a) Wanting To Be Normal b) Treading on Eggshells
3. Resolution	a) Resilience and Change b) Understanding Health

4.3.1 Responses

The first theme reveals issues relating to the responses of individuals known to the patient when faced with their breast cancer. The theme is divided into three further subthemes: Mechanical Help vs. Emotion Help, Appearance Shock and A Safe Home.

4.3.1.1 *Mechanical Help vs. Emotional Help*

The predominant finding from the interviews was the way in which the coping strategies of male and female supporters differ. In addition, their ways of providing support also appeared to be different. According to the participants, male partners were more practical than female support sources and were less able and/or willing to cope with dealing with emotional problems, whether that

was supporting someone else or seeking emotional support from someone else. They appeared to take a matter-of-fact approach to problems, whereas the patient and female supporters of the patient considered the more emotional side to these problems and strove for a solution.

Practical support such as driving to hospital appointments, cooking, cleaning was more characteristic of male supporters than female supporters and the patient. An example of practical thinking discussed by one participant was that her partner had bought a mini refrigerator to keep in their bedroom (as she was often too tired to walk down the stairs in her home to get herself something cold to drink), which is something that she said she would never have thought of doing:

“I’ll take you to the hospital, I’ll put a fridge in the bedroom, I’ll make sure you’re alright, have you got everything you need? You’ve got a fan, you’ve got your laptop, you’ve got your TV” – Cindy.

With a problem or issue that may be perceived to be out of someone’s control, such as breast cancer, a man may not be able to solve the illness related issues that his partner may have as he might wish. To compensate, participants felt that their male partners did their best to provide support that will be of practical benefit to their partner in some way. Practical support from male partners was appreciated by all participants, with the overall consensus being that these practical issues were not considered by the patient and were rarely considered by the female supporters, suggesting a need for male support.

There was also an element of anxiety that was present across the accounts, where even though the partner provided support as best they could, it was not enough to make them feel as though they had helped the woman

with breast cancer, even though they may not have solved or removed the problem..

“He wanted to fix me or he wanted somebody to be able to fix me.” – Catherine.

This quote demonstrates an element of powerlessness. With regards to men as being practical and forward-thinking as demonstrated in the dataset, not being able to “fix” their partner, like they might fix mechanical equipment, is likely to result in upset and frustration which in turn may impact on the support that they provide to their partner.

It was revealed in the transcripts that female supporters provided mainly emotional support:

“We’d meet and go for lunch and talk and I’d cry and they’d hug me and listen.” – Cindy.

This level of emotional support was not provided by male partners but was provided by female supporters according to the participants in this study. It was not clear whether the female supporter sought social support from the woman with breast cancer. All participants claimed to have at least two female supporters who provided them with opportunities to openly talk about their breast cancer and they turned to these sources for emotional support rather than to their male partners. This idea leads on to the next section of “A Safe Home”, where the notion of the home being a protected place is discussed.

To summarise, when partners did provide support, it was more practical support which did play a large role in helping the patient, particularly as some of the practical help or solutions to problems related to issues that they themselves had not considered, e.g. placing a mini refrigerator in the bedroom

where the patient was resting to save her from walking down stairs – something that she may not have had the energy to do. Emotional support came from female friends and it was more likely for the patients to express emotional concerns, to cry and to talk in detail about their feelings to them rather than with their partner. This could be because the patients did not want to worry their partner or upset them, particularly if they were finding the treatment difficult. This example of protective-buffering was evident across all transcripts. From the interview transcripts, women were aware of their social support networks and who they could approach for emotional and practical support.

“If I wanted to talk about how shit I was feeling, I’d call my friend Harriet. If had to be taken to the hospital, I knew Mike [husband] would take me” - Joyce

One participant expressed dissatisfaction with their support network as a whole (Mel. This is discussed further in the next section). However the remaining four participants stated that they felt that their needs (with regard to social support) were met by a variety of sources. Furthermore there were two individuals who felt that their male partners could have done more to support them emotionally, even though they were provided adequate support from female sources.

“More for his sake than mine. It was a lot for him to deal with and I think I would have liked it if he talked to me about how he was feeling.” – Mel.

4.3.1.2 A Safe Home

As discussed in the previous section, men seemed less open to discussing emotional issues with their partners which related to their breast

cancer although there was no indication that participants attempted to take part in a dialogue with their male partners. This links to the notion of keeping the family home safe; that is that male partners are trying to keep unpleasant matters from their home by not discussing them directly. In some cases, it may result in maladaptive coping mechanisms when dealing with their partner's breast cancer. This was indeed the case with Mel, whose husband began to drink heavily following her diagnosis.

"...being in that hospital on that Boxing Day and he (partner) was saying "My wife's got breast cancer and I can't cope with it so my only escape is drinking." That to me...it broke my heart really." – Mel.

According to Mel, her partner blamed his excessively drinking on her breast cancer diagnosis. She stated that he did not provide any support to her, practically or emotionally. They never discussed her diagnosis but whenever he went to the pub, he would exclaim how brave his wife was but she herself never heard these words from him. This was relayed to her by male and female friends. This fits in with the idea of keeping the home as a safe place.

"I'm not sure looking back if that was me putting the barriers up or it was him just not coping with it and going off and doing his own things, his way of dealing with things" – Mel.

Consequently, Mel relied on her sons and friends when she felt that she needed support. In particular, she discussed her interactions with online support groups for seeking information and sharing breast cancer-related stories.

With an illness that could potentially be fatal, there seemed to be a fear amongst the male partners, in that they realised that their partner could die

and this had an effect on how they helped and treated their partners and their outlook:

“... I guess they suddenly thought “Oh my god, you know, she might not be here anymore...I’m not going to say wake-up call but he probably thought “My God!”, you know, “She might die! (2) Let’s have, like, a nice life together.” – Karen.

Catherine described the Christmas after her diagnosis where her partner insisted on taking many photographs of her, particularly with her children. This kind of behaviour is easily attributed to the fact that he thought his partner might die and he considered that it might be her last Christmas with the family. The participant recalls how he went *“over-the-top with the festivities”*. This couple had young children at that time who were may not have been aware of their mother’s illness and it was as much for them as well as his partner, that he was making a big effort.

The concept of men not actively seeking out or providing emotional support was evident throughout all the transcripts. It is unclear if these men did not want to discuss the breast cancer with their partner. This could be due to fear of upsetting them, or maybe they were seeking support elsewhere or being avoidant. It seemed that no male partners of patients were perceived to support them emotionally, according to participants. However, without talking to the respective male partners, it is difficult to confirm this. It may have been the case that male partners did provide support, but this was somehow misinterpreted by their female partners. In addition to this, now that all the participants were in remission, breast cancer was not something that the partner was willing to discuss, again keeping the home as a safe place:

“It’s almost like my partner wants to forget about it because it’s done and it’s dusted and I’m still here and I’ve got through it and I’m now back to normal.” – Cindy.

“I mean he didn’t bear his soul to me about this... he was just out to support me.” – Joyce.

According to the participants, they perceived that once in remission men seemed to want to forget about the breast cancer and move on, but the women who have experienced it found that it is something that would always remain part of them.

“...but I still live cancer 24/7. It’s always in my, you know, being really. It’s part of me.” – Karen.

It is difficult to draw concrete conclusions about the support provided by male partners. Although the participants felt that emotional support provided was minimal, perhaps male partners had been providing this support but it was not received as intended. Also emotional support appeared to largely have been sought from other individuals, particularly female friends, who met any emotional support needs (apart from Mel, previously mentioned). Emotional support was described mainly as taking part in emotive conversations. Finally with regards to male partners wanting to forget about breast cancer, they may not discuss it post-treatment because they do not want to upset the participant by talking about it.

4.3.1.3 Appearance Shock

One major side-effect of chemotherapy is hair loss but this was not something that the patients themselves felt upset by. From the interviews, it seemed that any steps that were taken to hide the hair loss, such as wearing a wig or a scarf, were more for the patients’ family members. In particular, some

participants felt that they ought to wear a wig whilst they were in public, particularly when with their partners.

“I think it was the least I could do [wearing a wig] considering that he was supporting me through everything.” – Cindy.

As hair loss is the most visually striking side-effect of chemotherapy, it seems that some family members of the participants saw hair loss as an indication of illness and having the hair grow back was a sign of health. This was particularly the case for one partner:

“It was almost like it, visually it was like, “oh she’s back to normal” so she must be better.” – Catherine.

It seems that for the male partner, if the patient does not look sick, then she is perceived to be healthy again. This may suggest that physical appearance is an important indicator for male partners when considering the health status of their female partner – if she looks well, she is well. It seems that the association between hair loss and cancer is well-recognised:

“...and so I think he thought that all of the sudden, everyone around him’s gonna die. He didn’t like that visual [baldness]. He hated it and I had to wear my wig.” – Cindy.

Throughout the topic of hair loss, it seems that the family and friends of the patient appear to be more embarrassed or uncomfortable about hair loss compared to the patient and they seem to demonstrate better insight of the long-term impact. A good example of this is the son of one participant encouraging his mother to wear her wig for his graduation photographs:

“...and he [patient’s son] said “Well just think Mum – you’re going to look at that photograph for years to come. And now, every time you

look at it, you'll think of the cancer, but if you've got your wig on, do you not think that it will make you feel better, when you look at the photograph?" – Mel.

This example is quite complicated and interesting in that the son is considering his mother's feelings in the future and this in itself, could be considered to be social support. This also lends support to the idea of hair loss being an indicator for poor health. It seems that baldness is a very strong visual reminder of cancer for some people and so taking measures to hide baldness, particularly in photographs or at the request of family members or friends, could be considered to be a coping mechanism. It could be an indication that breast cancer is something that wants to be forgotten by the patient, their family and friends in the future.

These women with breast cancer were somewhat unaffected by hair loss as a side-effect, potentially because over time the hair grows back. In contrast, family and friends appear to be more troubled by hair loss and the transcripts suggest that this is due to the presence of hair implying good health and the absence of hair suggesting illness due to breast cancer.

4.3.2 Maintaining Equilibrium

The second theme developed from the transcripts is that of Maintaining Equilibrium. This relates to the women with breast cancer trying to keep a level of normality throughout the illness trajectory, as explained by the subtheme Wanting to be Normal. The second subtheme, Treading on Eggshells, discusses the difficulties of socialising with people with the notion of death in the minds of their family and friends.

4.3.2.1 *Wanting to be Normal.*

One of the most debilitating side-effects of chemotherapy and radiotherapy is the fatigue that follows each treatment session. The participants described that they wanted their family and friends not to change the way they treated them or view them as a cancer patient, but rather treat them the same as they had before. Due to levels of weakness and exhaustion, this was nearly impossible:

“Everyone was expecting me to be normal because I’d asked them to treat me normally and then I’m saying “Oh actually I can’t walk.”” – Cindy.

Feeling tired, in turn, would have an impact on the social lives of the patients, who found that they simply did not have the energy to see friends, go out etc., as they once did before they were diagnosed. In addition to this, it seems that there was a certain amount of frustration, not just relating to the symptoms, but also to the extent that they felt that family and friends did not and could not understand their side-effects.

“I used to say “I’ve got absolutely no energy to walk up the stairs” and to say that to somebody who doesn’t know what it feels, just sounds completely unreal.” – Cindy.

This desire of being treated normally is evident across all transcripts but this desire did not seem to be fulfilled, as family and friends were unable to treat the patients as normal. The patients, as the subtheme explains, found this rather annoying. This is discussed further in the next section.

4.3.2.2 *Treading on Eggshells*

All participants wanted to be treated normally by friends and family, but found frustration in the fact that these family and friends were too apprehensive and

nervous around them, which in turn, isolated some of the participants even more. Because of not being treated as normal, some participants felt that they could not be completely honest with those closest to them regarding their treatment and their breast cancer experience (protective buffering - as mentioned in the previous section regarding gender stereotypes). One particular example of this was Catherine saying that she constantly told all of her support sources that she was “*fine*” because it was easier for her to cope when people did not seem like they felt sorry for her. This links in with an issue raised by all participants; that they felt that when a conversation was about death or dying, it caused people to shut down. In the case of breast cancer, where loss of life is a possibility, it meant that many family members and friends did not know what to say and this in turn tended to annoy the participants because they were being treated as a sick person, rather than a normal, healthy person.

“She said, you know “I don’t know what to say to you” and I said “That’s fine, but I’d rather you said nothing but be your normal self rather than walking on eggshells around me”. – Mel.

“I mean you say the words “dead” and “death” and people just shut down, don’t they?” – Cindy.

“People treading on eggshells around me...it was a bit much for me, you know?” – Karen.

To summarise, women had a desire to be treated as they were prior to their diagnosis. When family and friends did not treat them in this way this actually frustrated and annoyed them. This is a complicated idea. Potentially from the perspectives of family and friends, the woman with breast cancer is viewed as a patient: someone who is unwell. With regards to breast cancer treatment,

side effects may be very apparent, making the patient physically appear to be unwell. In addition, with the uncertainty of the prognosis in many cases, family and friends may have been treading carefully so as not to upset the patient or perhaps even themselves. From the perspective of the patient, the feelings of annoyance or frustration could be attributed purely to the breast cancer diagnosis and treatment side-effects, with family and friends almost being a scapegoat.

4.3.3 Resolution

4.3.3.1 Change and Resilience

Experiencing such a traumatic change had a long-lasting and enduring effect on the patient. Across all transcripts, the most dominant change was having a more positive outlook on life and being more relaxed, both of which could be considered to be positive changes. The participants all stated that they tend not to get stressed anymore, because when things that are considered stressful are put into perspective, they tend to be fairly inane.

“It is what it is and if you can’t change it, it’s a waste of time getting stressed about it” – Cindy.

All participants say that having a long-term condition like breast cancer and surviving meant that they tend to enjoy life a lot more than they previously did and appreciate things that they took for granted.

“You know, you’re here to enjoy your life, you’re here to live, not to watch it pass you by in the rear-view window as you busily get on with stuff.” – Joyce.

This appreciation for life is evident in this quote. It portrays the idea that the demands of day-to-day living are taxing and that due to this, there may not be the opportunity to be thankful or enjoy actually living. Surviving breast cancer

has encouraged these individuals to understand the importance of appreciating health and life. This interpretation may relate to the time that the participants were in remission. As the minimum time in remission for inclusion into this study was six months, this may have allowed individuals to be more reflective of their experiences. It is debateable whether similar findings might be found in women who have been in remission for less than six months or in women who are placed in an earlier position along the illness trajectory.

4.3.3.2 Understanding Health

Breast cancer survivors had a better understanding of health and their own bodies following breast cancer. This has both positive effects in that they are more health conscious, but they can also be more fretful and worried when they come across new symptoms or potential signs of ill health:

“Is that headache a brain tumour? Is my backache brain cancer?” –
Cindy.

It is encouraging to discover that despite experiencing breast cancer, all participants were able to draw some positive benefits from the journey.

“I don’t drink now. Or smoke. Because they could make it come back. And I appreciate my health now.”– Joyce.

In addition, being more health conscious has resulted in all participants exercising more, eating better, drinking less alcohol etc. so despite the fact that they may become more worried if they experience certain symptoms than prior to their diagnosis, leading a healthier lifestyle is certainly of benefit in the long-term.

4.4 Discussion

The main finding of this study was the perceived differences in the types of support offered by male and female sources. Men provided more practical and problem-solving support, whereas women had a more emotional focus when providing support. All participants stated that their male partners did not seem to actively seek or provide emotional support, but two interviewees said that their partners did provide emotional support when they requested it. Again, this support was not provided as much as female supporters provided it, nor were these male partners as understanding as female friends, according to participants. Emotional support was mostly sought from female supporters. This could be because these individuals had known the patient for a long time and have always provided emotional support to them. The notion of caring is socially constructed as a central component of a women's gendered role, leading to women being positioned as emotional nurturers of others with an expectation of self-renunciation (O'Grady, 2005). This could result in women engaging in caretaking to please the patient in an attempt to meet relational needs. In addition, there is evidence which suggests that women are more affected by the emotional well-being of others (Hagedoorn et al. 2001).

Drawing on the social support facets described in Chapter 1, the findings of this study provide evidence of emotional support and instrumental support (Heaney & Israel, 2002; Bogossian, 2007) with the breast cancer context. Emotional support involves providing love, empathy, trust and care to an individual and instrumental support involves providing tangible aid and services that directly assist an individual. According to these definitions, both types of support were provided by both male partners and female supporters. It is important to note that in the theme of "Mechanical Help vs Emotional Help", the emotional help discussed is what is perceived by the participants:

that is, their perception of emotional support is being able to show emotions about their breast cancer and discuss how they were feeling. The practical help involved with everyday tasks such as getting lifts to hospital appointments, cooking, cleaning etc. Their perception of emotional help and practical help is different from the theoretical definition stated by the literature. However as mentioned in Chapter 1, it is the perceived support which is important (Cortes et al., 2014), regardless of how it may be defined in scientific literature.

Without interviewing male partners, it is not possible to know if male partners were perceived to avoid the subject of breast cancer because they did not want to upset the patient or because they themselves simply did not want to discuss it. Ussher and Perz (2010) found informal male cancer carers reported higher levels of self-silencing due to their own desire of wanting to prioritise the needs of the patient or to avoid conflict. Men adopt this self-silencing position and accept it as a normal aspect of their masculinity, with their belief being that expressing their needs or emotions is a sign of weakness, and they therefore maintain a positive front as a means of coping (Batty, 2006). They may also not develop the emotional vocabulary to communicate relational and emotional needs and so, self-silencing becomes the only available option (Gratch et al., 1995). It could also be that men simply do not like to talk about this topic with their partner. At the point of the interviews, all participants were in remission and still, their male partners did not wish to discuss their partner's illness. According the participants, their male partner's breast cancer journey is now complete, but as suggested in the interviews, it is not as easy for the patient to forget. Indeed, Coyne & Borbasi (2009) found that in a sample of younger women with breast cancer (age 28-45 years), treatment began so quickly following diagnosis that there was little time for the patients to adjust to the concept of having a life-threatening

disease. The notion that male partners are not talking about the breast cancer post-treatment does not necessarily mean that they have forgotten about it or that they have adjusted or adequately coped during the illness trajectory. In the case of Mel, she felt that her husband's excessive drinking throughout her illness was demonstrative of the fact that he was not coping. This must be interpreted with some caution as her husband was not available for interview. Her husband may not have believed that he was drinking excessively.

The idea of keeping the home as a safe place was also revealed through the transcripts. This related to the male partner trying to provide a safe environment for himself which is free from any distress related to breast cancer. If the male partner talked to the patient about her cancer, then this home would no longer be a safe place. Although this could be considered a positive strategy for male partners, this manner of coping may upset the patient who might wish to talk about the breast cancer with their partner. This idea has been presented in research relating to war veterans who try and keep their homes free from any war-related memories (Hunt & Robbins, 2001).

The side-effect of hair loss was mentioned by all women and revealed to be an indicator of health for family and friends. It seems that the woman with breast cancer did not have a problem with their hair loss but family and friends did. Because of this, measures were taken by the patient, such as wearing a wig or head scarf, to appease those around them. At the time of interview, the hair of all participants had grown back so perhaps in hindsight, the idea of hair loss during treatment did not seem as bad for them. Previous literature has suggested the symbolic links between hair and sexuality, attractiveness and personality to hair, particularly for women (Hunt & McHale, 2005), and so can seriously affect self-esteem and body image. For breast cancer survivors, hair loss has been reported as more difficult psychologically

than the loss of a breast (Freedman, 1994). McGarvey et al., (2001) found four common reactions to hair loss in women after chemotherapy: not prepared, shocked, embarrassed and a feeling of loss of sense of self. From this study, none of the participants revealed any details which might place them in any of these groups, rather they saw hair loss as an inevitable, normal consequence of undergoing chemotherapy. It might be that participants were “playing down” the notion of hair loss. Perhaps that now the participants were in remission and their hair had grown back, their perspective was different compared to their perspective when they were undergoing treatment and had lost their hair. The self-image had not changed and to them, it was only a temporary modification. Rosman (2004) found that hair loss was seen for some as a something positive when it is linked to the idea of being treated and the hope of being cured. This comes from a positive attitude towards chemotherapy and radiotherapy, where the side-effects of treatment are seen as a “price to pay for being cured”. Interestingly Rosman (2004) also found that in some cases, the level of hair loss was directly linked to the effectiveness of treatment – the more hair loss, the more effect the treatment is having. With regards to hair loss and the effect on family and friends, there is a stigma associated with hair loss and some patients will hide their baldness not so much to protect themselves from other people but to protect their family and friends and safeguard their feelings (Rosman, 2004; Harcourt & Frith, 2008). Other body image issues that have transpired from research include weight gain (Denmark-Wahnefried et al., 1997; Lankester, Phillips, & Lawton, 2002; Denmark-Wahnefried et al., 2001) and breast-related body image change (Helms et al., 2008; Contant et. al, 2004).

The findings from this study show that fatigue was likely to have an effect on socialising with friends and family. Fatigue that is secondary to

cancer and its treatment results in the patient suffering with feelings of weakness and tiredness that is not relieved by rest (Cella et al., 2001). Women with breast cancer report fatigue long after completing treatment which affects their QoL (Broeckel et al., 1998) and this has been found to be the most commonly unrelieved and distressing symptom related to chemotherapy (Patrick et al., 2004; Donovan et al., 2004) and can persist in the weeks and months after completion of treatment (Byar et al., 2006), and sometimes up to 36 months (Broeckel et al., 1998). Levels of fatigue can also vary along the breast cancer trajectory, with moderate symptoms found during the first chemotherapy treatment (Knobf, 2000; Boehmik, 2004; Byar et al., 2006) which did not rise with subsequent treatments (Berger de Jong et al., 2002). After treatment, levels of fatigue persist for about one-third of breast cancer survivors (Bower et al., 2000; Byar et al., 2006). Based on previous literature, it is not surprising that fatigue was found to be debilitating and participants were not able to socialise as much as they wanted. Fatigue has been found to persist beyond the treatment stage. Although the participants reported fatigue whilst receiving treatment, these may have also extended into the period post-treatment. This may have affected their access to social support sources and consequently affected the extent to which their support needs may or may not have been met. Indeed fatigue has been associated with psychological symptoms, such as depression, during and after chemotherapy (Badger et al., 2011) along with QoL (Ganz et al., 2002). Access to social support may mediate the psychological problems that may develop as a result of experiencing fatigue. As such, improving fatigue in women with breast cancer and survivors is of clinical importance

Improved outlook found in this study can indicate positive growth following disease. This has been coined in various terms including posttraumatic growth (PTG) (Tedeschi & Calhoun, 1996), existential growth

(Spiegel & Classen, 2000) and benefit-findings (Carver & Antoni, 2004; Cruess et al., 2000; Katz et al., 2001; Tomich & Helgeson, 2002, 2004). As with current literature, the findings from this study document positive changes with loved ones, satisfaction with and meaning in life, self-confidence and a sense of personal strength, life priorities and goals (Carver & Antoni, 2004; Bower et al.; 2005; Manne et al., 2004; Leorain et al., 2010). Data from previous studies were collected through well-validated self-reported measures and through qualitative methodology, this study has demonstrated the potential for (PTG) to be explored through interviews.

Understanding health and making the appropriate lifestyle changes was a finding in this study. This could be attributed to fear of recurrence (Black & White, 2005). Increases in physical activity and weight management have been identified as being key to breast cancer survivorship (Rock et al., 2012) and have an important role with regards to mortality, recurrence and prognosis (Protani et al., 2010; Ibrahim & Al-Homaidh, 2011) and reducing co-morbidities post-diagnosis (Rock et al., 2012). Previous research has associated physical activity with enhanced QoL post-treatment (Speck et al., 2010; Philips & McAuley, 2014). The findings from this study indicated also that participants were aware of nutritional intake: this may relate to weight management, which has also been associated with improved QoL and psychological well-being post-diagnosis (Philips & McAuley, 2014). Therefore an increase in health awareness and implementing long-term health changes in breast cancer survivors is likely to benefit their survivorship (Chlebowski, 2012) and long-term well-being (Kendall et al., 2005).

