

Submitted in Partial Fulfilment of the Lancaster University Doctorate in Clinical Psychology

Experiences of Support Following a Diagnosis of Breast Cancer

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Abstract

The literature review aimed to provide a greater understanding of male partners' experiences of their female partner's breast cancer. A comprehensive search for relevant qualitative studies was conducted which identified fourteen studies. The findings were synthesised using a meta-ethnography approach. Male partners were found to mirror the emotional reactions and responses of their partner's and also found to manage difficult feelings by gathering information in order to re-establish balance within the family system. Providing male partners with information in accordance with their individual needs may help male partners meet the expectations of their role, reduce uncertainty and enable them to approach the diagnosis from a more informed position.

The research paper aimed to explore the experience of friendships following a diagnosis of breast cancer. Using a qualitative design, ten women who had received a diagnosis of primary breast cancer were interviewed. Data were analysed using interpretative phenomenological analysis. Three super-ordinate themes were selected and discussed. The first theme explored ways in which breast cancer tested women's expectations of their friendships, causing them to re-evaluate their quality and value; the second theme related to the importance of the proximity of their friends during the treatment phase of their illness; and the third described how time with friends post active treatment was re-evaluated based on the time and effort they had received from friends during their illness. Receiving a diagnosis of breast cancer therefore provided individuals with an opportunity to learn about the value and quality of their friendships.

The critical appraisal reflects upon issues that arose while completing the research for this doctoral thesis. Obstacles and dilemmas faced during the different stages of the research process were discussed, the limitations of the research were explored and the potential implications for future research in this area were also considered.

Declaration

This thesis represents research undertaken for the doctorate in clinical psychology at the Lancaster University. The research reported is the work of the named author and has not been submitted for any other academic award.

Signature of author:

Date: 23rd September 2015

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First and foremost, I would like to thank the women who took time out of their busy lives to take part in this research. I felt honoured that they were able to share their experiences with me, which I am extremely grateful for.

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I would also like to offer thanks to my supervisors Dr. Jane Simpson and Dr. Sarah Brearley for their time and commitment throughout the various stages of this research. I found their expertise and guidance extremely valuable.

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Section One: Literature Review

Men's experiences of their partner's breast cancer. A meta-synthesis

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Prepared for Psycho-Oncology¹ Journal

¹ See Appendix A: Journal instructions for authors

Abstract

Objective: Male partners of women diagnosed with breast cancer have to manage their own emotional distress in response to their partner's illness, as well as provide support to their partner. Recognising and understanding male partners' needs is important for health professionals to enable them to provide adequate support for male partners and to facilitate their ability to support their partner. This meta-synthesis aimed to provide a greater understanding of male partners' experiences of their female partner's breast cancer.

Methods: A comprehensive search for relevant qualitative studies was conducted using six online electronic databases. The search generated a total of 2413 papers after the removal of duplications. A total of fourteen papers were identified and the available findings were synthesised using a meta-ethnography approach.

Results: Two themes identified from the fourteen papers synthesised were discussed. Male partners were found to mirror the emotional reactions and responses of their partner's. Male partners were also found to manage difficult feelings by gathering information to adapt to the demands of the illness and re-establish balance within the family system.

Conclusion: These findings highlight the need for health professionals to regard both the patient and their partner as the client, as similar levels of distress may be experienced by each member of the dyad. Providing male partners with information in accordance with their individual needs may help male partners meet the expectations of their role, reduce uncertainty and enable them to approach the diagnosis from a more informed position.

Key words: Breast cancer; oncology; male partners; qualitative research; experience; meta-synthesis

Introduction

Breast cancer is the most common of all female cancers worldwide [1]. Although men can also be diagnosed with breast cancer, this paper will only focus on men's experiences of their female partners' illness due to the greater prevalence rates of female breast cancer. While rates of female breast cancer are variable across different countries, the incidence rates of the illness are increasing in both the developed and developing world [2]. Despite recent advances in the detection and treatment of breast cancer, the side-effects of those treatments can be invasive, leaving survivors with enduring physiological and psychological difficulties [3-6]. Indeed, due to the length of time women can be receiving treatment or be affected by the side-effects of the various treatments, breast cancer has often been regarded as a chronic illness [7]. Receiving a diagnosis of breast cancer can be a source of extreme distress for a woman [8]; the term 'distress' is used here as an umbrella term referring to the mental anguish and physical discomfort individuals may experience as a result of a chronic illness such as breast cancer [9-11].