Two women in the sample claimed that their husbands were their main source of support, who they felt that their emotional support needs were not adequately met. These two women were the only interviewees who had had a

mastectomy – maybe having radical surgery meant that husbands felt that they needed to provide more help – any supporting lit on mastectomy. As mentioned in the previous section, the physical side-effects of breast cancer do not go unnoticed by friends and family and in some instances, is an indicator for health. Perhaps having an operation resulting in such a dramatic change to physical appearance elicited more help from male partners. It could also be that these women were particularly pleased that their partners had stayed with them after such a major surgery. In the light of this, in the context of breast cancer, an idiographic approach is ideal (how the situation is relevant to each individual's personal goals) as individuals differ and common patterns are limited.

One participant expressed dissatisfaction at their support network and felt that there had been more external sources that they could have accessed. This participant claimed that accessing online support groups and forums was very helpful to her. It was discussed earlier in this chapter that experiencing fatigue could act as a barrier to physically accessing social support sources. She stated that being able to read about other women's experiences and to recall her own experiences and ask for advice was helpful. Of particular benefit to her was the fact that she could access these services from her bed (especially helpful when she was feeling weak and unwell from treatment). Not only does the Internet provide support but it also provides health information (Fox et al., 2011). Online communities have been defined as "*virtual social space(s) where people come together to get and give information or support, to learn or to find company*" (Preece, 2000). These online communities have been found to provide breast cancer survivors reassurance, a sense of community and hope for the future, reduce feelings of stress, validate concerns that are ignored by healthcare professionals, enable individuals to

become more informed and prepare for interactions for healthcare professionals (Hoybye et al, 2005; Shaw et al., 2009; Vilhaur, 2009; Roger & Chen, 2005). Having access to such groups was of benefit to the participant in this study as it reduced her social isolation due to fatigue.

Finally the aim of this study was to answer the research question “What role does the male partner play in supporting the woman with breast cancer?” The study intended to recruit both female breast cancer survivors and male partners but unfortunately no male partners offered their participation. As such the findings of this study must be interpreted with caution as the results presented are based on perceptions of the female breast cancer survivor in relation to their male partner. Nonetheless, the findings from this study have detailed the perception of breast cancer survivors of their male partners and social support and thus have relevance to the thesis overall.

4.5 Conclusion

The study was interested in understanding the role of the male partner with respect to helping the woman with breast cancer, and it appears that men provided more practical and problem-solving support, whereas women had a more emotional focus when providing support. This study was also interested in the dyadic relationship with the assumption that intimate dyad was the key dyad but this is not actually the case, as female friends may actually be the source providing the most support. However this study has highlighted the fact that there might be a variety of sources of support which may be providing different types of support to the woman with breast cancer. It would be useful to explore this social support network further to understand who the significant other is with regard to social support. This study has also highlighted a number of factors that may influence social support such as hair loss, effects

of treatment and the long-term consequences of being a breast cancer survivor.

5. STUDY 2A – EXPLORING THE SUPPORT NETWORKS OF BREAST CANCER SURVIVORS.

5.1 Introduction

Study 1 demonstrated that contrary to the ideas presented in the literature relating to dyadic support and coping, male partners are not always the main overall source of social support, although they appear to be the main source of instrumental support. With regards to exploring the marital dyad, results from Study 1 have suggested that an important dyad with regards to support may not be the male partner but could potentially be another individual. Study 2 aimed to investigate not only the male partner, but the wider social support networks of breast cancer survivors with a view to understanding the type of support (e.g. emotional, practical, medical) that was provided from sources and the way that these sources are linked and the extent to which they support each other. Understanding the whole social support networks of women with breast cancer is important in its own right, in addition to the support dyads is necessary as links with other support sources may influence the dyadic coping of the two members in the dyad. The support dyads will be returned to in Chapter 6. The current chapter in particular aims to understand the wider social support network of breast cancer survivors.

5.2 Methods

5.2.1 Participants

A summary of the ten participants interviewed can be found in Table 5-1.

Table 5-1. Demographic characteristics of participants in Study 2A and 2B.

Participant name (alias)	Age (Years)	Date of diagnosis	Treatment	Date of remission	Years living with partner
Sandra	56	March 2010	Mastectomy Chemotherapy	September 2010	30
Jessica	69	April 2010	Mastectomy Chemotherapy	December 2010	38
Martine	65	May 2006	Mastectomy	July 2006	21
Chris	65	September 2007	Mastectomy	January 2008	45
Jeannette	56	January 2000	Mastectomy	April 2000	29
Kerry	57	June 2010	Lumpectomy Chemotherapy	January 2011	10
Carol	56	August 2008	Lumpectomy Chemotherapy	January 2009	6
Kim	53	February 2011	Double mastectomy + reconstruction	April 2012	1
Julia	56	2006	Mastectomy Radiotherapy Chemotherapy	2008	27
Karen	51	November 2004	Lumpectomy	April 2004	17

5.2.2 The interviews

The interview process for Study 2A and 2B differed from Study 1 as the construction of an ecomaps provided the focus for discussion. Details of this can be found in Appendix 2. As described in Chapter 3, an ecomap provides a visual representation of the relationships by means of a depiction of the network that exists between members of a social group and their connections with larger social networks (Wright & Leahey, 2000), which give researchers evidence relating to the size, structure and function of that network. (Tracy et al.1994). The development of an ecomaps took place as part of a collaborative discussion in Study 2A and 2B.

At the beginning of the interview, an example ecomap was shown to the participant and the relationship mapping was explained with the aid of the example. This was done to allow the participant to fully understand how different relationships could be depicted and also to allow them to begin to consider who they might include in their own ecomaps. The identification of different sources allowed the researcher to explore each relationship in some detail with the participant. The interview followed the schedule presented (see Appendix 2). When an individual was identified by the participant, this was drawn by the researcher on the ecomap. For example, if the participant recalled that she had told her partner about her diagnosis, the partner was drawn as a support source on the ecomap. Once the participant had come to a natural stop, the researcher asked the participants further questions about her partner and negotiated the role that was played along with the strength of the relationship.

The semi-structured interviews took place either in the homes of the participants or a place of mutual convenience. The mean length of the interviews was 119 minutes and they were recorded using a digital recorder.

5.2.3 Analysis of results

The interviews were transcribed verbatim by the researcher. Of the ten participants, three consented to their data being used to present three varied case studies (see Chapter 6). For the other seven participants, the transcripts were thematically analysed (as outlined in Chapter 3).

5.3 Results

The thematic analysis of the seven transcripts suggested a number of themes that were evident between all participants. Themes that were developed in Study 1 were present in this analysis. However there were additional themes and subthemes developed from the thematic analysis. These are outlined in Table 5-2. One theme which was present in Study 1 and Study 2A was Maintaining Equilibrium and the subtheme of Understanding Health. Details of this theme and subthemes can be found in Appendix 4. It is not included as part of this chapter as these themes and subthemes have already been discussed in Chapter 4. The new themes developed in this study reflect the slightly different focus of Study 2A, which was interested in the social support network rather than just the perceived social support provided by male partners.

Table 5-2. Themes and subthemes from Study 2A. New themes and subthemes are shown in italics (developed from the new data). Themes from Study 1 (which were not found in Study 2A analysis) are shown in strikethrough).

Theme	Subtheme
1. Reactions of Others	<i>a) Protectors and Helpers</i> <i>b) Initial Perspectives.</i> <i>c) Hair Loss Shock</i> <i>d) Feeling Disfigured</i>
2. Maintaining Equilibrium	a) Wanting To Be Normal b) Treading on Eggshells
3. <i>Resolution?</i>	<i>a) The Longevity of Breast Cancer</i> <i>b) Resilience</i> <i>c) Feeling Grateful</i> d) Understanding Health e) <i>Aftercare</i>
4. <i>Faith as Support</i>	
5. <i>Medical Support</i>	<i>a) Making Treatment Decisions.</i> <i>b) Being Treated for Breast Cancer</i> <i>c) The Manner of Health Care Professionals</i>
Themes from Study 1	
Theme	Subtheme
1. Responses	a) Mechanical Help vs. Emotional Help b) A Safe Home c) Appearance Shock
2. Maintaining Equilibrium	a) Wanting To Be Normal b) Treading on Eggshells
3. Resolution	a) Resilience and Change b) Understanding Health

Theme 1: Reactions of Others.

As outlined in the previous chapter, the theme of “Reactions of others” reveals factors relating to the responses of individuals known to the women with breast cancer. This is further divided into four subthemes, the first of which is Protectors and Helpers, which relates to individuals within a social group taking on the role of protectors or helpers. Thematic analysis of the transcript also revealed a new issue faced women with breast cancer with regards to their physical appearance and their own reactions to being diagnosed with breast cancer (as demonstrated in the new theme of “Initial

Perspectives”). In the previous chapter, the subtheme of “Appearance Shock” dealt with the reactions to women with breast cancer’s hair loss. This theme has been renamed “Hair Loss Shock” as the new subtheme of “Feeling Disfigured” also relates to physical appearance, but with regards to scarring from surgery.

a) Protectors and Helpers

Similar to the findings of Study 1, when discussing support from family and friends, this fits into two categories of practical help and emotional help. Study 1 found that male partners provided more practical support and less emotional support. However analysis of the transcripts revealed that there were several instances of male partners providing emotional support. This may be due to the type of practical support provided or the situation that arose which warranted emotional support:

“I mean, I have a lot of girlfriends, but he’s my main support by far...I needed looking after, I felt like I needed it and I felt that someone should watch my back and pick things up. He is more than capable of that.”

Here this participant has acknowledged her wider support network and makes it clear that they are available to her. Drawing on the idea of female friends providing more emotional support this participant was aware that her female friends would provide more emotional support. She explicitly states that she considered her husband to be the main support source for all of her support needs. She explains that she needed someone to take care of her closely, and to almost act in a way that she would, but might not have been able to when she was undergoing treatment. Rather than taking on the role of a carer, the woman with breast cancer saw their partner as a protector as well.

This mutual relationship between the male partner and woman with breast cancer was evident across other transcripts:

“He would speak up for me, because I felt like I couldn’t.”

This indicates a level of understanding from the male partner. Although the woman with breast cancer felt unable to speak for herself, her partner knew her needs and relayed them when she felt that she could not. It was not clear if this was the case for female supporters. Again, this lends support to the idea of the male partner taking on the role of protector.

Finally the transcripts reveal more explicit examples of male partners providing emotional support:

“And when I did get frightened, he’d hold me.”

The use of the word “hold” instead of hug/cuddle/embrace lends support to the idea of the male partner as a protector. For example, a mother would hold her child, potentially defending it. An individual might hug a friend which suggests a level of affection. A male “holding” their partner who has been diagnosed with breast cancer has the possibility of not only showing affection to their partner, but also physically shielding her from harm.

Male partners’ interactions were not limited to providing solely emotional support and as described in Study 1, also provided more practical support:

“He’d organise food for the table...he did all the housework, he just organised everything.”

Practical issues such as cleaning the house, providing food whilst the participant was undergoing treatment (and children in some cases) and driving to hospital appointments were organised primarily by the male partner,

whether they themselves transported the patient to hospital or they organised so that other friends or family took them.

Female friends were discussed and described as playing a helpful role in supporting the woman with breast cancer emotionally, particularly if there were issues pertaining to the relationship with the male partner:

“My girlfriends played a big part when I wanted to talk about some of the more intimate problems I had with Jon [partner].”

One participant went to chemotherapy with two other girlfriends as she did not want her male partner to take time off work. The girlfriends bought along lots of magazines and sat with the patient whilst she received her treatment. She recalled how lively her friends were and how they were making jokes and trying to make her laugh. She said that distracted her from being in the hospital and how she appreciated them being there. They allowed her to laugh in a situation which she might have not have found enjoyable had they not been there.

Other individuals apart from the male partner and girlfriends were discussed in this study (see Chapter 6). These individuals, such as members of the church community, work colleagues, etc. provided practical help, not just to the woman with breast cancer, but to their male partner (and children) as well:

“My husband doesn’t drive so lots of people offered to take us for my chemo.”

“Lots of people would bring food to the house: “Oh it’s your chemo day, we’ve bought some food.”

When considering the practical help that they were provided, they were particularly grateful because this help meant that their families had one less thing to worry about.

To summarise, in this study, male partners as well as female friends provided emotional support to the patient. The extent that this emotional support helped their partners is evident across the transcripts and there is an indication that the male partners were acting in a way to protect the patient. Male partners provided emotional support as well as practical support by organising transport to hospital appointments, taking care of the children and ensuring that food was available. Five of the participants in this study described their male partner as being their main source of support. Female friends were also discussed and patients were likely to cry in their company and talk about their feelings at length. Other individuals were also discussed and they were described as providing mainly practical support. This was helpful not only to the patient, but also to their families. In addition, healthcare professionals were mentioned. This is covered later in the chapter.

b) Initial Perspectives

One theme that was discussed by participants was their reactions to having breast cancer. After diagnosis, the initial perspectives of participants in this study can fit into two groups: showing disbelief or knowing.

Some participants described their shock at being diagnosed with breast cancer:

“There was nothing to indicate that I had breast cancer at all. It was not on my horizon.”

This was the view shared by participants who felt that they had very healthy lifestyles. They did not drink excessively, never smoked, had a healthy

body mass index (BMI), exercised regularly and ate healthily. They felt that there was no physical reason for them to be diagnosed with breast cancer. It is relevant to mention that these individuals were mostly diagnosed due to finding a lump in their breast, rather than being diagnosed as a result of attending a routine mammogram. With regards to this, there was a level of shock that registered:

“I got very, very cold at the thought of having breast cancer”

This quote represented the fear that was felt. The idea of being diagnosed with breast cancer was something to be afraid of. However the main basis for this fear was the potential fatality of the disease:

“I would be running on the treadmill thinking “Oh my god, oh my god, this is my last year, I’ve got breast cancer, I’m going to die. Don’t be silly, don’t be silly, don’t be silly.”

The fear of death was evident across all transcripts. The idea of death was considered by all women at the start of the illness trajectory.

In contrast to the women who felt disbelief at their diagnosis, others felt that they knew that they might be diagnosed with breast cancer:

“But I got this letter on the Saturday and it said that I’d got to go back to the hospital the following Wednesday. Well you, straight away...you know. You do know.”

This idea of “knowing” does not necessarily equate to acceptance of the situation. As such it is difficult to state whether “knowing” would result in a quicker adjustment to the illness compared to the women who felt disbelief or were perhaps more unaccepting of their diagnosis.

The initial perspectives of being diagnosed with breast cancer can broadly be divided into individuals showing disbelief or knowing. Individuals who show disbelief do so because they feel that their lifestyles are not typical of individuals who are diagnosed with breast cancer. They described feeling fear. This fear was also described by women who were knowing, that is they had a feeling that they would be diagnosed with breast cancer. Knowing the diagnosis suggests that these individuals would be more accepting of the diagnosis and potentially adjusting to it more readily.

c) Hair Loss Shock

As discussed in Study 1, one major side-effect of chemotherapy is hair loss. Again, this was not something that the patients themselves felt self-conscious about or upset by in retrospect, but they felt inclined to take steps to conceal their hair loss, for example wearing a wig or a scarf. This was more for the benefit of family and friends:

“He didn’t want me to look like a typical cancer patient.”

In this example, the male partner of the patient is concerned about her looking like a cancer patient. In Study 1, hair loss is the most visually striking side-effect of chemotherapy and is synonymous with good health. It is not clear exactly why this partner does not want the patient to look like a cancer patient. It could be because he feels that the loss of hair is a reminder to him of how she was unwell. It may be because he feels protective of his partner and does not want other people to look at her with sympathy. It could perhaps be that he is embarrassed about how she looks or does not like how she looks without hair and would prefer her to cover her head so that he did not feel uncomfortable:

“I think that a lot of the time, other people are more embarrassed than you are about your appearance.”

The notion of the women with breast cancer not being embarrassed about their hair loss shows a level of acceptance to their illness. They feel that there is no point in trying to hide that they are undergoing treatment for breast cancer. In addition they do not feel that they should be embarrassed.

As mentioned in Chapter 4, the presence of hair is an important indicator when considering the health status of an individual:

“He hated seeing me with no hair, he wouldn’t talk to me, he wouldn’t look at me. But everyone else was fine with it.”

This example refers to an experience with this patient’s nephew, aged 8 at that time. She described how she met him at a family party and he screamed when he saw her and was withdrawn after he initially saw her, having seen her without a wig or scarf on. Obviously this reaction was due to seeing this individual with no hair, but it is difficult to ascertain whether this reaction is because he knew and understood that she had breast cancer or because she was not looking typically like a healthy person and he was shocked by this. Although a child of 8 year old might not have the awareness of older individuals, other individuals could feel uncomfortable in the presence of an individual who has lost their hair. This could have effect on the support that family and friends might provide to a patient: they could be unlikely to provide support if the patient’s appearance makes them uncomfortable.

Hair loss is not something that these participants seemed particularly concerned by. Family and friends were perceived to be more troubled by hair loss and the transcripts suggest that this is due to the presence of hair implying good health and the absence of hair suggesting breast cancer. As a

result of this, patients felt inclined to wear a wig or head scarf to appease their family and friends and ensure that they did not feel embarrassment.

d) Feeling Disfigured

For those women who had a mastectomy, they have been left with scars from the procedure. The immediate period following surgery was not discussed in detail:

“At that time, I didn’t want to look at it, but now I think the scar is just fantastic, the surgery was so well done it was unbelievable.”

This quote does address the aftermath of surgery and the invasiveness of a mastectomy and the physical mark it would leave. Over time, the scar was accepted and the surgeon even praised for the operation. A long-term issue related to the loss of a breast was discussed, particularly with regards to finding clothes.

“It irritates me when I can’t wear clothes that I want to wear, and when I wear my mastectomy bra, it comes up quite high so unless you wear something to hold it down, it’s not nice.”

This frustration was considered to be important by the participant. It relates to ongoing frustration relating to their mastectomy. This situation is such that even though they eventually get used to scars on their body, it can be irritating when they are dressed but there is still indication of their surgery.

Theme 3: Resolution?

The theme of “Resolution” in the previous chapter has been altered slightly and is now “Resolution?” This is because the data in the transcripts did not suggest that all participants felt a sense of resolution following their illness. Five subthemes fall under the umbrella of “Resolution?”: New subthemes

include “Legacy of Breast Cancer, “Feeling Grateful” and “Aftercare”. The subtheme of “Understanding Health” was demonstrated in the transcripts of this study. The previous subtheme “Resilience and Change” has been renamed as “Resilience”. This is because the idea of showing resilience was not necessarily an outcome of being a breast cancer survivor.

a) The Legacy of Breast Cancer

The trajectory of breast cancer has many stages. Once an individual has been diagnosed as being “in remission” that is where the trajectory moves in a survivorship stage and the individual’s life may then return to normal. However this is not the case.

Signs or reminders of breast cancer continue to manifest themselves even post-treatment. They could be as inconsequential as the patient’s hair growing back curly instead of straight or blonde instead of dark:

“So I kept looking in the mirror and instead of having dark hair framing my face, there was this grey hair. And I thought “Who’s that?”

Although the re-growth of hair was described as a relatively insignificant side-effect of chemotherapy, the main issue is that of self-identity. Post-treatment, there were occasions where the patient would look into a mirror and not recognise herself. If this is her perception, family and friends might also struggle to recognise her as the person that she was prior to being diagnosed, which this could potentially change relationships.

Permanent reminders of breast cancer could be more troubling, such as mastectomy or lumpectomy scarring:

“The physical changes are the worst for me.”

“I’ve got a scar under my arm. That’s never going to go away. I don’t ever want to forget it. Not that I ever could. Now I know that sounds really weird...I guess it’s just something that will be with you for the rest of your life.”

Scarring from surgery can be difficult to deal with in the first instance. These scars may fade over time but are likely to be there forever, acting as a constant reminder. For the participants who had mastectomy but had not had reconstruction, this is a very striking reminder of having breast cancer, lending support to the notion that even post-treatment, breast cancer can still have a physical impact on the patient. Also, these scars (from lumpectomy, mastectomy or mastectomy with reconstruction) might be seen by their male partners, who might accept them and not have any problem with them (see Kim’s ecomaps in Chapter 6). There is also the chance that they might find the scars unsightly which might in turn impact on the intimate relationship.

Long-term consequences of breast cancer may relate to how the participant now perceives themselves. That is they linger in the person’s conscious, even post-treatment:

“It’s [cancer] always in my, you know, being really. It’s part of me.”

This idea of cancer being a part of a survivor even though they have been told by a medical professional that they do not have cancer relates to a changing identity. They do not identify themselves exactly as the person that they were before their diagnosis. They have incorporated the subject of cancer into the way they identify and perceive themselves.

The ideas discussed in this section relate to the long-term impact that breast cancer can have, even after treatment has finished and individuals have been diagnosed as “in remission”. Physical reminders of breast cancer

can continue to manifest themselves in many ways. Some seem comparatively unimportant to the patients, such as their hair growing back in a different colour. Others relate to scarring as a result of surgery, which act as a constant, physical reminder of having breast cancer. Others are cognitive. The longevity of breast cancer could impact on the patient. They perceive themselves differently and their changed appearance may influence how they are perceived by family and friends and this might have an effect on their social support network. The scarring might have an impact on their intimate relationship, depending on how the scarring is received by the male partner.

b) Resilience

The previous section discussed how experiencing breast cancer had a long-lasting and enduring effect on the patients. Across the transcripts, the dominant change related to having a more positive outlook on life and being more relaxed:

"Whereas before I'd get cross with people, I now think "What's important?" And it's my husband, my children and my health."

Getting cross with people is seen here as a waste of energy. This energy could be expended on more important matters, such as health and family. It could also be attributed to the fact that feeling stressed about small matters is a waste of energy, when put into perspective. In addition, a new appreciation for family may have a positive effect on the relationship between family members, bringing them closer together.

There was an understanding of breast cancer being a shocking, potentially traumatic event. The initial shock can be difficult to adjust to, may have devastating effects on the patient in a physical and psychological way, but this may not be a longer lasting issue:

“A crisis like this can leave you broken, but you can put bits back together and actually be stronger.”

“You can only wallow in self-pity for so long before you have to get it out of the way and say “Right OK. This is what’s going to happen, let’s go for it, let’s just do it and get it over and done with.”

The necessity of being resilient is evident in these quotes, with both individuals trying to channel all of their energy into getting better. Despite the fact that they experience an initial shock, they understand that to get better, they need to be active in their own care. It is not entirely clear what the role of the social support network is in this process: it may be the case that women with greater support sources have a greater drive to get well for the sake of their family, friends, etc.

c) Feeling Grateful.

There were undertones of feeling grateful that the patients had survived. In addition to this, they showed appreciation for those around them:

“I will share things more and if I’m feeling tired, I’ll sit down and ask people to do things for me.”

Being diagnosed with breast cancer and drawing on family and friends for help is a long lasting outcome of surviving breast cancer. This quote demonstrates gratitude towards those who helped them and an understanding that they can ask these people for help in the future and enjoy the company of other more than pre-diagnosis. This is demonstrated in the follow quote:

“We are more relaxed as a family and really appreciate one another even more.”

The gratitude for life as well as family members is apparent. Greater appreciation for each member in the family suggests stronger bonds between members. Although not explicitly stated by family members as they were not interviewed, the participants felt that they are appreciated by their friends and family more, perhaps because they are thankful for her survival. Similarly the breast cancer survivor themselves are thankful for their good health post-treatment:

“You can have all the money in the world, but if you’re not well enough to enjoy it, what’s the point?”

This is demonstrative of an appreciation of their good health having completed treatment. The emphasis is being well enough to enjoy life.

e) Aftercare

There was still an element of concern about the breast cancer returning:

“Is it going to come back? There’s anxiety. I’m looking forward to finishing my Tamoxifem but there is some anxiety about whether I can rely on my body not to give me cancer again.”

The implication here is that having completed treatment, there is not a team of medical professionals that patients can turn to when they do experience such concerns (that they were aware of). This was explicated stated in the transcripts. This is further demonstrated when one woman was considering individuals who are not stronger post-treatment:

“Some people don’t come out of it stronger. Or better. I feel lucky. But what about those people? Who do they turn to?”

There is awareness on the long-term psychological impact of breast cancer and a concern over the lack of medical/psychosocial care after the end of

treatment. The quote above is thinking about other women with breast cancer particularly those who do struggle post-treatment. This may still be a current concern of the participants involved in this study. The long-term impact of breast cancer has not been explored in detail in this study, but the lack of services that might help these women (should they need it) is unknown to them.

Theme 4: Faith as support

Analysis of data allowed for the creation of this new theme, “Faith as support”. Across all transcripts, there was evidence of individuals using religion to help them during their illness:

“My faith has been my rock... I have never been away from God really.”

This participant explicitly talks about God, but there were other instances where spirituality (aspects of religious faith in addition to inner peace and meaning (Garson & de Jager Meezenbroek, 2007)) was discussed. In other cases, the social aspect of the church was supportive to the patient:

“It’s not just about the God bit; it’s about people saying “How are you doing?”

“And people from the church would always come by. And Matt [vicar] would too. And it would be therapeutic to me.”

The church community seemed to be interested in supporting Caroline in particular. She recalls how several members would come round to their house with meals and sit and chat with her. She recalled talking to the vicar in her home about her faith. The practical and spiritual support offered by the church was of benefit to her.

Theme 5: Medical Support.

The final new theme developed from this analysis is “Medical Support”. This theme encompasses the aspects of participants’ experiences with regards to the medical treatment that they received. This is divided into two subthemes: “Making Treatment Decisions” and “The Manner of Health Care Professionals”.

a) Making Treatment Decisions

The first issue of concern having been diagnosed with breast cancer is choosing the appropriate treatment (see Chapter 1). Although there are several options, medical professionals will not push patients to choose one over another, but will relay the positives and negatives of each treatment programme to them. The mentality of the patients was to get well as quickly as possible, so often chose the more radical treatment options:

“I just wanted to get rid of it and stay alive. I don’t want to compromise any of it at all.”

“It was more like “I just want to get through it and I want to get it over and done with.”

The majority of participants in this study had full mastectomies. With regards to social support, the role of the male partner in choosing a treatment option is relevant. Across the transcripts, participants stated that their treatment decisions were ultimately made by them, but their male partners played a role in terms of discussion of each option. In this case, having a male partner to discuss treatment options with was of benefit.

b) Being Treated for Breast Cancer

All participants received NHS treatment and were very critical of visiting the hospital and the environment:

“The hospital was always really full, really busy, really stressful. It was always a feeling of maybe you’ll have treatment today, maybe you won’t.”

“What they don’t tell you is whether your chemo takes an hour and a half or five hours, you will be at the hospital all day.”

The experience of breast cancer is stressful. These quotes serve to demonstrate the extent that the hospital environment only added to the stress of the patients themselves. The uncertainty of treatment and the fact that hospital treatments were generally longer than first thought was unlikely to help the patients cope and or adjust to their illness as easily.

c) The Manner of Health Care Professionals

This final section discusses the interactions of the patients with various medical professions that they met, particularly at the diagnosis and treatment stages. This quote is the most representative of this section:

“Most of the doctors and nurses I met were brilliant, but true to human form, the ones that weren’t stuck in my mind quite heavily.”

The hospital where several treatments took place is a teaching hospital. As a result, student and junior doctors were often present and allowed to carry out minor medical procedures, particularly in the case of chemotherapy:

“And then there was... it was fine if you got an experienced nurse, but if you got a trainee...I had so many veins broken and damage done to my arm from people trying it out.”

As discussed in the previous section, the hospital environment is not pleasant. The addition of inexperienced trainees perhaps not carrying out procedures well on the patients is not ideal for them. It was not just trainee doctors who

the patients felt were not warm. In the cases of the women who underwent mastectomy, the manner of some of the surgeons was not desirable:

“She didn’t intend to, but I just felt like a piece of meat. I did not like that at all.”

“So I went and spoke to them [about reconstruction]... I didn’t find that particularly pleasant. I felt a bit like a cat or dog...All along it was like “You have breast cancer, but we can make you a real woman. We can make your breasts come back.”

These quotes show a lack of compassion and empathy for the patients. The idea of needing breasts to be a “real women” is not going to help the self-esteem and adjustment of the patients. In addition, there is a lack of treating the patient with respect and humanity.

This section discusses interactions with medical staff whilst undergoing treatment. The first quote in this section is the most important, stating that many medical staff were professional but it is the ones who were not who the patients report.

5.4 Discussion

The aim of Study 2A was to investigate the role of the wider social support network of the breast cancer survivor with a view to understanding the type of support that was provided from sources. Thematic analysis of seven transcripts revealed a number of themes and subthemes, some of which were directly linked to themes from Study 1, but others were created from the new transcripts. The themes from Study 1 (Mechanical Help vs. Emotional Help, Appearance Shock, Wanting To Be Normal, Treading on Eggshells, Resilience and Change and Understanding Help) were linked to new themes developed in Study 2, including Protectors and Helpers, Hair Loss Shock and

Feeling Disfigured. New themes developed in Study 2 that were not evident in Study 1 included Initial Perspectives, The Legacy of Breast Cancer, Feeling Grateful, Aftercare, Faith as Support and Medical Support. The theme of A Safe Home was not included in Study 2 as there was no evidence alluding to this in the transcripts.

With regards to social support, the theme of Reactions of others gives the greatest insight into women with breast cancer, their sources of support and the type of support given. In this study male partners were able to provide both emotional and practical support, unlike the findings of Study 1, where male partners were not perceived to provide emotional support. In support of the findings from Study 1, female friends were likely to provide emotional support but it is not the case that they would be approached for this rather than the male partner. The idea of male partners being “protectors” is evident through the transcripts with other support sources being “carers”. Partners in this study were perceived to take on a protective role. This has been found in research by Coyne et al., (2012). The partner’s role has been discussed in previous research, who reported that women experience an improvement in emotional closeness through open communication with their male partner (Walsh et al., 2005). As this study presented how the male partner was perceived to support the participant, there is no information regarding the males’ own levels of emotional distress and support sources. This is noteworthy; high levels of distress have been found in male partners of women with breast cancer when facing the challenges of providing support after a diagnosis has been made (Fergus & Gray, 2009).

As with Study 1, the emotional and practical help discussed is what is perceived by the participants: that is, their perception of emotional support is being able to show emotions about their breast cancer and discuss how they

were feeling. The practical help involved with everyday tasks such as getting lifts to hospital appointments, cooking, cleaning etc. Their perception of emotional help and practical help is different from the theoretical definition stated by the literature, suggesting a need to redefine these concepts. In this study, emotional support and instrumental support was provided by female support sources and the male partner, consistent with previous research (Gass et al., 2007; Wilkes et al., 2002). Aside from male partners and female friends, other individuals were also revealed to be involved with the provision of social support, for example, members of the church community and healthcare professionals. Informational support involved providing advice, information and suggestions that an individual can use to address problems. This was certainly the social support provided by healthcare professionals. This study has revealed a number of social support sources to the woman with breast cancer.

The participants who took part in this study all expressed disbelief that they were diagnosed with breast cancer. This is one of the most stressful points in the breast cancer trajectory, along with waiting for the results of diagnostic testing and awaiting surgery (Gurevich, 2002). The diagnosis in particular can evoke various emotions such as uncertainty, anxiety, despair and hopelessness (Shaha et al. 2008; Zabora et al., 2001, Landmark & Wahl, 2002; Fu et al, 2008). The diagnosis, in particular, may also result in fear of the disease spreading and death (Kaufmann & Ernst, 2000). The coping strategies employed during the diagnostic phase of breast cancer are indicators of psychological adjustment after surgery (Jadoulle et al., 2006; Stanton et al., 2006) and keeping the diagnosis at a distance was found to be beneficial for women who were awaiting surgery (Drageset et al., 2009). Spending time with others has been found to be helpful when coping with the

breast cancer diagnosis (Drageset et al., 2009). This serves to provide emotional support and also serve as a distraction through positive activities (Arora et al., 2007). Consequently it may be of benefit for healthcare professionals to encourage social interaction during the diagnosis phase to alleviate any negative symptoms that may impact on long-term psychological adjustment. However they must also be aware of the variance in coping strategies employed by each individuals and tailor their care accordingly.

As in Study 1, the side-effect of hair loss was mentioned and again, revealed to be an indicator of health for family and friends. Although not considered to be a major issue to the patient, their concerns stemmed from protecting those around them from their illness. Discussion of this finding can be found in Chapter 4 and Chapter 8.

The ongoing side-effects of treatment had an effect on the social lives of the patients who found that they could not carry on meeting friends, taking part in activities etc. as they did prior to their illness. This led to them feeling frustrated. In addition, they also felt anger when they perceived family and friends to act in an overcautious manner towards them. This might have resulted in some individuals not being as open towards their sources of support.

The Legacy of Breast Cancer describes how breast cancer continues to manifest itself in the lives of survivors. The findings in this study and Study 1 describe a) how as a patient, participants wished to be treated as if they were not patients and b) how the participant perceived themselves post-treatment. Expectations of family and friends for the patient to become normal again post-treatment has been linked to emotional distress (Cappiello et al., 2007). Deford et al. (2011) found that women wanted to look normal for others (even

if that was not what they wanted), consistent with the findings from this study. In addition, the same study also found that treatment impacted their ability to carry out routine tasks as if they would before they were diagnosed, and emotions towards this were mixed: “rebuilding normal”, “not normal”, “new normal” and “similar but different”. This re-evaluation of what is now “normal”, particularly the idea of a “new normal” may link to a change in identity.

Survivorship is recognised as a phase of care (Institute of Medicine, 2006) and there is consciousness of women who have been diagnosed with breast cancer and various cancer charities have attempted to raise awareness through the use of the pink ribbon as a global symbol of breast cancer. The change in identity suggested in the previous paragraph may relate to the transition from a woman with breast cancer to a survivor. Kaiser (2008) found that in a sample of breast cancer survivors, 51% identified themselves as survivors with the remainder rejecting this claim. Those who identified themselves as survivors felt empowered by the strength needed to complete treatment and is also related to better psychological well-being (Park et al., 2009). They also identified themselves as a larger group of breast cancer survivors. In contrast, those who did not identify themselves as survivors felt uncertain about reoccurrence and did not wish to be part of a group who identified themselves by illness. Other ways in which breast cancer survivors identify themselves is by maintaining their personal sense of identity (Beatty et al., 2008) or as a victim (Park et al. 2009). To clarify, the term “cancer survivor” can refer to individuals who have completed treatment. However not all people with cancer identify themselves as a cancer survivor (Morris et al., 2013). As such, social support sources should communicate sensitively and in line with the preferred identity of women with breast cancer from the end of treatment into the long-term.

The theme of Resolution? has implications for the social support networks of women with breast cancer. First a more relaxed and positive outlook on life could have a direct impact on the development and maintenance of relationships. This could also be affected by feeling a greater sense of appreciation for the sources of their support network. Renewal and appreciation for life has been demonstrated in other studies (Andrykowski et al., 2005; Kessler, 2002; Cordova et al., 2001).

Religiosity is a phenomenon that may have a profound impact on individuals and is related to subjective experiences, such as meaning, personal happiness and effects of traumatic events (Van-Ness and Larson, 2002; Ellison, 1991). Religiosity is multidimensional and addresses human experiences, systems of belief, religious attitudes and/or behaviours and religious identification and affiliation (Emmons & Palouzian, 2002). In this study, some participants revealed that religiosity played an important role. This can be considered in two ways. The first point to consider is that faith in God and having a religious identify resulted in participants being able to cope better with their illness. This is relates to providing meaning in the breast cancer context (Chamberlain & Zika, 1992), as having belief in a religious framework serves as a resource for explaining life events (Spilka et al., 1985). Studies have support the notion that religion gives meaning and hope, and as a result, can influence positive health outcomes (James & Wells, 2003; Van-Ness & Larson, 2002). In addition, the construct of religiosity has been linked to coping in the chemotherapy, outpatients and those in a home setting (Herth, 1989) but religion has also been linked to both positive and negative coping styles (Hasson-Ohayon & Galinsky, 2009). Negative and positive religious coping does appear have an impact on adjustment to breast cancer, though the literature does not allow specific conclusion. Hebert et al. (2009) used

questionnaires to investigate positive and negative religious coping styles, who found that in a sample of 86 Jewish and Christian Caucasian women, 76% used positive religious coping. However positive religious coping was not associated with any measures of wellbeing. Negative religious coping predicted worse overall mental health, depressive symptoms, and lower life expectancy. Other studies have shown that greater positive religious coping was associated with better quality of life (Balboni, 2007; Laubmeier et al., 2004) and more physical symptoms and negative religious coping was associated with poorer quality of life (Tarakeshwar et al., 2006; Zwingmann et al., 2008; Pargament et al., 1998; Manning-Walsh, 2005). Nairn and Merluzzi (2003) found that religious coping has no relationship to quality of life, a positive relationship to adjustment and in this study, were more important than social support. Positive religious coping is used at the beginning of the breast cancer trajectory (Gail et al., 2009; Thuné-Boyle et al. 2010). The participants involved in the present study described themselves as belonging to Christianity and spoke positively of their religiosity. The second point to consider when discussing religion is the fact that being part of a wider religious community may increase the number of support sources which are available to the woman with breast cancer.

Medical treatment and support and healthcare professionals were discussed during the interviews. During diagnosis and treatment, the interactions with staff, including doctors, clinic nurses and specialist nurses, and the more social aspects of cancer clinics play a valuable role in the provision of support (Dunkel-Schetter & Wortman, 1982; Costain & Hewison, 1999) and patients may form a valuable relationship with those involved in their care (Clarke et al., 2006). This was not the case in this study and healthcare professionals were not viewed in a positive light. In addition, some

participants spoke of their dissatisfaction of follow-up care post-treatment.

Raupach and Hiller (2002) found that after completing treatment, contact with professionals and information provided to patients is considerably reduced.

The findings from this study suggest that this is not in the interests of the patient.

5.5 Conclusion

This study was interested in understanding the wider social support network of breast cancer survivors with a view to understanding the type of support that was provided by sources. It has demonstrated that the social support network extends beyond the male partner and female friends, as suggested in Study 1.

This chapter used thematic analysis on data from seven transcripts, which resulted in production of closely related themes but also original themes. The next chapter presents three case studies, with the view understanding the type of support (e.g. emotional, practical, medical) that was provided from sources and the way that these sources are linked and the extent to which they support each other.

6. STUDY 2B – EXPLORING THE SUPPORT NETWORKS OF BREAST CANCER SURVIVORS: CASE STUDIES

6.1 Introduction

This chapter provides a more detailed account of the social support networks using case studies of three individuals; Kim, Julia and Karen to answer the research questions of “Who are the sources of support that help women with breast cancer and what type of support do they provide?” and “Does social support provision and needs change along the illness trajectory?” Ecomaps were developed in collaboration to illustrate the networks of individuals at the time of diagnosis and the treatment phase. Then, using the ecomaps as elicitation tools, changes to the social support networks along the illness trajectory were discussed. This was to establish the ways in which certain relationships may have changed, for example, strengthening, maintaining and dissolution. Each support source included in each case study is discussed. The three case studies presented in this chapter are distinctive not only with regards to the sources present in social support networks themselves (Engaged, Private and Lonely Social Support Network), but the way in which the breast cancer survivor utilises these sources. This chapter ends with a discussion of the findings.

6.2 Methods

As outlined in Chapter 3, after spending a few minutes getting to know the participant, an overview of the study was reiterated and the outline of the interview was clarified. The first stage involved an explanation of an ecomap and the relationship mapping process was explained with the aid of an example (the data within the example ecomap was fabricated) by the researcher. This was a simple diagram of an ecomap where examples of

different relationships were shown (see Figure 1 above). Using a simple representation to explain the concept of an ecomap allowed the participant to understand the process of mapping without getting distracted by unnecessary details. It allowed participants to understand how different relationships could be depicted and gave them the opportunity to begin to think about who might be included in their own ecomap. The ecomaps were developed in collaboration with the participant, with the researcher using an interview schedule to ensure that topics which directly related to the research question were answered.

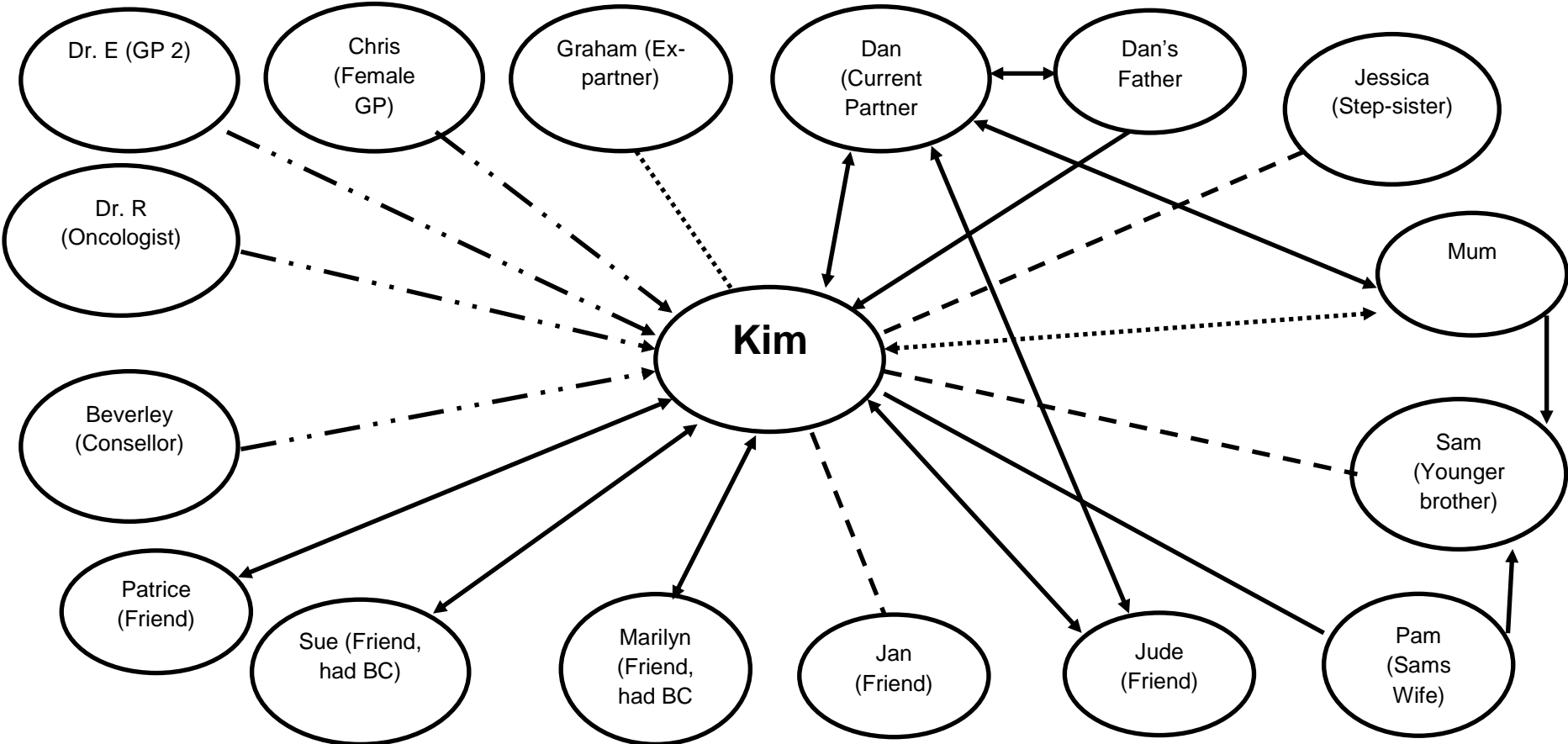
6.3 Results

In conducting a thematic analysis of these three transcripts, the researcher found that the individual impact of each story was lost. As such, the data were treated as three narratives and are presented in the next section.

6.3.1 Case Study 1: Kim – An Engaged Social Support Network

Kim is a 53 year old woman. Born in the USA, she had moved to the UK and was settled in Surrey at the time of the interview. She was married to Graham, but they had separated towards the end of 2010 and from this point, she was living with her new partner called Dan. She was diagnosed with breast cancer in February 2011 having found a lump in her breast. Her treatment involved double mastectomy and reconstruction in early April 2011. From the beginning of 2011 (and from when she was diagnosed and had treatment) she and Graham were going through divorce. Kim does not have any children. The interview with Kim took place in April 2012. Kim's ecomap can be found in Figure 6-1.

Figure 6-1. Kims Ecomap.



Key For ecomaps:	Strong Relationship	—————	Weak Relationship	- - - - -	Turbulent Relationship
	Professional Relationship	- . . . - . . .	Indicates flow of resources →			

Kim's partner (Dan)

Kim described Dan as her main source of emotional support when she was diagnosed, was undergoing treatment and post-treatment:

"Dan was absolutely my rock during everything."

Dan would accompany Kim to every hospital appointment where possible. She recalled the day of her diagnosis, and how she reached out to Dan in the first instance:

"I got the results and it was upsetting so I went and called Dan and he came right over to the hospital from work to pick me up and reassure me."

The first thing that Kim's did once receiving the diagnosis was contact Dan as she felt that he would provide the support that she needed at that time. Dan provided emotional support to Kim as she was upset by the diagnosis. The level of emotional support provided by Dan was continued into the treatment phase as Kim described the loss of her breasts:

"I was very upset with losing my breasts... and we both had a very good sexual relationship which was one of the things I was really afraid would change after the surgery. And we talked about that a lot. It was something that we talked about but we always ended it on a positive note He would reassure me all the time that no matter what, he'd still love me."

The notion of losing both breasts was clearly very upsetting for Kim. There were also issues regarding the reconstruction of both breasts and whether this was something that she wished to go ahead with. Kim stated that she feared losing her breasts because of the potential effect that this would have on her physical relationship with Dan. Although not explicitly stated, her long-term fear may have been whether Dan would still find her physically attractive. She

might also have worried about whether their relationship would survive if there was an effect on their physical relationship. As later discussed, their relationship was relatively new (three months). She and Dan did discuss this often, suggesting that it was a major concern for her, and he appeared to support her treatment decisions. For Dan, it seems as though his main concern was for Kim to get better, not how her appearance would change.

This would be of comfort to Kim, and it possibly because of Dan's attitude, it was one less thing for Kim to worry about and she was able to adjust to having breast cancer more readily compared to if she was worried about Dan's perception of her.

Dan continued to openly communicate with Kim (as she states he did before she was diagnosed with breast cancer) about the loss of her breasts after she had the treatment of mastectomy (with reconstruction):

"I had reconstruction using a thigh flap so my breasts were replaced with tissue and muscle from my inner thighs so later on he got to see those scars and he was also really lovely about that and we would laugh about it. He would actually call me "Frankenstein chimpanzee" because of my scars and when I first got out of bed, I would kind of walk like a chimpanzee walks."

Post-treatment, Kim and Dan were able to laugh together about her surgery, potentially as a coping mechanism. This is reassuring given Kim's concerns about her invasive surgery, the scars her body would be left with, and her fears that Dan would not find her physically attractive.

Kim's fears about Dan leaving her had their foundation because they had been romantically involved for three months before she was diagnosed (despite living together for just over a year). This is a relatively short time to be

with someone. She was also aware that Dan's mother had died of breast cancer three years previously and she felt as though Dan would not be willing to relive a similar experience:

"I said, "Please Dan. We can talk about it. It's ok if you want to leave me because of what you've been through with your mum. And I don't want you to have to go through that again. I'm strong enough that if you say you can't do it, I will take care of myself. I'll be fine" and he said "No absolutely not". He didn't want to lose me, he loved me and he would be there with me."

Kim's perception of the situation suggests that she thought it was almost unfair to Dan to stay with her now that she had been diagnosed, especially because of the early stages that their relationship was in. She seems aware that it will be difficult for Dan to effectively relive breast cancer again and go through the same (and potentially different) motions, but with her instead of his mother. However Dan's confidence in saying that he would stay with Kim and help her made her perceive him as resilient: that his past experiences have equipped him with the means to be able to help her. As explicitly stated in the quote above, it may be because he loves her and wanted to help her.

Kim was also protective of Dan and did not always relay to him the extent that she was suffering. This could be attributed to that she did not want to upset him or make him worry more:

"At times I didn't want to tell him how bad I felt, but to a certain extent it's because I'm very much a survivor."

Kim believed that her protection of Dan was a mutual behaviour, in that she felt that Dan would sometimes not reveal what he was feeling in an attempt to protect her. She understood that he talked to his Dad and his friend Jude a lot,

because *“there are some things you don’t talk about to your partner such as your suffering about them or your woes about them.”*

Although Kim’s adjustment to her breast cancer was moderated by the support received from Dan, she was not immune to occasionally feeling low. These negative feelings always were alleviated by Dan, specifically through the emotional support that he provided Kim. In addition, Kim’s gratitude towards Dan might have served her in motivating herself to keep active and to keep positive.