A diagnosis of breast cancer can cause a woman to question the safety of the world around her and jeopardise her ability to feel connected to others [12]. Moreover, following treatments, many women have reported changes and losses in their lives and a sense of feeling different from their previous selves, altering their overall perspective of their lives and the relationships within them [3,13]. Survivors of breast cancer are also reported to experience a number of unmet psychological and supportive care needs following their diagnosis and treatments [14,15]. Supportive care needs consist of informational, physical, spiritual, psychological and social needs experienced by an individual throughout their cancer journey [16]. A recent study explored factors that may be associated with the supportive care needs of 175 women receiving treatment for breast cancer [17]. Using a cross-sectional survey it was found that conflicts within participants' personal relationships were associated

with participants' unmet supportive care needs, and that perceived social support was associated with fewer reported unmet care needs [17]. Therefore in order to meet the supportive care needs of women diagnosed with breast cancer, the relationships with those closest to them needs to be explored and addressed by health professionals [17].

A number of empirical findings on the experiences of people with cancer have been underpinned by a family systems approach, which focuses on the interactions between each member of a family system, and the interactions between the family as a whole and the systems around them [18]. The term 'system' refers to a collection of elements that interact with each other such as community systems, healthcare systems and education systems [18]. A family systems approach suggests that when one member of a family is diagnosed with an illness such as breast cancer, the effects of that stressful event are also experienced by other members of the family [19-22]. Moreover, as changes take place for one individual within a family system, compensatory changes are made by other members of the family in an attempt to adapt to the demands of the illness and re-establish a sense of balance [19-21,23,24]. As such, cancer is increasingly being conceptualised as an illness experienced by a whole family, as opposed to a diagnosis belonging to one individual [25]. Breast cancer may therefore generate a ripple effect, impacting on the lives and psychological wellbeing of those closest to the individual faced with the diagnosis [26-28].

As the majority of patients diagnosed with cancer receive treatment and interventions as an outpatient, they often rely on the informal care and support of their family and friends [29]. For many women diagnosed with breast cancer, the majority of the informal care they receive is likely to be provided by their partner, who may be intimately involved in their support needs [30]. Although breast cancer is noted to impact on the family as a whole, the chronicity of a woman's support needs is experienced by their partner as the couple attempt to manage the illness together [31]. It is recognised that not all partners of women diagnosed

with breast cancer are males. However, throughout this article the term 'partners' denotes male partners of women diagnosed with breast cancer.

Research exploring the impact of breast cancer on couples has produced mixed findings. For example, an illness such as breast cancer has been regarded by some as a potential risk factor that can negatively affect the stability of a relationship [32]. However, couples have also been reported to have experienced positive growth and felt that their relationship had been strengthened by a diagnosis of breast cancer [32,33]. Moreover, these contrasting effects of breast cancer on a relationship are also reflected in research by Walsh, Manuel and Avis [34] who found that out of 117 women diagnosed with breast cancer, 75% reported feeling closer to their partner following their diagnosis, 25% described their relationship as strained and 12% separated or initiated divorced proceedings as they felt unable to cope. Similarly, a systematic review of 15 quantitative studies explored the function of attachment and how this affected the adjustment of individuals diagnosed with cancer and those closest to them [35]. The term 'adjustment' encompasses the behavioural and cognitive processes individuals use to cope with cancer and subsequent treatments, and the threat that it poses to an individual's wellbeing [36]. Attachment has been defined as the relational security between an individual and those close to them [37,38]. When faced with a threat such as breast cancer, support seeking behaviours linked to an individual's attachment style may be activated [38]. The studies included in this review used various measures to assess and categorise an individual's attachment style. Findings from this review suggested that caregivers who were reported to have an insecure style of attachment were noted to have greater caregiving difficulties, increased levels of depression and higher levels of stress. Similarly, those diagnosed with cancer who were also reported to have an insecure attachment style had poorer outcomes in terms of their adjustment to their diagnosis of cancer and ability to recognise and access support from those around them. Findings from this

review highlight the impact interpersonal relationships may have on those diagnosed with cancer and those around them. It also demonstrates that an illness such as cancer is not only experienced by the individual who receives the diagnosis but also by those closest to the individual.