Finally Dan provided Kim with some practical support during her illness and was perceived by her to provide more practical support than other sources:

“He would help me with things like getting to the pharmacy at the hospital for prescriptions and he would also offer, you know, to clean the house and help out around the house if needs be.”

From Kim’s reflection on the support provided to her by Dan, he was instrumental in the emotional support provided. In addition he was the main source of practical support. Prior to the treatment phase, Kim stated that she did not need any practical support. In the time period that followed her mastectomies, she was dependent on Dan’s practical help, such as cooking her meals and taking her to the hospital.

Kim’s Family

Dan’s father was also eager to help Kim while she was ill. Dan’s father was a widower as his wife had died after being diagnosed with breast cancer. As a result of this, he was willing “to go that extra mile” to help Kim and was very

open with his experiences with his late wife, providing her with emotional support and practical advice based on his own experiences with his late wife:

“He would share things about his wife when she was going through chemo and he knew some of the nurses so it was very familiar to him so he was comfortable in supporting me... he felt that he knew enough about the hospital that he could help me through my issues of going to chemo.”

Here Dan’s father is pre-empting some of the issues that Kim might face which Kim took comfort in and found useful. By sharing his own experiences, he is not only providing a level of emotional support to her, but also practical advice. This was helpful to Kim. It is worth also considering that Dan’s father might have felt worried about Kim’s diagnosis: as his wife did not survive, he may have felt particularly worried about her prognosis and also how it might affect Dan, so he wanted to support not just her, but also Dan.

Kim suspected that Dan and his father supported each other during her illness as it was likely to have brought up memories of Dan’s mother. She described the three of them meeting and thinking about her:

“They talked about mum and talked about things she went through that were similar to me and his dad would come over and you know, we’d all cry together and talk about her.”

These meetings, Kim felt, brought them closer together as it allowed them to share their fearful emotions about her illness. The relationship between Dan and his father has been maintained post-illness to a certain extent and Kim described her illness as resulting in Dan acting “softer” towards his father, in that he has been treating him with more compassion.

Kim's mother is living in USA but they would talk frequently on Skype. Kim's mother is a nurse and Kim describes that because of this, she felt comfortable talking to her about how bad she felt, due to her mother having an in-depth understanding of breast cancer and chemotherapy. Kim states that during her illness trajectory, her mother's behaviour towards her changed:

"And she was able to just listen to me and just give me love and kindness and kind words. She hadn't been able to do that before."

Kim described how she and her mother had a falling out several months prior to her diagnosis. Once Kim told her mother about her breast cancer, her mother wanted to know the details of what was happening and was ready to listen to Kim. Kim stated that her mother was the only person who knew the extent of her suffering, revealing details that she did not reveal to Dan. Kim felt that because of their falling out some months previous, her mother was trying to make up for that by supporting her.

"She told me I was a terrible daughter. We didn't speak for months but I had to tell her I was ill... And then we both kind of forget about the things she said".

This was appreciated by Kim. She thinks that now that she is not ill, her relationship with her mother is not as good. It is not clear whether Kim felt as though she still needed her mother's support post-treatment and was unsatisfied that this was not available to her.

Kim's mothers' relationship with Dan also improved over the course of her illness. She stated that Dan would often call her Mum when she was undergoing treatment in the hospital and they would talk every day. Kim thought that had she not been ill, this would not have happened. She

attributed this to them sharing similar fears. Similarly, she feels that Dan's relationship with her Mum is not as close, now that she is not ill.

Sam, Kim's brother, also lives in the USA. He and his wife Pam own their own business and struggled to come to the UK to visit Kim whilst she was ill. Kim wished, at that time of her illness, that she could have spent more time with him as she believed that she might not get the chance to. She described how she and Sam do not talk much on the phone or over Skype because she feels it is not a good medium of communication for them. She stated that she and Sam have similar interests so when they are together, they took part in activities they both enjoy, such as hiking. She said that they do not talk about sad things, because she feels that he can be very sensitive, and that she asked Sam's wife, Pam, to relay her diagnosis to him. Pam had told Kim that Sam was very upset and angry. When Sam spoke to Kim after finding out that she had breast cancer, he was calmer and they were about to talk very briefly. Kim perceived Pam as the carer of the family and her brother to be an emotional person. Kim knew that Pam would be able to console and support Sam when he found out the diagnosis. Kim found out that Dan had been communicating with Sam to keep him updated on Kim's condition. To summarise, Kim communicated very little with Sam on the phone/Skype and was seemingly reliant on Pam and Dan to relay information about her illness to him. The fact that both Pam and Dan undertook the role of informing Sam about Kim's illness was supportive to Kim, who felt that they were more suitable to talk to Sam about breast cancer.

Kim has a step-sister called Jessica, who she has known for a few years. She says that they have not had the chance to develop a level of closeness. Jessica did contact Kim to find out how she was. Kim stated that

Jessica did not actively support her, but the fact that she would contact her regularly to check how she was doing made Kim feel cared for.

Acquaintances and Friends

Kim's ex-partner, Graham, was told of her diagnosis fairly soon after she found out. She remembered him being unkind to her, with their relationship not being amicable for several years before her diagnosis, continuing to the day of the interview:

“He said something like “It figures you would get something like that” and he wasn't very kind about it really and made jokes about me having implants and having reconstruction and even forgot that I told him that I was having reconstruction and he was “lots of people wear those falsies these days, you'll be fine”.”

Completing her treatment programme whilst going through the divorce proceedings added to Kim's stress. However she said that she wanted to be with Dan, so it was something that she felt she had to do.

Kim and Dan are musicians who regularly play in an orchestra. Many of their friends are a part of this group and Kim took comfort because he was seeing them regularly when she was undergoing treatment. In addition, these musician friends would visit Kim to offer company to her. In particular, she recalled Jude, who she considered to be like a sister to her. Jude would arrange meetings with Kim outside of her home to ensure that she did not feel stuck there. She says that she could talk to Jude about *“anything I wanted”*. She described Jude as being very strong, so she felt that she was able to support Kim. Jude in particular spent a lot of time with Kim and they were often to discuss how Kim was feeling. Jude was, in fact, friends with Dan first. According to Kim, Dan often spent time talking to Jude, although it was not

clear if they spent time talking about Kim's diagnosis. Kim attributed the closeness of her relationship with Jude because of Jude's original friendship with Dan.

A close friend of Kim's named Jan struggled with Kim's diagnosis and she "*pulled away*" from their relationship. Kim attributes this to Jan having her own breast cancer scare in the past and that she "*would struggle with the intimacy of someone going through a difficult time.*" At the time of Kim's illness, Jan was distant from her, but now that she is in remission, they have rekindled their relationship, although they are not as close as they used to be, prior to diagnosis.

Patrice is a friend of Kim's living in the USA. Patrice's mother died a few months before Kim's diagnosis so they were already communicating frequently over Skype, Facebook and over emails. Kim states that she was very supportive of her, due to the sensitive state she was in after losing her mother. She was not afraid of talking about death with Kim and was very pragmatic. In their communications, Kim stated that there was reciprocity in providing emotional support:

"She never opened up about losing her mother until I was diagnosed. Then she talked freely about it and I talked freely too. I think it was good for her. It was definitely good for me."

Kim felt that Patrice was incredibly supportive, but longed for her to be there in person.

Sue is another friend living in USA who was diagnosed with breast cancer two years before Kim's diagnosis. Kim describes being very close to Sue, talking about issues that "You couldn't even talk to a mother about those things". They communicated using Skype and Facebook. When Sue had

cancer, she did not want to talk about it, and Kim felt that this was her choice and that she believed that Sue was coping with her diagnosis. After Kim's diagnosis, Sue revealed to her that her having cancer was helping her move on from her own experiences. Sue was able to share her own experiences of breast cancer which Kim took comfort in, in the same way that she took comfort in Dan and Dan's father's secondary experience with breast cancer. Kim felt that the sharing of experiences allowed them to both grow from the experience.

Marilyn is a friend living in USA who is a breast cancer survivor. She was an old friend from high school who Kim had recently got back in touch with, though she did not explain why they fell out of touch with one another. Kim describes her relationship with Marilyn as very good, feeling able to talk about marital problems and her cancer experience, with the relationship remaining strong along the illness trajectory. Kim was particularly grateful for recommendations about what to do post-surgery but also for the fact that she could talk openly about how she was feeling.

Kim's support network is primarily made up of female support sources. Kim felt that she made friends with women very easily and always has done. She considered the fact that she does not have as many male friends as she prefers people to be open and talkative.

Health professionals

During the interview, Kim did not mention any health professionals that she felt helped her when she had breast cancer. When questioned about this, she said that she saw them as authority figures, who were there to help medically, and that they seemed so busy that she did not want to waste their time. Her oncologist, Dr R. was viewed in this manner: as someone who could provide

medical advice/information only. Kim did have a period of feeling depressed and she visited her GP to address this. She also met with a counsellor.

When Kim was initially diagnosed, she spoke to her GP (Chris) who prescribed some medication for her. Chris knew Graham and she understood how difficult he could be and therefore was very supportive to Kim. Kim also stated that because of this, she was able to tell Chris more than her current GP. Kim then moved from that geographical area (where she used to live with Graham) to a new area and as such, got a new GP, Dr Edwards. Dr Edwards was very kind to Kim and she felt that she could openly talk to him about her depression. However she felt that the six minutes allocated to her per appointment was not enough for her to talk about her issues thoroughly and so she opted to have private cognitive-behavioural therapy.

Kim's counsellor, Beverley, taught Kim to enjoy life more. She taught her to "*be tough and hang in there*". Kim attributes her good relationship with Beverley with being the same age, having many things in common but also having a good communication style with one another.

Discussion of Kim's Case Study

Kim's social support network revealed a variety of sources providing different types of support, including emotional and practical support and medical advice. Kim identified her main source of support, or significant other, as her current partner Dan. Though they had been living together for six months prior to diagnosis and intimately involved for three months, Dan's support had helped Kim. The relationship vulnerabilities of couples during breast cancer have been noted by Fergus and Gray (2009), noting different levels of support and adjustment, but found that although women wanted close support, they were mindful of the emotional needs of other members in their family. In line with

previous research, Kim's described her partner as supportive, especially with regards to instrumental support. Other individuals who were included in Kim's social support network included Dan's father and her mother, both of whom had prior experience and/or knowledge of breast cancer and were able to share this with her. The role of Kim's mother in this case study has highlighted an important relationship in the breast cancer context. Kim's stated that she was able to openly discuss her breast cancer with her mother despite the fact that they had a difficult relationship in the past. The literature looking at the relationship between a woman with breast cancer and her mother has not been widely researched. Coyne et al. (2012) found that mothers felt anguish regarding their daughters' diagnosis and wanted to take their pain away. Research into paediatric cancer found that the burden of the mother of caring for an unwell child influenced the whole family and that mothers' tended to report higher emotional and physical burden than fathers (Svavarsdottir, 2005). Further investigation into this relationship would be of benefit. As individuals are living longer, it is likely that a parent may have to care for their adult child at some point. The experiences of mothers supporting their adult children needs to be acknowledged by healthcare professionals and opportunities to grieve and accept the situation must be provided.

Kim's relationship with Sam post-diagnosis was largely mediated by his wife Pam and Dan, who relayed information about her illness to Sam, because they all felt that Sam would be very sensitive to the news about her diagnosis. This finding is consistent with Coyne et al., (2012) who found that some people were not able to cope with the diagnosis of breast cancer. As such, the family avoided contact with these people to reduce their own distress and maintain a positive self-belief (Low et al., 2006; Sears et al., 2013). However, lack of acceptance and withdrawal of others may increase distress in women with breast cancer (Northouse, 2005).

Kim's ex-partner Graham did not provide any support to Kim, but rather his unkind comments made it difficult for her to cope with the diagnosis and treatment stages. Holmberg et al. (2001) found that a diagnosis of breast cancer would often act as the catalyst for ending unhappy, intimate relationships and universally, unpartnered women with breast cancer received little support from their ex-partners and were likely to be ignored or criticised openly. The findings from this case study are similar.

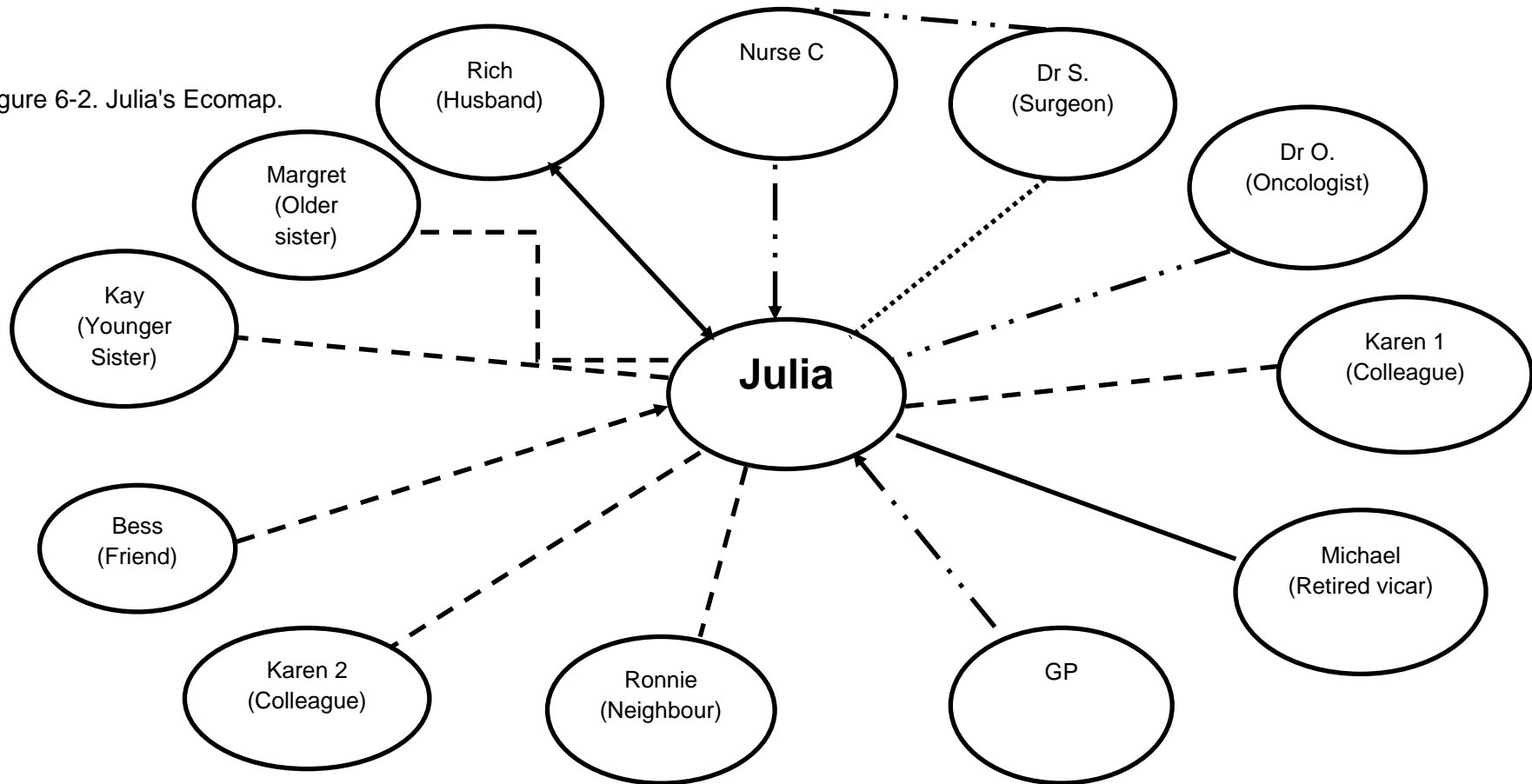
The most prominent changes in Kim's relationships relate to those with her mother and also the relationship between Dan and his father. From the interview, the breast cancer diagnosis and treatment brought these sources closer. In the long-term period, Kim actually did not communicate or rely on her mother for support and similarly Dan grew apart from his father again. It seems that breast cancer can unite individuals in an attempt to help the patient, but once they become a survivor, they do not seem to offer support and from the perspective of Kim, once a survivor, she did not need this. Women who identified themselves as survivors felt empowered by the strength needed to complete treatment and is also related to better psychological well-being (Park et al., 2009). This identity of survivor meant that Kim no longer needed support and this was not provided by her social support network. These family support sources and the way that they united during Kim's breast cancer is congruent with previous research (Walsh, 2006).

6.3.2 Case Study 2: Julia – A Private Social Support Network

Julia is a 56 year old woman. She was diagnosed with breast cancer in 2006 after finding a lump in her breast. There is a history of breast and ovarian cancer in Julia's family: Julia's mother died of breast cancer when she was eight years old and her sister has also been diagnosed with breast cancer. At

the time of her diagnosis, she was working full-time. As part of her job, she flew from London to Dublin once a week. She decided not to continue working whilst she was undergoing treatment. Her treatment involved mastectomy, chemotherapy and radiotherapy which she underwent under private health care. She has been married to Rich since 1985. Julia does not have any children. The interview took place in May 2012. Julia's ecomap can be found in Figure 6-2.

.Figure 6-2. Julia's Ecomap.



Key For ecomaps:	Strong Relationship	—————	Weak Relationship	- - - - -	Turbulent Relationship
	Professional Relationship	- . . . - .	Indicates flow of resources			

She made a conscious decision not to let anyone other than her husband and sisters know about her diagnosis:

“I was trying to keep things and people at arm’s length to a certain extent. I just didn’t want to get into getting asked questions I didn’t know the answers to. I would feel that I should know the answer and have to do my homework... I think some of it is about control.”

Julia stated that she deliberately did not engage with individuals to avoid questions, many of which she did not have answers to and she attributes this to control. For example, getting a diagnosis of breast cancer and having to decide on subsequent treatment is largely based on the advice of medical professionals. The input from the patient would vary from case to case. In addition, the various hospital appointments for treatment would be the main focus of the weeks that followed, with other activities that that Julia wanted to take part in (for example, the role of Treasurer, discussed later in this chapter). Julia felt that information about herself and her diagnosis was one thing that she felt she had control over. It also appears that she did not want to be burdened with other people’s questions, partly because she felt as if she would not know the answers herself. As such, she decided to share this information with certain people, due to their familial links or for practical reasons but made it very clear to these individuals that they were not to discuss her diagnosis with anyone else.

Julia’s husband (Rich)

At the time of interview, Julia was not keen to reveal much detail regarding her husband Rich. She described telling her husband of her diagnosis after they had been for dinner together in a local pub. She did not tell him immediately after her appointment due to being in a state of disbelief or not wanting to

worry him whilst he was at work. She had chosen to attend her hospital appointment alone earlier that day and she took her husband to her next appointment at the hospital because that is what she felt she needed from him. He did not attend any subsequent appointments. She stated:

“We’ve not had a conversation about whether he wanted to come with me but he is the type of guy who wouldn’t impose himself...”

Julia described herself as always being independent (*“I’ve never felt the need to take somebody with me everywhere I go”*), and that this had always been respected by Rich, and this was reflective of their relationship as a whole. She claims that he would have been happy to go along with what she wanted and she wanted to attend her hospital appointments alone feeling confident that she would cope by herself, which she felt she did. She understood that this was probably not the most common reaction displayed by newly diagnosed women and their male partners:

“When I think of my next-door neighbour for example, she had a similar diagnosis and her husband said “Right, that’s it, I’m coming with you” and would have been more in the driving seat let’s say.”

Julia did not explicitly state that she was in “the driving seat” but it was clear that Rich would follow whatever she wanted to do. That was what she expected of him and that is what he did. In addition Rich’s working hours would not permit him to attend appointments. It is not clear whether Rich was happy for Julia to attend the appointments alone or whether he would have liked to have been there. Julia identifies herself as part of a team with Rich, but also her own independent person :

“When people say their husbands’ are their other half, I cringe at that because I don’t consider myself to be half a person. I’m half a team because there’s two of us but I’m not half a person.”

It seems that Julia does not like this because it implies that she is incomplete without her husband. She does not think that this is the case, suggesting that they work together but can operate separately as well. When asked about certain action that Rich took to help Julia, she claimed that she did not rely on him for anything. This is not surprising given the fact that she considers herself to be independent and she relates this to her mother dying when she was very young. Her perception of herself appears to have a direct impact on her support needs. Compared to the participants in this thesis so far, Julia had very few support needs and was seemingly self-reliant. She was happy with this.

Margaret (older sister) and Kay (younger sister)

Julia has an older and younger sister. She is two years older than her sister Kay and five years younger than her older sister Margaret. They grew up separately following the death of their mother. Margaret was living in Canada at the time of interview. She was married and has children and grandchildren. Kay is single, also living in Canada at the time of interview. They do not see each other in person very often, but speak on the telephone. This has been the case for most of their lives. Julia stated that they do not always get along and attributes them to having different personality types. She identifies with Kay’s perception of family:

“My younger sister is quite conscious that family is important and that she hasn’t really got anybody there and there’s nothing much left of our family.”

This point of view is something that Julia agrees with. The fact that the three of them are the only relatives alive in their family means that Julia and Kay are conscious of keeping in touch with one another. As Kay is single, she is even more aware of keeping cordial relationships with her sisters. However she is considered to be inquisitive which can be annoying to both Margaret and Julia. As a result of this, Julia relied on Margaret to tell Kay about her diagnosis. Margaret had told Kay about her own diagnosis at the time of interview, for the same reason.

She identifies with Margaret:

*“My other sister is a lot more pragmatic and stoic and just says
“that’s life, shit happens”.”*

Margaret has been diagnosed with breast and lung cancer. This might be the reason that Julia felt more of a connection with her. They are unified by breast cancer and have adopted the same coping mechanisms. The shared experience resulted in Julia talking with Margaret more than Kay about her breast cancer. Julia did not state the specifics of what she and Margaret spoke about but the fact that there was a dialogue of sorts is indicative of a level of mutual support between the two.

In Christmas 2008, the three sisters spent their first Christmas together in 38 years. They had not spent Christmas together for such a long time, not through choice, but rather because they were all busy. Julia considered the fact that they spent this Christmas together because of Kay’s fear that he sister might die and it was important to her to spend time with her. It is hard to distinguish this as an act of providing support. Julia did not comment whether she was happy to have spent Christmas 2008 with her sisters.

Non-Family/Friends

Bess (WI Deputy Treasurer)

At the time of diagnosis, Julia was Treasurer for the Women's Institute (WI) group in her local area. She was unsure whether she would be able to continue her duties whilst undergoing treatment and although she had wanted as few people to know about her diagnosis as possible, she felt it necessary to ask someone to deputise for her as Treasurer. This person was another member of the WI and called Bess. Julia very briefly explained her condition to her, explicitly stating that she did not want her to tell other people about her diagnosis. Julia describes Bess as follows:

“She’s quite a quiet lady actually... She’s always very busy. I never made a point of going to her but she would come and see me.”

One of the reasons that Bess was picked by Julia to deputise is because she is quiet. This would be an important attribute because then she might be less likely to discuss Julia's condition with other people. In addition, the fact that she was busy might also have been beneficial and detrimental to Julia: she would be too busy to have conversation with people about Julia but because she was seeing so many people when doing tasks, they would be likely to enquire about Julia and she would be too busy to see Julia often, which was what she preferred. In short, Bess' non-disclosure was to be a supportive factor to Julia.

Julia understood that several people had approached Bess to find out more about her condition:

“She’s the kind of person who wouldn’t tell a barefaced lie and they could invade into her confidence. Some women are like that. They’ll keep prodding and probing until they get an answer.”

She suspected that Bess might find it difficult to keep Julia's illness a secret, but she was very sceptical of the behaviour of other women in the WI. This quote demonstrates distrust towards women. This might explain the lack of friends, specifically female friends within Julia's social support network.

However Julia was disappointed that Bess told her husband about her diagnosis:

"She told her husband which I wasn't so happy about but if you tell one half of the team, I realise now that they're bound to share it and I was unrealistic to expect them not to. I was naïve."

Julia's relationship with her husband is such that she will not discuss everything with her husband and vice versa. This is largely to do with respecting other people's privacy, but since her diagnosis, she realises that this is not the way in which all couples work.

Overall Julia was happy with Bess for taking over the role of treasurer for the WI. In particular Julia appreciated the fact that Bess did not visit her often and kept conversation away from breast cancer. There was disappointment over Bess sharing news of Julia's breast cancer with her husband. However Julia agrees that it was naïve of her to think that this would not happen, addressing the fact that different couples might have different dynamics and act in different ways.

Karen 1 and Karen 2

Karen 1 and 2 were work colleagues of Julia, whom she saw sporadically during her treatment and after, one based in France and the other in Dublin. They never discussed breast cancer with Julia, in line with her wishes.

Ronnie (neighbour)

Julia did not want her neighbour, Ronnie, to know about her diagnosis. However she found out after sending an email to Julia's work address and received an autoreply message stating that she was on sick leave indefinitely. Julia recalls:

“A neighbour of mine received my out of office reply and was obviously alarmed and rang me a few days afterwards. She said “I’ve seen your out of office reply. Is there anything I can do?”

Although she did not want people to know about her diagnosis, she was appreciative of her phone call, in particular, asking if there was anything that she could do to help. She did not call to find out details of what was wrong, but rather offered her help if needs be. Although Julia did not ask Ronnie for help, she was grateful that an offer had been made and that no enquiries were made about what was actually wrong. Ronnie did go round for coffee a few times but treatment was never discussed. Even if Julia was feeling unwell from treatment, she never revealed this because she felt that it was none of Ronnie's business and she did not want to have a detailed discussion about it. Ronnie was respectful of this. This could be because of previous experience of other friends having breast cancer and knowing what not to talk about. It might also have been that she knew Julia did not want to discuss anything.

Michael (vicar)

Michael was told about Julia's diagnosis by Ronnie, who had asked that he include her in prayers at church. This was something that Julia was unhappy about and asked that she would not be named, again protecting her privacy. Michael is a retired vicar, but would often take part in services on certain occasions. His wife is a member of the WI but Julia does not know her well. Although not heavily involved with the services at the church, Julia was active

in fundraising for them. She did not appreciate the fact that prayers were said for her, but was happy to have Michael come round for a chat, again, as long as the conversation was not to do with breast cancer. This was an important factor throughout the interview with Julia. It seemed to be the case that she was deliberately distancing herself from individuals in her support network. The fact that she stated that she was happy to have Michael come to see her suggests that she did want some support, but avoided talking directly about her breast cancer.

Health professionals

Unlike Kim, the health professionals that Julia encountered were the first support sources that she described during her interview.

Dr S

Dr S was the first surgeon that Julia saw to discuss her treatment programme. She mentioned that there was very little choice for her with regards to her treatment options, but she also felt confused regarding some of Dr S's decisions but felt uncomfortable asking him questions:

“...then he mentioned that the next couple of years would be very uncertain for me and he didn't expand on that. I didn't ask him to expand because at that stage I was still in the patient- doctor relationship, which I think in this case had barriers and I didn't feel in a position to question him.”

Given the fact that Julia previously said that she did not feel that she had the knowledge to answer peoples questions about her breast cancer, it is not surprising that she did not take the opportunity to ask her surgeon questions to find out answers to certain questions. Julia may have found herself in a state

of shock and find the initial hospital appointments slightly surreal or they may be avoidant of the situation. With this in mind, they might not think of immediate questions to ask their doctor. The doctor is likely to be perceived as the expert and although certain individuals might have queries which they want answers to, some might be resigned to this fact and listen to their advice unquestioningly. Women with breast cancer might feel vulnerable and very trusting of people in the medical profession, because it is assumed that they would not cause the patient harm or withhold any information. Julia described Dr S as a “patriarch” and after four years of being under his care, discharged herself, as he disagreed with her desire to see another doctor for a second opinion regarding her ongoing care.

“People warm to the surgeon because he is charming and patriarchal and some people might be accustomed to that but I wasn’t to be honest. Maybe because certain ladies need that depending on their lifestyle.”

Julia appears to assert her independence again here and distinguishes herself from other women. She believes that certain women need someone to lead them, akin to how she believes she and Rich function in different ways compared to other couples that she knows.

Dr O

Dr O is the oncologist that Julia saw for the majority of her hospital appointments. She described his as being “straight-faced” and was able to build a good rapport with him:

“He’s the sort of person that I would describe as a fence sitter – if you had to make a decision, he wasn’t biased one way or the other, he pretty much left me with the decision, outlining the pros and cons.”

Unlike Dr S, Dr O made Julia aware of all information before any decisions were to be made by her. She appreciated this, presumably because this is connected with her desire for control as mentioned before. The fact that she was given an opportunity to actively engage with a clinician and make decisions regarding her own treatment was something that she wanted to do.

Nurse C

Julia built a rapport with Nurse C who was completing her formal training whilst Julia was undergoing treatment. Julia had discussed many of the issues that she had with Dr S. with Nurse C., who considered herself to be an advocate of women with breast cancer.

“She is a very caring person and I think she realises that my treatment wasn’t as it should be under him and she is determined that this shouldn’t happen to other people and patients should stand up for themselves.”

Julia stated that she never actively sought help from Nurse C. regarding some of the problems that she was having with Dr S. but she happened to be present for many of their appointments, almost acting as a mediator. Julia stated that she admired Nurse C.’s determination to ensure that women with breast cancer are involved with decision-making regarding their treatment. For Julia, this was a key issue in her own treatment and she was encouraged that other clinicians were trying to promote this view to other patients.

GP

Julia had visited her GP a few times whilst she was undergoing chemotherapy as she was suffering from side-effects. She felt that she did not want to bother Dr O, so opted to see her GP instead. She recalls her GP being able to provide medical advice regarding her side-effects but also being able to write prescriptions to alleviate these. She was particularly pleased that her GP would see her as an emergency case.

Changes to the support network post-treatment.

Julia spent a lot of time reflecting on how she was utilising certain support networks at the time of interview, which she had not during her diagnosis and treatment. In particular she discussed how she now used online breast cancer support groups and forum. She was not aware that such communities existed during the earlier stages of her illness and stated that had she known about them, she would have explored them as she was doing at the time of interview. She also attributed this to her age, claiming that it was difficult for her to get accustomed to using these forums.

Finally Julia reflected on her decision to use private health care services rather than using the NHS. She regrets this decision, based on the fact that she was not made aware of the specialist breast clinic that was available at her nearest NHS hospital, which she felt could have provided her with better care and information:

“...the NHS hospital with two full time nurses dedicated to the role and I realised what I’d been missing out on in terms of support, information and someone to bounce questions off.”

With regards to clinical care specifically, Julia felt that she did not received the best care. The fact that she did not get on with Dr S. is likely to have strengthened her views on this. She strongly felt that her private health care did not provide the same quality of support that she would have received compared to NHS care, particularly do to the lack of specialist care.

Discussion of Julia's Case Study

Julia's social support network has revealed sources which provide different types of support. The emphasis of the interview was on the health professionals that she encountered along the illness trajectory.

A main feature that arose from Julia's interview was that she appeared to be keeping people at arms-length: that she wanted support but did not want the discussion to focus on breast cancer. She stated that this was because she felt that people would ask her questions that she did not know the answer to. Privacy was another important feature of Julia's social support network, whereby she actively did not discuss her breast cancer. She relates this to wanting control over the aspects of breast cancer that she felt she could control (Wilkes et al., 2002).

Julia failed to mention any of the sources of support as her significant other. She implied that she was not reliant on anyone for any kind of support apart from the health professionals involved in her care, from whom she sought medical support from. With regards to changes in Julia's relationships, there did not appear to be any changes with regards to support. The impression from Julia was that she was always a private person and very self-reliant even before her diagnosis. As such, the role of social support and its effect on how she coped with breast cancer is not as clear as the case of Kim.

Post-treatment, Julia stated that the only difference in her social support network is the individuals that she communicates with online through various breast cancer websites and forums. Hoybye et al., (2005) described how social isolation following breast cancer may be alleviated through online support groups. This may be an ideal medium for Julia to communicate with other women with breast cancer and survivors as she would be able to maintain her anonymity and thus her privacy. Similarly she may find it easier to communicate with others with a shared experience as they may not ask the same questions as individuals in her face-to-face support network might.

Julia's social support network and narrative revealed mismatches in her support needs and what was offered to her, especially when discussing members from the WI. Negative support transactions have a strong correlation with negative psychosocial outcomes (Manne et al., 1997). Negative interaction may be more memorable than positive interactions and may have a stronger impact on psychological wellbeing (Rook & Pietromenaco, 1987). Indeed, many of Julia's support sources were talked about in a negative light and it is important to state that these negative interactions may have been an additional stressor to her (Wortman & Dunkel-Schetter, 1987). Work by Reynold and Perrin (2004) also found that unwanted but received support was associated with poor psychosocial outcomes.

Finally Julia expressed dissatisfaction towards Dr S whom she placed in her social support network but was pleased with the support that she received from the nurse. During the treatment and diagnosis stages, doctors, clinic nurses and specialist nurses are perceived to play a valuable role in the provision of support and often patients form valuable relationships with those medically involved in their care (Dunkel-Schetter & Wortman, 1982; Costain & Hewison, 1999; Clarke et al., 2006). This was not the case with Dr S, but may

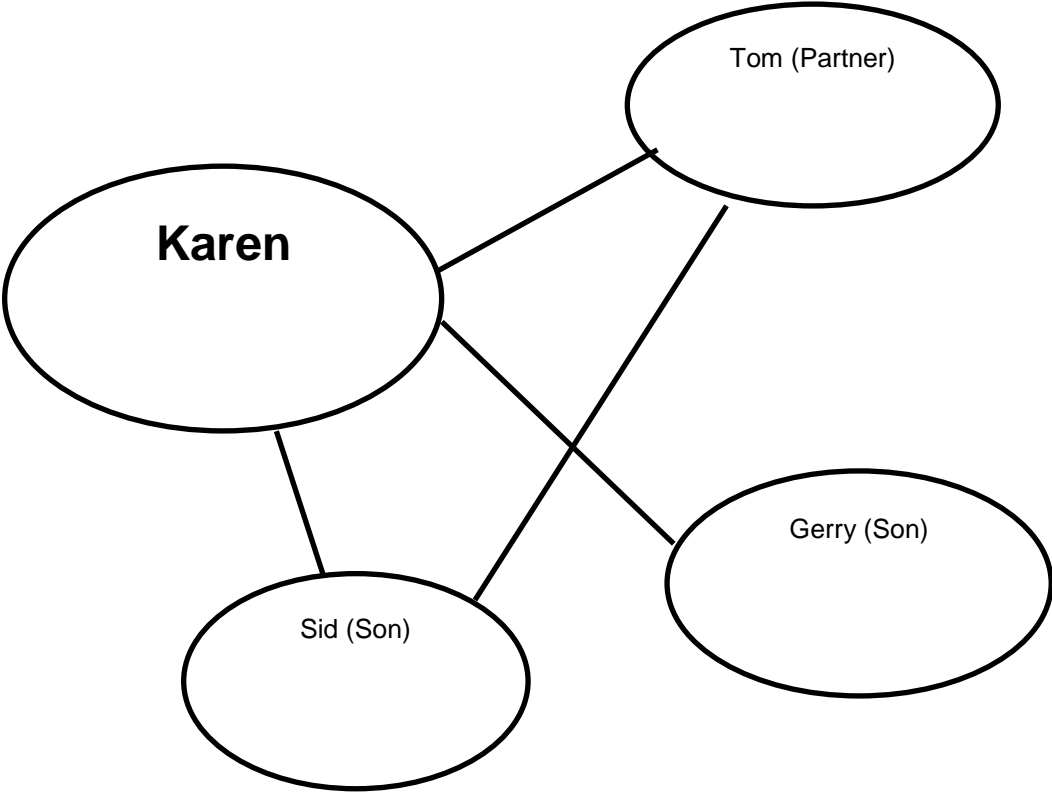
be for relationships formed with other healthcare professionals. Usta (2012) described nurses as healthcare professionals who act like a bridge between the healthcare system and the patient most of the time and are usually the closest medical staff for breast cancer patients to turn to for anything they needs. This was indeed the case for Julie, who reported a good relationship with her nurse. Nurses have previously been noted for the support that they provide to women with breast cancer (Remmers et al., 2010).

6.3.3 Case Study 3: Karen – A Lacking Social Support Network

The events leading up to Karen's diagnosis are atypical compared to the stories shared by other participants. In mid-2001, she started having episodes of dizziness. This affected her mobility and her speech and resulted in a week long hospitalisation in November 2001. She was treated at that time with steroids and she gradually began to feel well. However after Christmas, the symptoms returned. She was admitted to hospital again for three weeks in May 2002, underdoing several diagnostic procedures, such as blood tests and lumbar punctures to ascertain the cause of her symptoms. No diagnosis was made. In late 2003, she underwent a mammogram and was diagnosed with breast cancer in November 2003. She was still experiencing severe bouts of dizziness and she described severe problems with her cognitive function and speech. Her treatment included lumpectomy, chemotherapy and radiotherapy. She completed treatment in 2004. She was working full-time until November 2003 and explained that she fell out of contact with all of her work colleagues. She is married to Tom since 1995 and has two sons with him, Gerry and Sam. The interview took place in May 2012. As the interview occurred a long period of time after diagnosis and because Karen was experiencing various cognitive difficulties during her treatment, she was unable to recall events clearly. She stated that she did not receive emotional support from anyone and largely

relied on herself. This was not through choice. Karen's ecomap can be found in Figure 6-3.

Figure 6-3. Karen's Ecomap



Key For ecomaps:	Strong Relationship	—————	Weak Relationship	- - - - -	Turbulent Relationship
	Professional Relationship	- . . - .	Indicates flow of resources			

Karen's partner (Tom)

When Karen was diagnosed, her husband had accompanied her. Due to her issues with dizziness she was unable to drive. It is not clear whether her husband had accompanied her because he wanted to or just to provide transport. She stated that she wanted him to be there. She claimed that she could not recall whether they actually did talk about her breast cancer after her diagnosis.

Karen speculates that her husband was more afraid of her diagnosis than she was:

"I think he was more frightened than me because he told everybody. You know, sat there listening to the same old story."

Tom might have told many people about Karen's diagnosis as a means of actively seeking support from others. Telling people about how his wife was unwell might have elicited soothing words, encouragement, sharing of experiences and knowledge or offers of help.

Aside from driving Karen to her hospital appointments, Tom helped with domestic chores such as cooking and cleaning and also took on a more primary caregiver role to their children. Karen stated that he did attempt to provide her with emotion support:

"He did the cooking and he tried to help me emotionally but he wasn't very good. I think he tends to bottle things up a lot. He was probably talking to other people more than me. I wish he would've talked to me, but you know, it was ok at the time."

Karen was not specific with what measures Tom took to help her emotionally. Her emotional needs were not met by his attempts. It could be assumed that

he was not talking to her about his thoughts and was maybe talking to other people. He might have sought help from other people outside his family, to ensure the family home stayed “a safe place” (see Chapter 4). Karen wished that she and her husband did have a more open dialogue, probably because she did not have any other emotional support sources available to her.

“But I couldn’t talk to them. I wouldn’t want to burden them. I think they would have felt burdened.”

She felt like a burden because she was not working anymore but her husband was. Tom might have been under stress not only because of working to support her and their sons financially, but also with the news of her diagnosis. In this respect, she might have felt like she was placing a financial burden on her husband and did not want to inconvenience him with other problems. She also felt that her husband was happier before her diagnosis:

“I think my husband was happier when I was running a swimming club and going to work.”

This might appear to be because Karen was also playing a part in terms of financially supporting their children. However, the fact that Karen was still unemployed might act as a reminder for Tom, of her breast cancer and the fears and uncertainty that he might have experienced.

Karen’s children: Gerry (13 year old at the time of diagnosis) and Sid (16 year old at the time of diagnosis)

Tom told Gerry and Sid about Karen’s diagnosis. There were two main reasons for this. The first was that due to problems with Karen’s speech, she was physically unable to talk to them to tell them. Second, Karen felt that she was not able to control her emotions when talking to them about her diagnosis:

“You know, my sons set me off to cry and it does me head in. So I haven’t cried since in front of them.”

Karen was concerned about her sons, especially if her treatment was unsuccessful in controlling the disease. She did not want to cry in front of her son’s because she did not want to worry them. She felt the need to put on a brave face to encourage them to also be brave. She obviously did not want to cry at all. This could be attributed to the fact that she stated that she lacked any emotional support and so there would not be anybody to comfort or reassure her if she was to show how upset she was feeling. She was unlikely to discuss her illness in detail with her sons because they were young at the time of diagnosis.

Karen’s ideal support sources.

It had been over five years since Karen’s treatment had finished at the time of interview. Although she felt that her support needs were largely unmet by her social support sources, she was able to explain what support would have been of use to her. First she described wanted to talk to other women with breast cancer:

“I think you probably need to talk to somebody who’s in the same boat.”

This is because it would be possible to share experiences, stories and information and talk candidly. In the case of Karen who specifically did not speak to her family out of fear of being a burden, this is likely to be of benefit to her. She would be able to openly talk about any issues without feeling like an inconvenience.

Karen's mother had died in 2001. They were extremely close and spent much time together.

“Even when I was 40 and she needed to know that I had got home. I'd have to call her after visiting her to check that I'd got home alright.”

Karen felt that her mother would have provided her with the social support that she needed.

Discussion of Karen's Case Study

Karen's issue with seeking support was that of being a burden to other people. She felt as though she would not have been a burden to her mother were she still alive, as she looked after her, even into her adult years. This related to findings by Coyne et al., (2012) who found that mothers felt anguish regarding their daughters' diagnosis and wanted to take their pain away.

Loneliness is embedded as a psychosocial variable that affects women with breast cancer (Fogel et al., 2002). This has been documented in a study of online breast cancer support groups, where the word “lonely” was used in 100% of the narratives (Hoybye et al., 2005). Rosedale (2009) coined the term “survivor loneliness”, which described how breast cancer survivors felt alone in their awareness of mortality, symptom burden and change of identity. In particular, this loneliness stemmed from the feeling that other individuals were not able to recognise or tended to misunderstand the ongoing experience of their breast cancer post-treatment.

Karen's narrative suggests that she felt in a crisis after her diagnosis with breast cancer and she was not able to utilise her social support network. She appears to be disconnected from the sources. Feminist theories are

useful to understand the way in which women may self-sacrifice and self-silence (Jack, 1991, Belensky et al., 1986).

One of the main issues with the interview with Karen was that it had been eight years since she had completed her treatment. In addition, she mentioned that she experienced some cognitive difficulties pre-diagnosis and post-treatment but these had not completely resolved long-term (she had not been diagnosed with any cognitive illness). As such, the researcher felt that Karen could not remember in as much detail as possible and hence this case study is rather limited. Nonetheless, this case study has provided evidence in support of the notion that smaller social support networks do not provide as many emotional and instrumental support resources compared to larger ones (Bloom et al., 2001). However as discussed previously, it is not about the size of the support network, but rather the quality of sources with regards to the social support needs of the women with breast cancer. Although Karen did have support sources available to her, she was reluctant to express a need of support to them because she did not want to burden them. Similar findings have been demonstrated elsewhere (Langellier & Peterson, 2004).

6.4 Summary of Findings

This chapter has presented three variable case studies with different social support sources. Kim had several support sources and she knew who to approach for the support that she needed. She identified her partner as her main source of support but drew on the wider support network as well.

Julia actively tried to keep her breast cancer a secret. She referred to herself as independent and not needing to rely on other people. After her remission, she began using online support groups and forums largely because she was not made aware of their existence whilst she was undergoing treatment.

Karen considered herself to be her own main source of support, though not through choice. She did not want to burden her husband and children with problems she was having. In addition the symptoms that she experienced meant that she was not able to communicate effectively. She identified certain people that she would have approached for support if she had the opportunity.

These three case studies are examples of how diverse social support networks of women with breast cancer can be. The support needs of Kim, Julia and Karen are very different, the way in which they approach (or do not approach) and utilise the support sources also vary. The relationships between the breast cancer survivors in this study and their male partners also differ from case to case and it is concluded that when considering the dyad, the main source of social support can differ or may not be identified..

6.5 Conclusion

There are a lot of speculations and assumptions made about individuals identified in support networks by the participants in this study and why they behaved in certain ways. What is needed is to ask these individuals about the support that they feel they provided to the woman with breast cancer. This is addressed in the final study in this thesis, which involves interviews with breast cancer survivors and an individual that they perceived as providing the most support to them (significant other).

7. STUDY 3 – EXPLORING THE BREAST CANCER DYAD

7.1 Introduction

The findings from Study 1 and Studies 2A and 2B have illustrated that the male partner may not always be the main perceived source of social support to the woman with breast cancer. There is the possibility that this may be another individual or that they have different people providing different types of support without a significant other. It may also be that they do not perceive themselves to have any support at all. In addition, the previous studies in this thesis have illustrated the perceptions of social support received by the breast cancer survivor, but have not addressed whether these perceptions are the same for those providing support. The aim of this chapter, therefore, is to explore the breast cancer survivor-supporter dyad to understand how the social support provided by the support source met the support needs of the breast cancer survivor. The chapter provides three different dyads: the survivor-husband dyad, the survivor-daughter dyad and the survivor-friend dyad. The chapter concludes with a discussion of the findings, drawing on the theoretical framework related to dyadic stress and coping.

7.2 Method

7.2.1 Participants

Participants were recruited through a snowballing method through participants who had taken part in Studies 2A and 2B. Five participants who took part in these studies told the researcher that they knew breast cancer survivors who might like to take part. The researcher consented to her contact details being passed on so that if these individuals were interested, they could contact her directly. Three individuals had made contact via email and the researcher sent

them a study information sheet (details of the consent procedure can be found in Chapter 3).

Three dyads took part in this study and their demographic characteristics can be found in Table 7-1.

Table 7-1. Demographic characteristics of participants in Study 3.

Participant (Alias)	Relationship	Age (Years)	Date of diagnosis	Treatment	Date of remission (as relayed to the participant by a medical professional)	Years known to each other at the time of interview
Christine (BC survivor) James	Wife and husband	54 57	October 2010	Chemotherapy	February 2011	26
Mandy (BC survivor) Alison	Mother and daughter	66 40	April 2006	Chemotherapy (Preventative) Double mastectomy	May 2007	40
Sally (BC survivor) Abbie	Friends	42 45	July 2011	Radiotherapy Chemotherapy	January 2012	21

Participants had undergone a variety of treatments, including preventative double mastectomy, lumpectomy, chemotherapy and radiotherapy. The average time that they had known their significant other ranged from 21 – 40 years, with a mean period of 29 years.

7.2.2 The interviews

The interviews took place either in the homes of participants during June 2013. An interview guide was developed and this was followed (see Appendix 2) Participants were encouraged to answer all questions. The duration of interviews ranged from 22-35 minutes (mean = 28 minutes).

7.3 Results

In conducting a thematic analysis of these three transcripts, the researcher found that the individual impact of each story was lost. As such, the data were treated as three narratives. The following results sections presents each of the three dyads in turn with a discussion specific to the dyad after each section. A general discussion can be found after the three case studies have been presented and discussed.

7.3.1 Dyad 1: The Husband/Wife Dyad

James and Christine had been married for 23 years at the time of interview. Christine had been diagnosed with breast cancer in October 2010 (age 51) after finding a lump in her breast. She underwent chemotherapy and was in remission from February 2011. She had one daughter, Jane, age 19 at the time of interview.

When Christine was diagnosed with cancer, James stated that it was a massive shock:

“I couldn’t believe it. I just couldn’t understand why this had to happen to her”. - James

Christine echoed his feelings in the interview. She could not understand how she was one of the “unlucky ones”. However, Christine became more withdrawn post-diagnosis and felt that she did not want to attend treatment, and James felt as though it was his responsibility to make sure she did:

“You would give up wouldn’t you? If you got diagnosed. Told you might die... but I couldn’t let her do that. I needed her, Jane needed her.” – James

They both describe measures that James took to ensure that Christine did not have to focus on anything other than attending treatment. James commented that the company that he worked for allowed him to take days off when Christine was due to attend the hospital and he would drive her to the hospital and sit with her during each session. He also hired a cleaner to make sure that the house was always clean and tidy so that Christine could focus on her recovery. Christine was grateful for this:

“He had the fight that I didn’t have. I felt useless, weak. I felt like I couldn’t do anything”. – Christine

James felt that it was important to regularly tell Christine how much he loved her and how they would “fight this together”:

“I felt even though the cancer was in her, it was in me too. Everything changed for me. I was more than her husband when she was sick. I was looking after everyone too.” - James

Here James is referring to how he took on a caregiving role whilst Christine was undergoing treatment. He could also be referring to how he also took over the primary caregiver role to their daughter, ensuring that she was able to go to school and cared for, presumably because Christine felt too unwell to care for her prior to her diagnosis. Essentially James' role as her husband now extended to the role of carer as well.