Although previous studies suggest that a diagnosis of breast cancer may have positive or negative effects on a couple's relationship, reasons as to why the illness can have such different effects on a couple's relationship remain unclear. Moreover, outside the issue of relationship quality, studies exploring the effects of female breast cancer on male partners within those relationships have also been mixed. Numerous qualitative and quantitative empirical papers have reported that male partners experienced negative effects when caring for a partner diagnosed with breast cancer, exhibiting similar levels of distress to that of their partner [39,40]. For example, a qualitative study by Lethborg, Kissane and Burns [39] interviewed eight women who had either completed or had almost completed chemotherapy treatment following a diagnosis of breast cancer, and a 'significant other' which included husbands, partners, and a close female friend. Significant others in this study described feeling helpless, exhausted, and afraid that they may lose their loved one, while also experiencing fears regarding their own mortality [39]. Similarly, the physical health of male partners of women diagnosed with breast cancer has been found to decline throughout a woman's treatment journey and remain negatively affected for some years after the woman's treatment has ended [41]. Caring for a partner diagnosed with breast cancer can therefore have a negative impact on a male partner's physical health and psychological well-being. For example, a study by Wilson and Morse [42] interviewed 14 husbands to explore their experience of living with a partner who was undergoing chemotherapy for breast cancer. It was reported that the husbands felt responsible for finding ways in which they could help their partners overcome their diagnosis and, when unable to achieve that, reported feeling a

sense of overwhelming guilt [42]. Male partners have to therefore manage their own emotional distress in response to their partner's illness, as well as provide support to their partner. These findings suggest that caring for a partner diagnosed with breast cancer may negatively impact on the wellbeing of male partners both physically and emotionally.

In contrast to the numerous studies noting the negative effects experienced by male partners, very few studies were noted to report positive effects. A quantitative study, for example, explored 'post traumatic growth' of women and their husbands, which explored positive changes each participant experienced following the traumatic experience of breast cancer treatment [43]. This study found many of the husbands to report experiencing positive changes such as a greater compassion for others and appreciation for life [43].

In accordance with a family systems approach to illness, which describes change as a reciprocal process between members of a family [20,23,24], male partners' responses to their female partner's illness has also been noted to impact on the wellbeing of their female partner. For example, the reactions of male partners of women diagnosed with breast cancer have been found to have the potential to affect their female partners' psychosocial adjustment [44]. Poor support received from a woman's partner has also been identified as a risk factor affecting the way in which a woman responds psychologically to the diagnosis of breast cancer [45]. Research also emphasises that the support women receive from other family members and friends cannot compensate for inadequate support received from their spouse, highlighting the importance of the male partner's role [46]. Although findings demonstrate the varied effect of the experience of male partners on their female partners, research suggests that, when provided with support, male partners' physical and psychological wellbeing improves alongside the wellbeing of female partners [47,48]. Informal carers, such as male partners, should therefore be provided with support to help them in this role. Consequently, recognising and understanding male partners' needs is important for health

professionals to enable them to provide adequate support for male partners and to facilitate their ability to support their partner.

Although research suggests that male partners of women diagnosed with breast cancer experience their own worries and fears about the illness, they often repress those fears to others [49]. As male partners have been found to refrain from sharing their concerns, it may be more difficult for professionals and their female partners to recognise and attend to male partners' needs [31]. If health professionals were more aware of the experiences male partners may be faced with when supporting a partner through breast cancer, difficulties associated with the illness could be highlighted and normalised [50]. This could help male partners recognise and manage the changes associated with the illness and help them feel more supported. Therefore in order to develop appropriate interventions and methods, in which health professionals can better support women and their partners through the diagnosis and treatment of breast cancer, a greater understanding of the partners' experience is needed

Research exploring the experience of breast cancer from the woman's perspective is extensive [51], resulting in a number of systematic reviews [4,52]. Although research exploring men's experiences of their partners' breast cancer has increased over recent years, the number of reviews drawing these findings together remains limited. One recent systematic review of qualitative and mixed-methods studies [53] explored men's experiences of their partners' altered body image and physique following a mastectomy. However, this review was limited to the experience of male partners of women who had experienced a mastectomy and therefore did not include the experience of male partners of women who received other surgical and non-surgical treatments following their diagnosis. Similarly, a review by Petrie, Logan and DeGrasse [54] explored the supportive care needs of spouses of women diagnosed with breast cancer within quantitative and qualitative studies. Although this review included the experiences of male partners' of women diagnosed with breast cancer, the experiences of

women and their families were also reported within the included studies making it difficult to extrapolate the experiences specific to that of the male partners. This review was also an integrative review and therefore did not adopt systematic review processes.