James discussed that along with practical help such as attending hospital appointments, at the time of diagnosis, he felt the need to read medical information about breast cancer:

"I was so upset...I just couldn't think what would happen...I didn't know what treatment to have. I didn't understand the treatment. I didn't want to. I don't know if James hadn't helped...what...what would have happened really". – Christine.

"I sat down with her and we read it all together. I wanted to know. She needed to know. It was her decision". - James

Treatment decisions were obviously difficult for Christine as she was very upset by the diagnosis. James felt that it would be best for them to collaboratively read through medical information so that Christine could make an informed decision about her treatment. It also provided James with information about what would happen. This information-seeking was helpful to both members of the dyad, particularly Christine, who talked as though she would not have managed had James had not led this.

Prior to hospital appointments, Christine and James would discuss questions that they wanted to ask medical professionals when they were given the opportunity:

“Sometimes in the hospital, I’d forget stuff I wanted to ask. But if I told James before, he could ask for me.” – Christine.

In the diagnosis and treatment stages of Christine’s breast cancer, James had taken on the dominant role of the two, ensuring that both of them knew about the treatment. This dominance was sustained in the period post-treatment, especially when Christine was feeling weak from the chemotherapy and had lost her hair:

“I looked in the mirror and it wasn’t me. No hair. Ugly. I didn’t want to face other people. I was embarrassed.” - Christine

“I said to her “People know you’ve been poorly.” You don’t judge people with cancer. And if she had any problems, I could deal with them for her <laughs>”. – James

Christine’s embarrassment felt completely unjustified to James’ who felt very protective towards his wife. He wanted her to continue meeting with friends and going out and knew that she was apprehensive of doing this. He adds that he would help her if she did have any problems, but his laughter at the end of the quote perhaps suggests nervousness or that he did indeed approach individuals who did make his wife feel uncomfortable.

Finally, James tried to explain his dominance and protective attitude towards Christine:

“I love her with everything I have. And I’m the man. I need to protect her. And my daughter. That’s what I need to do”. – James.

This fits in with Christine and James’ lives prior to diagnosis. Christine was a home-maker and James had always been working to provide for her. His protectiveness of her during her illness was not different to how he always

behaved towards her. It was not clear whether he had always been the more leading member of the dyad, though his quote at the beginning of this section (*“I needed her”*) implies that she is very important to him.

Discussion Dyad 1: The Husband/Wife Dyad

This first case study illustrates the marital dyad of Christine and James. James took on the role of the informal caregiver to Christine whilst looking after their daughter Jane.

Christine’s levels of motivation were low following diagnosis, to the point where she did not want to attend the hospital for treatment. This feeling of hopelessness can be experienced in this stage (Oztunc et al., 2013) but can have negative consequences in terms of prognosis and recurrence (Arslan et al., 2009). James’ actions, though perhaps did not help to diminish feelings of hopelessness, encouraged Christine to attend treatment which was of benefit in terms of improving her physical health and potentially her psychological health.

Christine was James’ main priority and he often provided emotional stability to her as the main source of support (Aurora et al., 2007). This emotional support and stability helped Christine cope with attending chemotherapy, which is something she stated that she would have found difficult had it not been for James. The support provided by James may have shielded Christine from mental suffering (Pinkert et al., 2011), which is important as not only because it may have reduced her psychological stress, but might also have improved Christine’s QoL and self-confidence (Arora et al., 2007). It is not clear whether Christine provided James with the emotional support that he needed. Research with fathers in the breast cancer context found that many concealed or controlled their emotions so they did not upset

their children (Forrest et al., 2009). James may not have shown his emotions to their daughter Jane, but it is unclear whether, at that time, he sought emotional support from Christine.

James was actively engaged in learning about the medical aspects of breast cancer though less so in the decision-making processes, which he felt was entirely up to Christine. Partners of women with breast cancer have stated that they do want more information, either about breast cancer itself, or specific information regarding surgery, treatments and their side-effects, so that they can be informed when explain these issue to their children (Forrest et al., 2009).

Strategies that James employed helped him to buffer the situation, particularly with trying to help out, adapting his work life and keeping a routine. In particular, protecting their child was an important factor. In an attempt to keep family life as normal as possible, James may have put his own need on holds, emphasising the importance of keeping family life as normal as possible. Similar findings have been found in other research (Hunt & Robbins, 2004; Hilton, 1996; 2000). Studies have also found that children may express anger and disaffection at their father for failing to carrying out the mothers' role effectively (Forrest et al., 2009). This was not revealed in the interview, but might be a factor that warrants further investigation.

During the interview, James never mentioned that he struggled with the demands of Christine's breast cancer. Of course that is not to say that he did not struggle, but he may not have wished to discuss this in front of his wife. Previous studies have found that the spouses of women with breast cancer often carry a greater mental burden than the patient (Hasson-Ohayon et al., 2009), due to the demands that they face bought on by the illness, such as

renegotiating their role within the family, rearranging life plans and providing support to the ill partner (Fletcher et al., 2009). Relatives of cancer patients are subject to various strains and stresses such as psychological problems (depression and anxiety) as well as social burdens such as financial problems, isolation and problems with work (Stenburg et al., 2009). These issues can result in physical problems such as lack of sleep, headaches, backaches and diminished physical strength (Stenburg et al., 2009). Forrest et al. (2009) found that the complexity of completing practical tasks was shocking to fathers whose partner was a woman with breast cancer. The need to maintain normality in the home, the practical tasks of looking after children along with the demand of work were considered to be too difficult in some cases.

To summarise, Christine's perceived main source of support was her husband James. James' concerns were related primarily to his wife's wellbeing, what to do to support her from the stressor of breast cancer and its consequences. In addition, James feared for the future of Christine and their daughter. To address some of these concerns, James adapted his behaviour and role within the family to encompass the role that Christine played before she was diagnosed. This case study exemplifies Rolland's family systems health model (Rolland, 1987). This is based on family systems theory, which views a family as a system, with each family member constituting a subsystem, interacting with other subsystems, within the whole family system. Any change that affects one family member will also impact on other members in the family system. If one of the family members is affected by illness, for example, breast cancer, each stage of the illness will produce different demands on family members (e.g. crisis at the diagnosis and treatment stage, adaptation and the terminal phase). In particular, the diagnosis and treatment of breast cancer have a major impact on the practical and emotional features of family life. In

this case study, James, as the father, was trying to maintain the family system due to the incapacity of Christine, the mother. To do this, he actively tried to take over her roles and responsibilities. James provided emotional support to Christine and tried to maintain a stable home life for their daughter, their home and his own job. There is an understanding of the changing roles of father's, from the traditional view of sole breadwinner to co-parent (Cabera et al., 2000).

7.3.2 Dyad 2: The Mother/Daughter Dyad

Mandy was diagnosed with breast cancer after finding a lump in her breast in April 2006. She was 59 at the time. First she underwent chemotherapy, followed by a preventative double mastectomy and was in remission from May 2007. Her daughter, Alison, was 33 at the time of her diagnosis. Alison was not married at that time. Mandy had been married for 21 years at the time of interview, to a man who was not Alison's biological father. She does not have any other children.

Alison describes her feelings when Mandy told her about the diagnosis:

"I just didn't know what would happen, you know. I was scared. You only get one Mum".

Because Alison had little knowledge of breast cancer, but through reading various magazines she was aware that there may be a genetic component, she insisted that she accompany her mother to all the hospital appointments, much to Mandy's dismay:

"I didn't want my girl to hear what would happen to me. It doesn't seem right." – Mandy.

Mandy did not actively seek out her daughter for support after her diagnosis, but rather Alison chose to help, regardless of what her mother wanted. In

hindsight though, Mandy was pleased that Alison had attended every hospital appointment with her. Practical aspects, such as being driven there and having company whilst waiting to be seen were appreciated. In particular, Mandy felt that at time, she was given a lot of information that was difficult to retain:

“They don’t have much time in the hospital. They’re throwing words around like you’re meant to just know! Lymph node! Lumpectomy! Alopecia! BRCA! Straight over me head, it went”. – Mandy.

Having her daughter there allowed them to discuss between them information from doctor’s appointments, which ultimately helped Mandy choose her treatment. They also used online information sources to consolidate what they had been told by medical professionals that they had met.

Mandy was diagnosed with a particularly aggressive form of cancer and at initial stages post-diagnosis, the prognosis did not look good. As such, Mandy was keen to spend time reminiscing about time that they had spent together. In contrast, Alison was planning holidays that they could go on together post-treatment:

“I just kept thinking about when we went up Skeggy [Skegness] and you loved the sea... <voice cracks> you think about the good times you know?” – Mandy.

“<Put’s arm round Mandy> She kept going on about bloody Skeggy! And I were like “I’ll take you somewhere nicer once you’re better! Maybe Spain or somewhere worth crying about! <laughs>” – Alison.

Several years post-treatment, memories of Mandy's life which she thought about during the treatment phase were still very emotive for her. Due to the uncertainty of her prognosis, Mandy was thinking about fond memories and holding on to them, rather than focussing on the present, at that time, which would make her unhappy. Even at the time of interview, the long-term impact of breast cancer was obvious, with Mandy becoming very tearful in parts. In contrast, Alison was rather jovial when talking about certain events that her mother bought up, sometimes poking fun at them. This could be a way for her to cope with how melancholy her mother had become. It may also be that she was genuinely happy because her mother was still alive.

Finally, one issue warranted a lot of conversation between Mandy and Alison, which was the genetic component of breast cancer. Until the time period post-treatment, both found it very difficult to discuss the genetic trait that may exist in their family. This has created some hostility between the two, despite them supporting one another up until this point: Alison did not want to have a genetic test to find out if she is carrying the BRCA1/2 gene that Mandy carries. Mandy disagreed with this, insisting that she should be tested:

"I can't understand why you wouldn't want to know. You can think about what you'll do. You get time to think." - Mandy

"I know it's genetic... and I could have that gene. But I don't want to find out. I couldn't cope like Mum did. She is a fighter, you know?" - Alison

Mandy's recommendation for attend genetic testing is based on her own experience with breast cancer. From what she said in the interview, it may be assumed that her diagnosis was unexpected and maybe she would have coped better if she knew that this was what might happen to her. She wants Alison to have the genetic test so that she can make an informed decision

(perhaps with regards to preventative surgery or lifestyle changes) about what might happen, should she be diagnosed. On the other hand, Alison's fears stem from how she does not think that she will be able to manage breast cancer like her mother did, especially the decision to undergo a preventative double mastectomy. The issue with genetic testing had put a strain on their relationship up until the post-treatment period. Now, although Mandy is not happy with Alison's decision, she makes an effort not to try and change her mind about this.

Discussion - Dyad 2: The Mother/Daughter Dyad

The second case study presented illustrates the mother-daughter dyad of Mandy and Alison. From the interview, Alison's involved role in supporting Mandy was based on how she wanted to look after her mother and also how she was keen to get information on the genetic component of breast cancer.

Mandy did not actively seek out her daughter's support after diagnosis but rather Alison offered support. She was grateful for this in the long term, especially when dealing with a lot of information. The relationship between mothers and daughters represents an important interpersonal dyad within the broader family context (Berlin et al., 2011). In previous research investigating families coping with stress, adolescent girls and young adult women are likely to turn to their families for support, but more significantly their mothers, for emotional support and help with problem-solving and decision making in the breast cancer context (Spira & Kenemore, 2000). It has not been widely documented that the mother will turn to the daughter for support, and indeed, this is what was found in this study.

At the time of interview, Mandy was tearful recalling her experience with breast cancer. As discussed in Chapter 5, this could be attributed to

remembering how difficult this period in her life was, especially the treatment she faced along with the decision to have a preventative double mastectomy. It could also be linked to issues of survivorship and identity change (see Chapter 5), particularly with regards to the mixed emotions experienced as a consequence of becoming a breast cancer survivor but also the new identity that she may have assumed (Deford et al., 2011). Drawing on Mandy's decision to undergo preventative double mastectomy, this procedure does not prevent, but rather significantly reduces future breast cancer risk (Tuttle et al., 2010). The procedure itself is complicated, with operations lasting 5-6 hours, 2-3 days of inpatient care at hospital and a recovery period of 2-4 weeks (Tuttle et al., 2010). This procedure has been related to high levels of psychological distress, issues with body image and sexual dysfunction (Altschuler et al., 2008; Metcalfe et al., 2004). Although Mandy did not regret her decision to undergo this procedure, others have stated a diminished sense of sexuality and poor cosmetic outcomes (Montgomery et al., 1999). These factors may explain Mandy's emotional presentation during interview.

The issue of breast cancer risk and genetic testing was discussed in the interview, especially as Mandy had undergone BRCA1/2 testing and was keen for Alison to do the same, though she was adamant that she would not. Testing for BRCA1/2 is available to everyone, though to receive this without cost on the NHS, there needs to be a strong history of breast and/or ovarian cancer. A positive test for a women who does not have breast cancer would mean that she is at a higher risk of developing not only breast cancer, but ovarian cancer too (NHS Choices, 2012). It is noteworthy that not all women who test positive for BRCA1/2 will develop cancer, with there being a 50% chance of having the gene in the first place (Denayer et al., 2009) with the accompanying lifetime risk of developing breast cancer ranging from 56%-

85% (Easton et al., 1995; Chen et al., 2005). Extant research has addressed the issue of genetic testing and familial breast cancer.

Mothers have been identified as role models for their daughters as well as key sources of information (Austin, 1995). Mothers have also been found to be important communication partners to their daughters (whom they choose over their fathers) (Youniss & Smollar, 1985). Mothers have also been found to be a significant source of emotional, instrumental and informational support in the breast cancer context (Oktay & Walkter, 1991) and are concerned about their daughter's breast cancer risk (Silk et al., 2006). This information is relevant to this discussion for two reasons. First, Mandy was clear in the interview that initially she was not keen for her daughter to accompany her to hospital appointment and this could be attributed to the role of "mother" that she felt as though she needed to maintain. In particular, it seems as though Mandy was not supporting Alison, but rather it was the other way round, and in that respect, Mandy was not fulfilling the "mother" role as per previous findings (Oktay & Walkter, 1991). This may be why she was hesitant to accept Alison's help: she did not feel it was right that her daughter should be helping *her*. In addition, issues relating to family systems (as discussed in the previous discussion section of this chapter) may also play a role, with Alison renegotiating her role from daughter and extending it to a carer role in supporting her mother.

Second, previous literature has demonstrated mothers' concerns about their daughters' breast cancer risk (Silk et al., 2006; Schlich-Bakker et al., 2006). Mandy's specific concern is because of the genetic traits in her family, which has been illustrated previously (Neuberger et al., 2011). This is not a surprising or unwarranted concern, given that family history is a major factor in assessing breast cancer risk (Easton et al., 1995; Chen et al., 2005). It

appears that Mandy wanted Alison to be tested so that she could change her lifestyle or think about preventative measures that she could take to reduce her breast cancer risk (Denayer et al, 2009). Other women have condemned views about not wanting genetic testing, saying that women at a 50% risk displayed “ignorance” in not getting tested (Pautenaude et al., 2013).

However Alison’s reluctance to get tested was grounded in her perception that she would not be able to cope like her mother did. Other studies have found that genetic testing intentions varied from wanting to be tested immediately to stating a more distant time-frame (Pautenaude et al., 2013). Although at the time of interview, Alison was not interested in genetic testing, that is not to say that she would not change her mind in the future, either due to pressure from her mother or due to an independent change of intentions.

As discussed previously, during the interview Mandy was emotional recalling her experiences with breast cancer. In contrast, Alison was smiling and positive in what she recalled. Vodermaier and Stanton (2012) found that adult daughter who reported that they had provided emotional support to their mother and who received emotional support themselves reported lower depressive symptoms. In addition, the time since the mother’s diagnosis moderated the effects of emotional support of intrusive thoughts in the daughter: the daughters’ mothers who were diagnosed more than five years previously reported fewer intrusive thoughts, resulting in fewer depressive symptoms compared to the general population. Other studies have shown a similar effect of social support receipt on family members who are caregivers for their mother (Ell et al; 1988; Kurtz et al., 1997). Caregiver strain (or lack of) may also be affected by attachment styles, for example, younger familial caregivers with an anxious attachment style tend to experience higher levels of caregiver stress and depressive symptoms (Kim et al., 2007). With this in

mind, a secure attachment style to a mother with cancer may result in greater provision and receipt of emotional support which may in turn improve psychological adjustment and the converse may be true of those with anxious attachment styles (Vodermaier & Stanton, 2012). Finally Berlin et al. (2012) found that daughters' salivary cortisol levels (related to stress) were not related to maternal breast cancer history, specifically in response to potentially stressful discussions with their mother about breast cancer. It is important to note that this was a laboratory-based study, so may not be indicative of "real-life" conversations. Nonetheless, this adds an important point to the discussion regarding Alison's cheerful presentation in the interview.

To summarise Mandy's perceived main source of support was her daughter Alison. This was not through her choice, but rather Alison wanted to help her mother. In addition, she was particularly concerned about the genetic component in women with breast cancer. At first, Mandy did not want Alison to attend hospital appointments with her, feeling as though it was not right for her daughter to see her suffer, but also for her to be cared for by Alison, when as the mother, she perceived that she should be looking after her daughter. Due to an uncertain prognosis at that time, Mandy would often reflect on time that she had spent with Alison and even several years post-treatment, this was still very emotive for her. Finally an issue that arose in the survivor-daughter dyad related to that of genetic testing for the BRCA1/2 gene. This put a strain on the relationship due to conflicting views, but overall did not affect the relationship post-treatment.

7.3.3 Dyad 3: The Survivor/Friend Dyad

Sally (age 42) and Abbie (45) had known each other for 21 years at the time of interview, having met at work. Sally was diagnosed with breast cancer after finding a lump in her breast in July 2011. She underwent radiotherapy and

chemotherapy and was in remission from January 2012. Sally has been married for 10 years.

Sally revealed that immediately after her diagnosis, she first contacted her male partner and then Abbie:

“It sounds so selfish, but when she told me. I cried. Not for her. For me. I said to her “What am I going to do without you?”” – Abbie

Abbie’s reaction was perceived to be normal by Sally as they have always been close. After this initial conversation, in the week before her first session of radiotherapy, Abbie actively avoided Sally’s telephone calls:

“I didn’t feel like I could help her. I couldn’t even ask her how she was doing. The thought of it’d set me off!” – Abbie

“I thought, she is being a daft mare! She doesn’t need to close herself off! I want my friend to talk to!” – Sally

Abbie’s avoidance of and distancing from Sally was due to not being able to do anything to help her friend actively heal and also because of the potential fatality of cancer, which was difficult for Abbie to cope with. Sally’s response to this was one of anger. Sally felt Abbie’s behaviour was not acceptable, possibly because she was the one who had been diagnosed and wanted her friend’s support. They reconciled before Sally began treatment.

Sally felt as though she coped well with the breast cancer treatment, stating that issues with fatigue were difficult but she felt that her recovery went well. She claims that the reaction of Abbie to changes in her physical appearance did not affect her, but rather made it difficult for Abbie to cope, presumably because of the visual indicator of hair loss being related to poor health:

“I saw her in her scarf and I thought “Oh my God!” And that was it. I was crying again.” – Abbie.

“Honestly though, when she stopped crying, I could actually have a chat with her about the cancer stuff. But it was mostly me telling her that I wasn’t going to die!” – Sally.

In this dyad, it was Abbie who was often tearful when she saw her friend, and consequently, many of their meetings often began with Sally comforting and reassuring her. What is noteworthy is that Sally did want to talk about to Abbie about some of physical side-effects of her treatment and they often discussed this and browsed online forums for more information which Sally did want help with.

Over time, the meetings between Sally and Abbie became less emotive:

“I’m not the one with cancer. She is. And she’s had enough on without having to put up with my hysterics!” – Abbie.

Abbie had re-evaluated the situation that she was in and amended her behaviour to suit the needs of Sally, who she assessed as being more important. This was appreciated by Sally:

“I never said at the time but I found it hard to keep it together when you couldn’t keep it together.” – Sally.

Because Sally did need support, particularly with discussing the medical aspects of her treatment and how she was feeling, she was pleased that over time she was able to talk about this with Abbie. Sally did express dissatisfaction with the lack of support that Abbie provided initially but this was resolved over time. Abbie described herself as a sensitive person and Sally

corroborated this. In light of this, Sally accepted Abbie's behaviour. Abbie never attended the hospital with Sally, presumably because she would find this too upsetting. However in the year post-treatment, they both attended a local cancer support group to support other individuals. Though not explicitly stated, this may have been of benefit for them too.

Discussion Dyad 3: The Survivor/Friend Dyad

The third case study presents a friend dyad consisting of Sally and Abbie. In the period at the time of diagnosis, Abbie was very upset and avoided Sally until the period just before her treatment commenced. After this point, Abbie continued to be upset by the diagnosis, but eventually realised that she needed to support her friend. At this point, Sally and Abbie would discuss the breast cancer and looking for information online to help them. Post-treatment they continued to attend a local face-to-face breast cancer support group together.

Sally picked Abbie as her "significant other", that is, the person who she perceived to provide the most support to her from diagnosis to the post-treatment period. Sally and Abbie are not related, but are friends, lending support to the idea that informal care can include individuals beyond the family context (Arora et al., 2007; Himes & Ridey, 2000). Reasons for choosing a friend rather than a family member may be due to the changing nature and structure of family life and the ability of family members to provide the support that is needed. In this case study, Sally's support needs related to being able to openly discuss the issues relating to breast cancer.

Women tend to have very dynamic and close relationships with same-sex friends (MacRae 1996), and define their friends as people with whom they share experiences with. Friendship has received less attention compared to

other relationships, particularly those already discussed in this chapter, of romantic relationships and kin relations (Ryle, 2011). However it is not the type of relationship alone which is important but rather the aspect of social engagement. People who scored highest on life satisfaction scores were those who socialised the most with friends and the least time alone (Diener & Speligman, 2002). However this is not the consensus across the literature, as other findings include a marginal correlation between happiness and spending time with friends (Gundelech & Kreiner, 2004). This leads to the issue of the quality of friendship (Demir & Weitekemp, 2007), and indeed regular face-to-face interactions with close friends increases health and overall well-being and decreases stress (Fuller-Iglesias et al., 2013). Close friends, such as Abbie and Sally presented in this case study, were able to offer emotional support to one another, along with instrumental forms of support (such as information-seeking on the Internet). Women also tend to share greater levels of emotional expressiveness and self-disclosure with female friends (Caldwell & Peplau, 292; Ryle, 2011), a finding that was present in this case study.

This case study lends further support to the notion that informal care includes other sources beyond those of the partner, parents and adult children. Other family members, neighbours, colleagues and friends (Marks et al., 2002) should be considered to provide care and support to women with breast cancer along the illness trajectory and this may be a factor of clinical importance.

In the period post-treatment and into the long-term stage, Abbie and Sally continue to attend a monthly face-to-face support group in their local area. Research has provided conflicting results with regards to the benefits of participating in a cancer support group. Positive outcomes include using other group members as support sources, but with few participants stating that they

were perceived to be positive sources of support (Slevin et al., 1996). This could be attributed to the difficulties in bringing together a group of individuals who share a common diagnosis, but have variance in terms of their coping strategies, especially the potential disharmony that may result from optimistic individuals meeting pessimistic individuals. In addition, medical progression and irregular attendance also impact on the relationships that may form through these groups (Galinsky & Schopler, 1994). On the other hand, support groups can provide emotional support to patients (Dunkel-Schetter, 1984) and group involvement was considered to be an important factor in increased levels of psychological wellbeing (Montazeri et al., 2001). The differences in whether individuals perceive support groups as helpful or not is relevant to this thesis. In the breast cancer context, although there may be patterns in coping and support identified, there will be levels of individual variation dependent on the circumstance of the patient. As such, the personal factors must be taken into account when considering what types of social support will be useful and to whom.

To summarise, Sally's perceived significant other was her friend Abbie. This was the second person she spoke to about her diagnosis. Initially Abbie did not engage with Sally, but this changed just before her treatment began. As Sally moved into the post-treatment phase, they both attended face-to-face breast cancer support groups. During the treatment phase, Sally often wished to speak openly with Abbie about her breast cancer, but felt that this was difficult as Abbie would get upset. Over time, Abbie understood that she needed to support her friend and their relationship became much better.

7.4 General Discussion

The aim of this chapter was to answer the research questions of “Who is considered to be the main source of social support in the breast cancer context” and “Does social support provision and needs change along the illness trajectory?” Three different dyads were presented in this chapter: the survivor-husband dyad, the survivor-daughter dyad and the survivor-friend dyad. The chapter concludes with a discussion of the findings, drawing on the theoretical framework related to dyadic stress and coping.

This study used a systemic approach to dyadic coping, in which dyadic coping is defined as form of coping distinct from individual coping which characterises how partners cope together as a single unit (Kayser et al., 2007; Bodenmann, 1995;2007). This approach assumes that dyadic coping occurs when stress is experienced by one of the partners and this stress is communicated to the other partner. This communication of stress and the other partners perception of stress triggers dyadic coping. This approach assumes that this individuals share their social context and this conceptualisation of dyadic coping shares three main elements:

1. Interdependence of the spouses.
2. Communal concerns.
3. Mutual goals.

The findings in this study suggest that all participants maintained a level of interdependence, shared a communal concern of breast cancer and shared mutual goals of the patient at that time becoming well again.

These elements stimulate dyadic coping activities, usually in addition to individual coping efforts (Bodenmann, 2005). Dyadic coping can take on different forms (Bodenmann, 2005).

1. Communal dyadic coping.
2. Supportive dyadic coping.
3. Delegated dyadic coping (one partner asks the other to take over certain tasks and duties in an effort to reduce their own stress levels in the situation). This can be problem-centred or emotion-centred (as with work by Lazarus & Folkman) and may be positive or negative (hostile, ambivalent or superficial).

Drawing on the case studies presented in this chapter, each form of dyadic coping is discussed. Communal dyadic coping (both partners participate in the coping process symmetrically) was evident across the three dyads, but the extent to which each member of the dyad were symmetrical in their efforts is debatable. Looking at the survivor-husband dyad, it is clear that Christine had almost “given up the fight” and James was responsible to encourage her to attend treatment sessions etc. This is similar in the survivor-friend dyad, where initially Abbie was not coping in the period post-diagnosis but over time, there was a level of symmetry in the coping process. The final dyad of the survivor-daughter does suggest a symmetrical coping effort.

Supportive dyadic coping (support provided by one partner in an attempt to assist the other partner with their coping efforts) was evident in all three dyads. This included an open dialogue where both members of the dyad could communicate their feelings openly. Finally delegated dyadic coping (one partner asks the other to take over certain tasks and duties in an effort to reduce their own stress levels in the situation) was demonstrated in all three dyads, especially with regards to information-seeking about breast cancer. This was deemed as helpful to the survivors and is therefore positive. The survivor-friend dyad did have some elements of negative delegated dyadic coping, specifically hostile (one partner distancing themselves from the other) and superficial (with one partner appearing to be detached). Negative dyadic

coping was evident in one of the dyads and only at the beginning of the breast cancer trajectory. In the light of this, the period post-diagnosis may be a particularly difficult time for the non-patient member of the dyad. Indeed for women with breast cancer, this has been identified as one of the more stressful times along the trajectory (Drageser et al., 2009). There is scope for healthcare professionals to address this issue. In the findings in this study, negative dyadic coping was detrimental to the patient at that time and so there is justification for healthcare professionals to address this issue, to reduce levels of stress in both members of the breast cancer dyad.

The couples involved in this study were able to express their feelings, worries and needs and demonstrate supportive behaviours in the breast cancer context. Stress communication might be beneficial for several reasons. Talking about ones worries and needs allow members of the dyad to share the experience more adequately, building on the idea of cancer as a “we-disease” (Kayser et al., 2007) but also allows joint coping efforts to be implemented (Badr et al., 2010). Self-disclosure of both members of the dyad may be an indication of trust and intimacy within the relationship and that the members rely on each other. Breast cancer may affect both individuals’ lives but they can build on previous experiences of mutual support to lessen the negative effects of breast cancer (Hagedoorn et al., 2011). This self-disclosure allows for needs to be met and the building of mutual support resulting in higher relationship satisfaction (Cutrona et al., 2007). The theoretical framework on dyadic coping is limited to the intimate relationship, but the findings from this study suggest that it is possible for this framework to be applied other dyads

7.5 Conclusion

The three case studies presented amplify the important of emotional support to the woman with breast cancer. This has also been demonstrated in

previous research (Aurora et al., 2007). The survivor-husband dyad and survivor-daughter dyad have both drawn on issues relating to family systems theory, specifically the changing roles of the husband and daughter respectively (Rolland, 1987). The survivor-daughter dyad revealed issues related to genetic testing that caused some discontent at certain points during the breast cancer trajectory and at the time of interview, Mandy was still emotional when recalling her experiences whereas Alison had a much happier demeanour. Finally, the survivor-friendship dyad illustrated that a significant other can be someone beyond the family context (Arora et al., 2007; Himes & Ridey, 2000; Marks et al., 2002). In particular, the second and third dyad have exposed the dynamic and close nature of same-sex relationships in females (MacRae 1996).

To conclude, this chapter has presented three different survivor-significant other dyads in the breast cancer context. Each case is distinct along with issues pertaining to social support and the relationship. In particular, each case is representative of each individuals needs, highlighting the importance of an ideographic approach when considering social support in the breast cancer context. Each woman with breast cancer has their own coping styles and support preferences as illustrated by the dyads presented in this study.

8. DISCUSSION

8.1 Introduction

The final chapter of this thesis begins by presenting a summary and discussion of the research findings. Next the methodological strengths and limitations of the current research and unique contribution to the research literature is described. The next section discusses the clinical and practical recommendations based on the findings of this research and areas for future research are outlined. Finally the chapter will close with the conclusions of the thesis.

8.2 Summary and Discussion of Research findings

The main objective of the present research was to examine the role of social support networks and the significant other in breast cancer survivors. To begin to address these objectives, a scoping review of the literature was performed. In Chapter 2, the scoping review identified findings illustrating that a large social support network would provide more sources of support but failed to address whether these social support sources were utilised by the woman with breast cancer and the extent to which they were actually met the woman's needs. Findings were conflicting in regards to identifying a primary source of social support, but the social support network was shown to include male partners, children, family, friends and healthcare providers (Wilkes et al., 2002). However the review was limited in that it did not address whether different support sources varied in the type of support they provided. Finally the findings from the review demonstrated that emotional support was the type of support most sought by women with breast cancer. These findings from the existing body of research provided background knowledge for the

empirical studies presented in this thesis and the following research questions were stipulated:

1. What role does the male partner play in supporting the woman with breast cancer?
2. Who are the sources of support that help women with breast cancer and what type of support do they provide?
3. Does social support provision and needs change along the illness trajectory?
4. Who is considered to be the main source of social support in the breast cancer context?

This section discussed these questions in relation to the findings of the research.

What role does the male partner play in supporting the woman with breast cancer?

The findings from this research provide evidence of emotional support and instrumental support (Heaney & Israel, 2002; Bogossian, 2007) provided by the male partner in the breast cancer context. Emotional support involves providing love, empathy, trust and care to an individual and instrumental support involves providing tangible aid and services that directly assist an individual. According to these definitions, both types of support were provided by both male partners and female supporters when considering the findings from all studies. Study 1 provided no evidence that male partners provided emotional support because they were perceived to not want to talk about breast cancer and its effects. Male partners were perceived as providing more practical, tangible support. It is not possible to know if male partners were

perceived to avoid the subject of breast cancer because they did not want to upset the patient or because they themselves simply did not want to discuss it. Ussher and Perz (2010) found informal male cancer carers reported higher levels of self-silencing due to their own desire of wanting to prioritise the needs of the patient or to avoid conflict. Men adopt this self-silencing position and accept it as a normal aspect of their masculinity, with their belief being that expressing their needs or emotions is a sign of weakness, and therefore maintain a positive front as a means of coping (Batty, 2006). They may also not develop the emotional vocabulary to communicate relational and emotional needs and so, self-silencing becomes the only available option (Gratch et al., 1995). It could also be that men simply do not like to talk about this topic with their partner.

Studies 2A, 2B and 3 provided clear evidence that male partners did provide emotional support and in some cases were considered to be the main source of social support. There is evidence in this research which suggests that these male partners may have put their own need on holds, emphasising the importance of keeping family life as normal as possible. Similar findings have been found in other research about male partners attempting to maintain a level of normality in the home following adversity (Hunt & Robbins, 2004; Hilton, 1996; 2000).

Who are the sources of support that help women with breast cancer and what type of support do they provide?

In the four studies presented in this thesis, women (female friends and relatives) were cited as providers of emotional support. This could be because these individuals had known the patient for a long time and have always provided emotional support to them. The notion of caring is socially

constructed as a central component of a women's gendered role, leading to women being positioned as emotional nurturers of others with an expectation of self-renunciation (O'Grady, 2005). This could result in women engaging in caretaking to please the patient in an attempt to meet relational needs. In addition, there is evidence which suggests that women are more affected by the emotional well-being of others (Hagedoorn et al. 2001).

In all studies, the provision of emotional and instrumental support was discussed. For the participants who stated that they needed more support, this related to emotional support. Previous studies have found that women with breast cancer have expressed the need for emotional support above all else (Remmers et al., 2010). In this thesis, the additional need for instrumental support was not discussed. Although having social support may protect the patient against some negative psychological consequences of breast cancer, it is unlikely that social support will eliminate the impact of all stressful events completely (Kornblith et al., 2001).

The role of healthcare professionals were discussed in Studies 2A and 2B and the support they provide, in particular relating to giving information about the diagnosis and treatment. During diagnosis and treatment, the interactions with staff, including doctors, clinic nurses and specialist nurses, and the more social aspects of cancer clinics play a valuable role in the provision of support (Dunkel-Schetter & Wortman, 1982; Costain & Hewison, 1999) and patients may form a valuable relationship with those involved in their care (Clarke et al., 2006). This was not always the case in this research and healthcare professionals were not always viewed in a positive light. In addition, some participants spoke of their disaffection of follow-up care post-treatment. Raupach and Hiller (2002) found that after completing treatment, contact with professionals and information provided to patients is considerably

reduced. This was negatively perceived by the participants in this study. However there were instances, particularly revealed through study 2B where individual sources of medical support were praised.

Does social support provision and needs change along the illness trajectory?

Support needs may change and consequently the structure and function of the social support network may change along the illness trajectory. Considering healthcare professionals, especially nurses who were highly regarded in this research, the expectations of patients varied according to the stage of illness. Emotional support is an important resource for coping with disease by the patient and from the time of diagnosis up until surgery, informational support is useful (Saares & Suominen, 2005). Studies investigating the informational support needs of women with breast cancer have yielded various findings. Informational needs of women decrease along the illness trajectory (Saares & Suominen, 2005; Salminen et al., 2004) but others have found fundamental needs for information across every stage of the disease (Raupach & Hiller, Chantler et al., 2005). With this in mind, the role of nurses is important to address the potentially different needs of patients, depending on their own needs and stage of illness. Study 2A in particular found that the involvement and support of healthcare professionals post-treatment was lacking and not sufficient to the needs of participants. In term of unmet needs, participants felt that post-treatment, they were left by themselves with little support in terms of ongoing monitoring. In this research, it appeared that support needs were higher in the diagnosis and treatment stages and lowest at the time of interview (i.e. in the post-treatment stage).

Who is considered to be the main source of social support in the breast cancer context?

In studies 1, 2A and 2B it was not always clear who the main support source was and across all studies, one main source of support was not identified. In Study 3, the main source of social support was perceived to be the male partner, the daughter and the female friend. Previous studies that have focused on the breast cancer context have cited the male partner as the primary support source and other family members as important support sources. This findings from this study suggest that informal care can include individuals beyond the family context (Arora et al., 2007; Himes & Ridey, 2000). The reason for choosing a friend rather than a family member may due to due the changing nature and structure of family life and the inability of family members to provide the support that is needed.

In a recently study, women were asked to identify who was most helpful during their cancer experience, only 25% provided an answer, with friends and non-partner family members mentioned most often. However there is ambiguity regarding the remaining 75% who chose not to answer.(Christie et al., 2013).

A particular salient theme in this research is that women with breast cancer vary in terms of the support that they require. Support which is received but is unwanted may have negative psychosocial consequences for women with breast cancer (Rook, 1984). However this research has mostly found that participants in this study valued the support that they received.

8.3 Theoretical Implications

It is clear through this research that each participants' experience of breast cancer was unique. This could be accounted for by the way in which breast

cancer was appraised, which is influenced by the characteristics of the individuals. It is individual differences which help to explain why individuals may cope very differently when faced with the same stressor (Ferguson, 2001). Lazarus & Folkman (1984) dichotomised coping as either PF or EF but the findings from this research have demonstrated that this approach is too simplistic to accurately portray the coping efforts employed by breast cancer survivors. Moos Crisis Theory (Moos & Schaefer, 1986) considers factors related to the crisis, background and personal issues, along with the social and physical environment. Individuals cope by appraising the stress, undertaking problem solving related to it, and then completing other tasks relating to psychosocial functioning. Individuals then utilise specific coping strategies, for example seeking social support or not seeking social support. These processes combine to determine the outcome of a crisis (Sarafino, 2005). This research lends support to this framework, for example, the case study of Kim in Study 2B described many layers to her personal life – a split from her long-term partner, the relatively new relationship with her new partner and the fact that many of her friends were in her native county. With this variety of factors, Kim's social support network was described as engaged. In contrast, Julia's relatively large social support network did not play a role in helping her cope. The earlier theoretical models describing a dichotomy of coping styles is much too simplistic. The importance of context needs to be addressed as this does not only relate to an individual's situation but also the greater social environment in which they are operating. This research is strengthened by the fact that this has been considered.

One factor that may affect the patients' coping strategies is the coping strategy of their significant other. The construct of dyadic coping was pioneered using a systemic-transactional perspective (Bodenmann, 1995).

Dyadic coping comprises of the stress signals of one partner, the verbal or non-verbal coping responses of the other partner and joint coping efforts, which can be positive and negative (Bodenmann, 2005). Positive dyadic coping occurs in three main ways: supportive dyadic coping, common dyadic coping and delegated dyadic coping. Negative dyadic coping includes hostile dyadic coping, ambivalent dyadic coping and superficial dyadic coping. These categories are based on the experience and interpretation of the recipient and do not address how actions are intended. For example, superficial dyadic coping (this involves one partner appearing to be detached) addresses the fact that the recipient feel that their partner is detached, but does not address how that action was carried out, e.g. was it intended to give the impression of detachment or has this been misconstrued. A more recent systemic framework of dyadic coping was proposed by Kayser et al. (2007), which views coping with breast cancer specifically as a multi-process progression, involving the appraisal of illness-related stress, the reaction of the individual to their partners' responses, managing stress using behaviour and cognitive strategies and understanding and making sense of the illness. Again, this model does not take into account how actions are intended when they are carried out, which in the joint coping is a factor that needs to be addressed.

This research has illustrated further problems with the existing frameworks of dyadic stress (Bodenmann, 2005; Kayser et al., 2007). The first limitation is the assumption that members of a dyad will work through a stressful situation together, rather than employing their own individual coping strategies only. This has not always been the case in these findings. The frameworks also fail to take into account the family structures and personality traits of the dyad members which has been found to have an effect not only

have an influence on individual coping strategies but may also have an effect on dyadic coping.

Dyadic frameworks fail to acknowledge that if one individual in the dyad is faced with a diagnosis of breast cancer, they may not turn to the other member of the dyad for support, but may rely on additional sources of support external to the dyad. This research has found that although the dyad may play an important role it is not mutually exclusive from other social support sources and may be part of a wider social network.

The final criticism of the dyadic coping literature in the breast cancer context is that it is specifically related to intimate relationships (Hannum et al., 1991; Kershaw et al., 2004; Skerrett, 1998) and this assumes that the intimate relationship may be the most important when considering dyadic coping and that this can be the main relationship. This is not the case and relationship with a different significant other, such as another family member, friend, etc., may be perceived to be the primary dyad. Throughout this research but particularly explicit in Study 3, the male partner was not perceived to be main source of social support. With this in mind, it is questionable how applicable this framework is. Referring to work by Shand et al. (2006) who identified four core concerns of the traditional breast cancer dyad, the concerns identified included dealing with tension in the relationship, needing to be together as a couple, worrying about the children and managing the treat of breast cancer. It is argued that these concerns are specific to an intimate dyad. If the male partner is not perceived to be the main source of support, perhaps there needs to be steps to move towards a dyadic framework that is inclusive of individuals in a non-intimate relationship but also with more than one dominant relationship. The findings from this research have demonstrated the complexity of social support networks and the fact that it is difficult to drawn on

a single relationship without discussing other support sources and relationships.

Family Systems Theory describes an active interplay between family members such as partners, parent-child and sibling relationships. According to this framework, families can be understood as complex integrated frameworks including individuals with various needs and perspectives (Cox & Paley, 1997). One of the characteristics of Family Systems Theory is that families function by composition law. This states that processes at a family level cannot be reduced to an individual family member level. The findings from Study 3 support this idea as the members of the dyads interviewed described other family members that were not interviewed. However in the other studies, the accounts of one person were obtained which is not ideal.

A second principal of Family Systems Theory is that families are comprised of subsystems, for example marital, parent-child and sibling, and that every family subsystem contains a small group usually made up of two or three people (Cox & Paley, 1997). This principal has been strengthened by this research as in Study 3, multiple informants provided a picture of family composition and how these subgroups are interrelated but also function interdependently. A further characteristic of Family Systems theory is that families have the capacity to reorganise in response to external stressors (Minuchin, 1985). This is an important feature of this theory as it points to a need to consider how the family system responds to challenges. The findings from this research have shown that there is a change to existing patterns of interaction at all levels in the family during a transition.

Social support has been conceptualised in a number of ways, from the structure of one's available social network size (e.g., Sarason, Sarason, Potter & Antoni, 1985) to perceived satisfaction with functional aspects of support.

This research has demonstrated that social support is too complex a concept to be defined by the components as discussed in Chapter 1 of this thesis, and the components themselves are also too simplistic. For example, it is difficult to define emotional support. Through the findings of this research, the perception of what emotional support is tended to differ between participants. Some reported that having a lengthy, emotive discussion was perceived to be emotional support, whereas others described a hug as emotionally supportive to them. In light of this, further work must be undertaken to expand the definitions of support and ascertain subtle differences between them.

8.4 Methodological implications

The prominent criticism of the qualitative approach relates to the inherent subjectivity that is associated with qualitative study design and analysis (Bryman, 2012). As the researcher is the tool of enquiry, the objectivity of data collection and analysis could be questionable, with issues relating to reliability, validity and generalisability of findings being called into question (Lincoln & Guba, 1985). However there is also the problem that even if methodological processes are replicated, findings may differ dramatically and therefore generalisations may not be confidently made beyond the current context. With regards to generalisability, this thesis is not attempting to generalise its findings to the entire population of individuals who have experienced/survived breast cancer. In terms of answering the research questions, a qualitative approach enabled this.

Semi-structured interviews were chosen as the method of data collection for this study. The biggest strength of this method is that they can be structured to emphasise related topics whilst allowing room for new insights to be provided by the participant (Galletta, 2013). The in-depth interviews

explored important and detailed stories provided by the participants. The main limitation of using semi-structured interviewing is that of standardisation in general terms. However this was not an issue for this thesis, as the aim was not to standardise the findings to the general breast cancer population. The interview style differed from participant to participant. Even though an interview schedule containing core questions which all participants were asked, some participants were asked questions that others will not be asked. The skills of the interviewer will have an effect on the interviewing and the data analysis, possibly resulting in inaccuracy and misinterpretation (Becker & Geer, 1957). However it can be argued that one data collection method does not pose superiority over others but what is key is that the data collection method is deemed appropriate with regards to the research aims and answering the research questions (Silverman, 1985). The findings from conducting semi-structured interviews may have depended on a number of factors such as the background of the interviewer, the personality traits and engagement of the interviewee, the selection of participants and the interview setting (Silverman, 2000).

The use of ecomaps in Studies 2A and 2B was of benefit. Ecomaps provided a graphical representation of an individual's social network, therefore discussions were easily facilitated based on the structure and the strength of the network. Having a visual representation allowed people to identify each member in their own network, examine the strength of the relationship and establish the course of the relationship over time (Ray and Street, 2005). It is a useful research tool to help provide a visual representation to an individual's narrative. Using ecomaps not only aided and facilitated discussion of the social support networks, it allowed each source to be fully explored and for the relationship between the sources of support to be explored to understand how

this impacted on the breast cancer survivor. Although ecomaps did allow the size and structure of social support networks to be effectively documented, the strength of relationships was not adequately portrayed and is open to interpretation, particularly if displayed without any conversational data to contextualise the ecomaps. Visual methods are becoming more popular researching chronic health conditions. The Pictor technique, based on the principals of phenomenology, involves the creation of a chart which supports the exploration of participants' roles and relationships (Hardy et al., 2012) and is particularly useful when interviewing individuals with health problems affecting their functional ability. Visual methods used in interviews are effective tools because they serve as an effective focus of discussion and they are easy for participants to understand and are more engaging than an interview alone (King et al., 2014).

This thesis used a variety of qualitative methodologies in four studies to provide answers to the research questions. The researcher used Within-Methods Triangulation specifically to gain a deeper understanding and meaning of the subject area. Having different methods of data collection increased the credibility of the findings. In addition, the presentation of narratives in Studies 2B and 3 allowed interpretation of findings in more detail compared to a purely thematic analysis. The essence of the case studies was portrayed effectively by choosing to present the narratives rather than just the themes, which would have resulted in the loss of rich information.

Triangulation can increase the depth of understanding of a specific phenomenon (Olsen, 2004), which it has in this thesis. Specifically this thesis was interested in social support networks and the significant other in the breast cancer context. Using a qualitative approach but altering the interview schedules, the addition of an elicitation tool to guide and focus discussion in

studies 2A and 2B and finally interviewing dyads in Study 3 has provided data in alternate ways which have been used to answer the research questions. The inconsistencies in findings in the studies have been discussed but they are not considered to weaken the findings. Patton (2002) argues that inconsistencies, in fact, are likely due to the strengths of different approaches and these inconsistencies do not weaken evidence but rather provide the opportunity to explore deeper meanings. Indeed the inconsistencies allowed deeper analysis of the findings.

Although breast cancer is becoming increasingly recognised as a disease that not only affects the woman diagnosed but her partner too, the challenges of recruiting patients and partners are apparent (Christie et al., 2013). Non-participation has been linked to several factors, such as demographic and illness characteristics. Ethnic minorities appear to be less likely to participate than non-Hispanic White patients (Sears et al., 2003). In addition, greater emotional distress has been associated with non-participation (Norton & Manne, 2007) as well as fewer years of education (Sears et al., 2003). Indeed the sample for all studies in this research consisted of White women who appeared to be resilient when recalling the period of time where they were unwell. Unfortunately the researcher did not enquire how many years each participant was involved in education.

Patients who express an interest in participation in breast cancer research, and are able to convince their partners to also participate, are unlikely to fully represent the population of women with breast cancer (Badr et al., 2010). Patients and partners who participate in this type of research may have stronger relationships or greater sources of support compared to couples who do not participate. Christie et al. (2013) found that declines in dyad recruitment occurred at two time points: when investigators requested that the

patient invite the partner to participate and when partners decide whether to participate. The researchers found that greater income, perceived partner support and greater support from others would increase the likelihood that the patient would provide consent for their partner to be contacted. It is difficult to identify individual and relationship factors that are associated with individuals who choose not to take part in a study that their partner is participating in.

The data collection method of interviewing both members of the dyad together had advantages and disadvantages. The main advantage related to the development of a joint narrative. The main disadvantage is that conflict of discussion between two people in an interview setting might affect them more permanently because they are in a situation that is more open. There may have been negative consequences of members of the dyad having an open discussion with the potential of issues to be voiced that may not have been before. To address this, the researcher contacted the six participants of Study 3 a few days after their interviews by telephone. None of them reported any negative consequences by taking part in the research. Another way to interview the dyad members would be to interview them separately first and then together. However this also has problems in that participants may think that the researcher might tell the corresponding member of the dyad about the content of their discussion and this might result in them withholding information. Considering these factor, the option of interviewing members of the dyad together was the more appropriate option in order to answer the research questions presented in this thesis.

In order to protect the patient effectively, social support needs to be in place before the occurrence of a stressful event (Kornblith et al., 2000). The research presented looked at retrospective accounts of breast cancer survivors and the interviews addressed issues from the initial presentation to

the present day. The time since diagnosis varied in the participants in this study. The women who had been diagnosed more recently may have recalled their experiences more accurately. As such, it would be useful to interview women with breast cancer at specific time points in the illness trajectory, for example, before diagnosis (initial presentation of symptoms), and at regular intervals following this until the post-treatment period and even for a time period after this (Den Outsten et al., 2010). This would allow for more accurate details about social support sources to be discussed, rather than relying on retrospective accounts. Other studies involving individuals with cancer have found that social support network size decreased due to fatigue (Curt et al., 2000; Diaz et al., 2008) or due to the inability of the individual with cancer to provide support to their social network, causing inequity regarding the amount of support given to others and the amount of support received (Courten et al, 1996).

8.5 Reflexivity and reflections

The majority of participants in this research were women and I observed that my presence as a woman was of significance in the process of data collection. My gender seemed to act as a common identity and the fact that participants knew of my psychology background, I felt that they were more open in our discussion, with the assumption that I might be more understanding and empathetic towards them. In addition, I felt that the female participants may not have felt as comfortable discussing the loss of their breast(s) or hair if I had been male. For example, in one interview, the participant lifted her shirt up to show me her mastectomy scar. Therefore I strongly believe that the female participants and I were unified by our gender. This however may have been a potential issue with the recruitment of male participants into this research. However I discussed this issue with a colleague completing a PhD where he attempted to recruit prostate cancer patients. He felt that his gender did not

encourage participation and that male participants were generally less willing to take part in research.

I feel as though my age may have played a part in the research process. Generally, I interviewed older women and often, either before or after the interview they would ask my age and some would respond with “Oooh you’re young” or “My daughter’s around your age”. This may have affected the interviews in the following ways. As I was considered to be younger, participants may have not revealed as much in their interviews because they may have perceived me to be immature. They considered me to be the same age as their children and perhaps revealed to me only what they may have revealed to them. Therefore my age affected the interview process.

I was under the impression that in some interviews, the participants were trying to present themselves in a more socially desirable way, for example, justifying harsh-sounding feelings (particularly with regards to other people) immediately after vocalising them. It is possible that some participants may have mentally edited their thoughts before speaking, in order to present themselves in a socially desirable light.

Ontologically, the foundation for this research was embedded in the belief that social reality is an ongoing construction by individuals.

Epistemologically underpinning this research is a post-modern paradigm, where truth and knowledge acquired will never be complete, that it is relative and that no single method can capture the variety and variability of human experience. Having conducted semi-structured interviews with breast cancer survivors in study 1, semi-structured interviews guided by the development of ecomaps in study 2 and joint semi-structured interviews in study 3, I agree with the statement above

with regard to social support in the breast cancer context. Although there were common themes across the studies, each individual, their perspectives and their personal situation was unique and I could not say that the findings of this research demonstrate objective knowledge but rather serve to highlight the subjectivity of social support in the breast cancer context.

In terms of data collection, two potential issues were highlighted in Chapter 3. The first described the deletion of the interviewer, that is, the participants talk may be taken out of context and that the researcher will inevitably affect the interview questions asked and the direction of discussion. During the data collection stages I ensured that interruption of the participants talk was minimal but that conversation was focussed on the topic of social support in the breast cancer context. To minimise my influence on the participant, a jargon-free interview schedule was developed to ensure that participants were constructing their version of reality, and not what they expected me to hear. Finally, I felt that the standard orthographic transcription of interviews was adequate, due to my involvement in data collection and in the transcribing process itself. Given that I interviewed all of the participants, I listened to recordings several times and transcribed each one myself, I felt fully immersed in the data - I do not think that full Jeffersonian transcription would have increased my familiarity with the data.

8.6 Clinical and practical implications

This research has highlighted the need for psychosocial interventions in the breast cancer context. Psychosocial interventions may serve to improve

patients' social support. Meyer and Mark (1995) found that psychosocial interventions had a small, statistically significant effect on improving adjustment to breast cancer. For patient without a close relationship or adequate support network, a more long-term intervention could be used to overcome the deficit in social relationships. For example psychosocial interventions may consist of ongoing engagement with other breast cancer survivors through online and face-to-face support groups. For individuals who know and/or support a woman with breast cancer, having information readily available to them about the illness and available support may be of benefit.

Research is needed to develop effective psycho-educational material for daughters of women with breast cancer who are high risk (Patenaude et al., 2013). This implication has been determined through the case study presented between a breast cancer survivor and her daughter. In particular, the delivery of such material is dependent on healthcare professionals warranting a discussion of the role and responsibilities of healthcare professionals in educating high risk women about breast cancer risk. If healthcare professionals are able to communicate information to high risk women, this will be a valuable step in preventing breast cancer in later life.

The findings from this study have demonstrated the need for an idiographic approach to patient care. Care must fit in with the needs of individual cancer patients and their families (Osse et al., 2000). This has also been emphasised by the National Institute of Clinical Excellence in their guidance on supportive and palliative care (2005), attempting to ensure patient-centred care. Professionals need to consider the individual needs of women with breast cancer so that psychosocial factors (such as provision of social support) are taken into account which may have an impact on longer term survival (DoH, 2013; Fund, 2009). This means that each breast cancer

patient should ideally have the opportunity to speak with healthcare professionals to ensure the creation of a personalised care plan that is regularly referred. This should be revisited at different stages in the illness trajectory and amended to reflect the support needs of the breast cancer patient/survivor at that time.

There is a potential need to involve the partners, family or friends in the treatment plans of women with breast cancer. This would be beneficial as significant others can become aware of the problems faced by women with breast cancer during and after treatment. It may also be of benefit to educate women and their significant others about the importance of social support, e.g. how to ask for help, to recognise when they need to provide support and to learn how to discuss their needs if they are dissatisfied.

8.7 Future research directions

The findings from this study have highlighted the acquisition of an additional role for those supporting a woman with breast cancer, specifically the role of a carer. Although the findings from Study 1 suggest that the gender of a social support source may influence the extent to which they act in a caring role, this was not consistent in the other studies. To investigate this further, two specific populations are of interest; lesbian/gay/bi-sexual/transgender (LGBT) couples who are faced with breast cancer and heterosexual couples where the male has been diagnosed with breast cancer. Dyad types are changing due to an increase in same-sex couples, divorce rates and single women. To address the demographic changes in society, future studies should include elderly participants and single women. The sample in this research were White so it would be useful to look at ethnic populations in future research. The notion of ethnic minorities being underrepresented in cancer research is well known (Murthy et al., 2004).

As mentioned in the previous section, this research was based on the retrospective accounts of breast cancer survivors and their significant others. It would be useful to interview women with breast cancer and their significant other at specific time points in the illness trajectory, for example, before diagnosis (initial presentation of symptoms), and at regular intervals following this until the post-treatment period and even for a time period after this (Den Outsten et al., 2010). This would result in more accurate descriptions of social support needs and provision.

The ways in which couples cope with chronic illness are important to illness outcomes (Coyne & Fiske, 1992). The findings from Study 2B draw attention to the wider social network and how other support sources outside of the dyad may influence communication within the dyad. Study 3 presented three different breast cancer survivor-support dyads and presented an argument for applying the frameworks of dyadic stress (Bodenmann 2005; Kayser et al., 2007) to dyads other than the intimate dyad. This framework could potentially be applied to dyads in other illness contexts. Dyadic stress, coping and communication is not only relevant to the context of breast cancer, but is also relevant to life in general.

8.8 Concluding remarks

This thesis has highlighted the importance of social support sources and networks. In particular, the variety of social support sources and the different types of support provided have been presented and discussed. This research has also highlighted how social support needs are different depending on the individual.

Overall there is an increasing awareness of viewing cancer as a dyadic illness. However a more uniformly conceptualised perspective on dyadic coping is needed to generate more general conclusions. Specifically, benefits

of dyadic coping compared to spousal social support and under which conditions (e.g. contextual variables, individual variables and dyadic variables), and for whom this approach could be beneficial and harmful is of interest. In light of this, more personalised psychological interventions for dyads dealing with breast cancer could be developed which could emphasise the best practice for defined types of couples, individuals and could extend to other chronic illnesses beyond breast cancer. Further research into the breast cancer dyads is recommended to initiate new theoretical insight and the development of specific interventions for different dyads, with the intention of improving QoL of both members of the dyad, resulting in better adjustment and recovery post-treatment.

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APPENDIX 1

Studies included in scoping review

<u>Study</u>	<u>Participants</u>	<u>Stage of BC trajectory</u>	<u>Treatment</u>	<u>Time since diagnosis</u>	<u>Design</u>	<u>Methods</u>	<u>Summary of Findings</u>
Adams et al., (2009)	Cancer patients (BC=37.5%). Several countries included.	Diagnosis/treatment Post-treatment/survivorship Multiple specific stages Not specified	-	-	Systematic review	32 papers included.	Few papers moved beyond the diagnosis and initial treatment phase, and most did not distinguish between met and unmet needs.
Belcher et al. (2011)	45 women with early stage BC and their male spouses. Mean age: 53. USA	Some of the patients received radiation (15%) and chemotherapy (20%) during their participation in the diary study. The majority of patients (76%) also received antihormonal treatment	Lumpectomy Mastectomy Radiotherapy Chemotherapy.	At least 26 days after surgery.	Dyadic daily diary study.	Measures completed over 7 days related to relationship intimacy, support provision and support receipt.	When controlling for patient report of support receipt, spouse reports of support provision was uniquely associated with a significant additional increase in feelings of relationship intimacy for patients. Moreover, the independent effects of support receipt and support provision were also found to be beneficial for non-patient spouses' daily feelings of intimacy
Bloom et al., (2001)	336 BC survivors. USA Age range: 22-51.	Treatment to follow-up.	Mastectomy Breast conserving surgery Double mastectomy Chemotherapy Radiation therapy	1-7 months	Population-based cohort study. Mixed methods.	Structured interview. Social network index (SNI). Instrumental support measure (Seeman & Syme, 1987). 14-tem scale on emotional support (Flamer, 1977).	The size of the social network was related to greater emotional and instrumental support and greater emotional support was related to better mental wellbeing.

			Tamoxifem				
Budin (1998)	101 unmarried BC patients. Age range: 28-80. USA	Undergoing treatment.	Lumpectomy Mastectomy Tamoxifem Chemotherapy Radiotherapy	Not specified.	Survey	Psychosocial Adjustment to Breast Cancer Factor (Murphy, 1994) Symptom Distress Scale (McCorkle & Young, 1978) Social Support Network Inventory (SSNI; Flaherty, Gaviria, & Pathak, 1983)	Participants reported relatively low levels of psychosocial adjustment problems and perceived moderately high levels of social support.
Coyne et al. (2012)	14 women with breast cancer. Age range: 35-46 11 family members including adult children, male partners, mothers, aunt. Age range: 18-65 Australia.	Undergoing treatment.	Surgery Chemotherapy Radiotherapy Adjuvant therapies.	Not specified.	Qualitative, descriptive	Semi-structured interview.	Themes included "just being there", "paradox of help", "buffer from society" and "changing roles of family members".
Den Oudsten et al. (2009)	233 BC patients. Mean age: 57.6 years Holland	Before diagnosis (time 1) and 1 (time 2), 3 (time 3), 6 (time 4), 12 (time 5), and 24 months (time 6)	Variety of combinations.	Not specified.	Survey, longitudinal.	World Health Organization QOL assessment instrument-100 (WHOQOL-100; [28,	Personality factors substantially influence the way women with early stage BC perceive social support.

		after surgical treatment.				29]) at all time points. The Center for Epidemiological Studies depression scale (CES-D; [30]), the fatigue assessment scale (FAS; [31]), the neuroticism extraversion openness five-factor inventory (NEO-FFI; [32, 33]), and the state trait anxiety inventory (STAI; [34]) were assessed at time 1.	
Gass et al. (2007)	135 women Age range: 30-84	Treatment to follow-up	Radiotherapy Chemotherapy	0-214 months	Survey.	Questionnaire related to of primary support, emergency contact and healthcare proxy.	75% married. <40% of women did not name the same person to the roles of primary support, emergency contact and healthcare proxy. In partnered women, almost 50% did not name their partner.
Harrow et al., (2007)	26 male partners Age range: 30-77. Length of relationship: 10-50 years. UK	Treatment completed.	Wide local excision Adjuvant radiotherapy Mastectomy Adjuvant chemotherapy Neo-adjuvant chemotherapy,	7 months to 6 years.	Mixed methods.	Questionnaire with open ended questions. Interviews exploring the experiences of male partners of women who had just completed treatment.	Negotiating their role and finding a balance between the ambiguity and uncertainty and their need to maintain normality. Feeling 'in limbo' when expectations of being able to move on following their wives treatment were not fulfilled.
Kadmon et al., (2004)	50 male partners from each cultural framework	Not reported.	Not reported.	1 month – 96 months	Part of a larger descriptive comparative	Social Support Questionnaire (SSQ)	Israeli husbands reported significantly higher levels of support. Chinese husbands were significantly more interested in joining a support group. The results of this study show

	(Japan & Israel). Age range 28-79.				study.	Psychosocial Adjustment to Illness Scales (PAIS) Questions developed by authors	that culture has an impact on spousal responses to their wives' illness
Kroenke et al., (2006)	2835 women with BC. Age range: 46-71. USA	Not specified.	Tamoxifem Radiation Chemotherapy	Not specified.	Prospective cohort study.	Berman-Syme Social Networks Index	Women socially isolated before diagnosis had a 66% increased risk of all-cause mortality.
Kroenke et al., (2013)	2,264 BC patients and survivors. Age range: 18-70. USA.	Completion of treatment.	Not reported.	11-39 months.	Longitudinal study design/secondary analysis of data.	Data gained from Kaiser Permanente, Northern California Cancer Registry.	Social isolation unrelated to BC recurrence or BC-mortality. Socially isolated women had higher all-cause mortality. Women with small SS networks and low levels of support had significantly higher risk of mortality.
Lindop & Cannon (2001)	12 BC patients. Age range: 26-58. UK.	Different points including palliative patients.	Mastectomy Radiotherapy Chemotherapy Lumpectomy Hormone therapy.	-	Descriptive qualitative study.	Structured interviews to explore perceptions of need.	Husbands, partners and families were often mentioned as valuable sources of support. Children often a source of support to "keep going".
Makabe & Hull (2000)	16 BC patients. Japan	Recovering outpatient follow-up care	modified radical or radical mastectomy	7-53 months since surgery.	Qualitative, descriptive, interpretive.	Semi-structured interviews.	Women described social support. Doing For was the provision of instrumental aid and was most consistent with Western findings. Each of the three situations was perceived as emotional support.
Manning-Walsh (2005)	100 women with	Treatment and post-treatment.	chemotherapy, radiation, and hormone	1-24 months	Cross-sectional, correlational.	Symptom Distress Scale, (McCorkle & Young,	Personal support was positively related to quality of life and partially mediated the effects of symptom distress. Religious support did not mediate symptom distress

	BC. USA		therapy			1978) Religious Support Scale, (Krause, 1999b) FACT-B, (Cella et al., 1993) Facit-Sp-12. (Fitchett, Min, Peterman, & Cella, 1996)	and was not directly related to quality of life.
Oztunc et al. (2013)	85 BC patients. Mean age: 48.6 ± 10.6 year. Turkey.	Treatment or post-treatment.	Chemotherapy.	>3 months prior to the research being undertaken.	Survey.	Beck Hopelessness Scale (Beck et al., 1974). Multidimensional Scale of Perceived Social Support (Zimmer et al., 1998).	84.7% married. Perceived social support score were high and hopelessness scores low. Hopelessness decreases when social support increases.
Pinkert et al. (2013)	242 relatives of BC patients. 65.5% male spouses. Other relatives included relatives of the patient or friend (4.3%).	Not reported.	Not reported.	Not reported.	Survey.	Critical Care Family Needs Inventory (CCFNI) (Leske, 1991) Needs Met Inventory (NMI) (Warren, 1993)	Relatives need a) security and trust, followed by b) partnership of care and c) emotional support.
Sandham & Harcourt (2007)	6 male partners Age range: 43-64 years old. UK	Follow-up	Mastectomy + breast reconstruction	-	Descriptive qualitative study.	Interviews exploring partners' experiences of breast reconstruction post mastectomy.	Key themes: Involvement in the Decision-Making Process, Giving and Seeking Support, Opportunity to Talk, and Adapting Behaviour.
Tighe et al.,	BC patients. Age range: 34	First year following diagnosis. The stage of	radical treatment which involved	Up to 12	Descriptive qualitative	39 interviews conducted over one	Women related coping and meaning to their experience of relationships, return to work,

(2011)	youngest, no details on oldest, mean: 51. UK.	cancer at the time of the first interview varied across the sample, although the majority of the women were at an early stage,	mainly a combination of chemotherapy and radiotherapy (n ¼4), or hormone therapy plus radiotherapy (n ¼3)	months.	study.	year.	and self-management of breast cancer symptoms.
Wilkes et al., (2002)	6 BC patients. Age range: 50-64. Australia.	Not reported.	Mastectomy Radiotherapy Chemotherapy Lumpectomy Partial mastectomy.	6 month to 5.5 years	Descriptive qualitative study	Interviews to explore experiences from time of diagnosis to time of interview.	Primary source of support was family and friends. Surgeon and GP providing some support. Emotional support was lacking, particularly from nurses.

APPENDIX 2

Interview schedules for Studies 1-3.

Interview schedule for Study 1.

1. Participant is welcomed and the researcher will introduce the research area and the interview process.
2. Standardized instructions will be read by the participant and they will be given an informed consent form to sign.
3. The researcher will have a short practice run using the audio-recorder. This is to make sure that the participant is comfortable with it, and to check that it is working. Following this, the interview will begin.

Questions:

- Tell me about the events that led up to your diagnosis (opening question).
- At what point did you tell your partner about your diagnosis? (Prompts: What did he do? What did you talk about?)
- Who came with you to hospital appointments?
- Can you tell me about what your partner would do on the days you had treatment?
- How do you feel about the help that your partner provided you with?

Interview schedule for Study 2A and 2B (Ecomaps).

1. Participant is welcomed and the researcher will introduce the research area and the interview process.
2. Standardized instructions will be read by the participant and they will be given an informed consent form to sign.
3. The researcher presents an example of an ecomaps to the participant and explains it to them and allows questions to be asked.
4. The researcher asks the participant to think about who will be included in their own ecomap.

Questions:

- Tell me about the events which led to your diagnosis (opening question). (Researcher notes any individuals who are mentioned)
- Tell me a little about the people who you told about your diagnosis (This question tended to identify various sources of support. The following are prompt to identify all individuals in the support network: family, friends, work colleagues, healthcare professionals, religious group members).
- Who do you think helped you the most when you were diagnosed?
- What about when you were receiving treatment?
- Who do you feel you are still close to?
- Is there anyone who you feel you are not as close to now that you are well?

Interview schedule for Study 3.

1. Participants are welcomed and the researcher will introduce the research area and the interview process.
2. Standardized instructions will be read by the participant and they will be given an informed consent form to sign.
3. The researcher will have a short practice run using the audio-recorder. This is to make sure that the participants are comfortable with it, and to check that it is working. Following this, the interview will begin.

Questions

- Tell me about the events which lead up to your diagnosis (BC patient).
- How and when did you come to know about the diagnosis (Sig other).
- What were the greatest challenges that you both faced a) during diagnosis and b) after treatment?
- What do you think you dealt with well as a couple?
- What about things that you struggled to deal with?
- How do you think breast cancer has changed your relationship?

APPENDIX 3

Interview coding sample (Study 1)

Open Coding	Raw Interview Data	Emerging Themes
<p>Feeling fatigued from treatment. Wanting others to understand how they feel. Understand they can't. Frustrating to BC survivor.</p> <p>Chemo brain?</p> <p>Remembering self before diagnosis.</p> <p>Frustration. Does she want to be treated normal or not be sick? Are people really expecting her to be normal? Is it fair to ask?</p>	<p>I think it was the whole thing about (.) not (.) not being normal if you know what I mean. It was, sort of, when I was having chemo and stuff like that, I was normal for like one week and then the week after chemo, I wasn't normal and I couldn't do normal things, and I think (2) part of, sort of, like, accepting it is accepting (1) how you feel and it's really difficult to describe to someone how you feel, when they got absolutely no idea, you know, I used to say "I've got absolutely no energy to walk up the stairs" and to say that to somebody who doesn't know what it feels, just sounds completely unreal. Um, (.) I'm not saying that's a negative thing, I'm just saying that it's, it's really hard to (1) explain how you're feeling when (.) how you're feeling is just totally rubbish. I think it was quite difficult for me as well because I'm not used to sitting around doing nothing, and I found that during the chemo stage where I had to sit around and do nothing, ummm, (2) so that was a bit difficult. But I didn't want to give in myself so I tried to compound the situation because everyone was expecting me to be normal because I'd asked them to treat me normally and then I'm saying "Oh actually I can't walk because I just can't walk, I haven't got the energy" and forcing myself to do and paying the price to do it. It was sort of half of my fault and (.) half not if you know what I mean.</p>	<p>Wanting to be normal.</p> <p>Treading on Eggshells.</p>

APPENDIX 4

Theme 2: Maintaining Equilibrium. Developed as part of the thematic analysis from Study 2A.

The theme “Maintaining Equilibrium” has been validated through the data from this study. This theme relates to women with breast cancer trying to keep a level of normality throughout the illness trajectory, as illustrated by the subtheme “Wanting To Be Normal”. The second theme, “Treading on Eggshells”, discussed the difficulties of socialising with family and friends who are worried about the potential fatality of breast cancer.

a) Wanting To Be Normal

Results from Study 1 demonstrated that one of the most debilitating side-effects of breast cancer treatments, especially chemotherapy, is fatigue and tiredness after each session. Participants stated that they did not want to be treated differently by family and friends (discussed in the next section “Treading on Eggshells”). However this was nearly impossible being various treatment programmes meant that they were often tired:

“Some days you would have to scrape me off the floor.”

Unsurprisingly, feeling tired would have an impact on the social lives of the patients, who found that the effects of treatment left them so exhausted that they lacked the strength to meet friends and family:

“The only way my social life suffered was when I was having side-effects from chemo and I couldn’t do anything.”

This resulted in frustration at the fact that they could not go and take part in activities that they enjoyed.

b) Treading On Eggshells

All participants stated that they wished to be treated normally by family and friends. Unlike the results of Study 1, they found that family and friends were able to treat them as normal. This was unsatisfactory:

“...in the end, it was them treating me as normal which was stressing me out!”

Ironically, in treating the patients as normal, family and friends still appeared to be nervous and apprehensive around them. They were overly cautious, being careful not to say anything that might upset the patient. This was perceived to be unnatural behaviour to the patient, who felt that they could not be completely honest with these individuals, when they were forcing their behaviour. This is an example of treading on eggshells, but in a different way compared to that discussed in Study 1. Here, family and friends are unnatural acting in a way that is supposed to be in line with the wants and needs of the patient. This is perceived as being unnatural by the patient. As a result of this, the patient feels that they cannot be honest with their friends and family.

As discussed in Study 1, this issue with honesty links in with the same issue raised by participants: that when a conversation is about

death, people are not as responsive and shut down. In a situation such as breast cancer, death is a very real possibility. However when family and friends did not know what to say if this issue came up, it tended to annoy the patient more, because they felt that they were being treated like an ill person, rather than a normal health person.

“Something about serious illness for some people. The shutters come down and they can’t cope with it.”

To summarise, these participants had a desire to be treated as they were prior to diagnosis. When family and friends acted in a way that they believed were in line with the desires of the woman with breast cancer, they were perceived to be unnatural in their behaviour which frustrated the patient even more. This frustration in their support sources could have resulted in patients not willing to talk to them openly: either because they did not feel that they wanted to be honest with them or because they were trying to protect them.

a) Understanding Health.

Having been diagnosed with breast cancer, there was a natural reaction to learn more about the disease, especially with regards to causes:

“Now it’s like, OK, this breast cancer is linked to obesity, and I’m not saying I’m fat, but let’s do what we can to make sure it’s not gonna come back.”

This new knowledge about causes of breast cancer has meant that patients have a better understanding of health and their own bodies. This is encouraging as they have become more health conscious and are exercising more, eating healthily, drinking in moderation and so on. Although they could not necessarily relate their breast cancer to lifestyle, this is certainly of benefit in the long term.