In contrast to the previous reviews described, this review focuses on qualitative studies of men's experiences of their partners' illness. Qualitative studies were selected for this review as qualitative methods allow participants to provide further understanding of an individual's 'experience' using participants' own terminology, as opposed to quantitative studies which aim to explore the relationship between specific variables. A review of qualitative research exploring male partners' experiences of their female partners' breast cancer has, to the author's knowledge, not been completed. Consequently, this review aims to synthesise key empirical qualitative papers to draw together the findings from existing research in this area, to provide a greater understanding of male partners' experiences of their female partners' breast cancer. As breast cancer is reported to impact on the lives and psychological wellbeing of those closest to them, it is important to understand how this is experienced from the partner's perspective. [26-28]. By recognising and understanding male partners' experiences and needs following their female partners' diagnosis, health professionals may be more able to provide male partners with more adequate support to meet their care needs, enabling them to better meet the care needs of their partners.

Method

This meta-synthesis will draw on the findings from different qualitative empirical papers to provide new interpretations and understandings, enabling a greater insight into men's experiences than that which is reported by one paper alone [55]. Qualitative papers were selected for review as these enable participants to illustrate and describe their experiences using their own words, metaphors and terminology to provide rich and meaningful accounts of their experiences. This meta-synthesis was conducted using the

meta-ethnography guidelines defined by Noblit and Hare [56]. This approach is well established in health and illness research and was therefore considered the most appropriate method for this review [57].

Search Strategy

A search for relevant papers was conducted using the following six online electronic databases, as these were considered the most appropriate databases for psychological and social health care research: PsycINFO, CINAHL, MEDLINE, Web of Science, Academic Search Complete and EMBASE. The final search was carried out in December 2014. Papers were identified using variations of the following search terms 'breast cancer', 'partners', 'qualitative' and 'experience', connected using the Boolean operators 'AND'. Specific searches were carried out tailored to each database, using a combination of keyword search terms and subject headings specific to each database when available. Searches were also limited to English language journals and peer-reviewed journals, in keeping with the inclusion and exclusion criteria of this review, where available (see appendix: B)

Inclusion and Exclusion Criteria

The inclusion criteria set for this meta-synthesis meant that papers should: (a) be published in English (due to a lack of resources available for translation), (b) report empirical research that used qualitative methodology and inductive analysis, (c) have used participants' quotes to support findings, (d) have explored male partners' experiences of their female partner's breast cancer, and (e) published in a peer-reviewed journal (as these papers had been through a peer quality assessment process). Unpublished 'grey literature' was not included in this meta-synthesis due to the uncertainty regarding the quality of unpublished work [58] and the added time and expense involved in accessing this type of literature [59].

Papers were excluded if any of the following exclusion criteria were met: (a) included the exploration of partners of women diagnosed with other types of cancers or enduring

health conditions (as it was not possible to extract the experiences specific to partners of women diagnosed with breast cancer), (b) explored the experience of bereaved male partners (male partners whose partners were diagnosed and survived a diagnosis of breast cancer were reflecting on their ongoing, current experiences, as opposed to reflecting on what it was like to have lived with and lost a partner to breast cancer), (c) included the experiences of health professionals, family members, friends, and the women diagnosed with breast cancers within their sample (as it was not possible to extract the experiences specific to male partners), and (d) focused on the evaluative experience of a service or an intervention.

Search Outcome

The search generated a total of 4464 possible relevant papers. Details of each citation were stored in an Excel spreadsheet. After the removal of duplications, 2413 papers remained (see figure 1). The titles and abstracts of the remaining papers were reviewed by the lead author and their suitability assessed against the specified inclusion and exclusion criteria. Details regarding the exclusion of each study were recorded on an Excel spreadsheet. To minimise potential bias, the lead author reviewed the list of excluded papers on two separate occasions to ensure rigour. Although the integrity of the screening process could have been strengthened using additional independent researchers [55], the inclusion screening was only carried out by the principal author in this instance as this systematic review was completed as part of a doctoral thesis. Further exploration of this limitation is discussed in the strengths and limitations section of this review. Full text versions of 107 papers were reviewed where the article abstracts were thought to provide insufficient detail to assess their suitability. The screening process produced a total of 11 suitable papers. A hand search of the reference lists and an internet citation search of the identified papers was also carried out, identifying three additional papers. In conclusion, a total of 14 papers were found that met the inclusion and exclusion criteria set for this meta-synthesis.

Insert figure 1 here

Characteristics of included studies

The fourteen papers [60-73] included in this review were published between the years 1991 and 2014. Four papers used a sample from America, five papers used a sample from Canada, and the remaining papers used samples from Scotland, England, Taiwan, Brazil and Iran. Two of the papers included in this meta-synthesis were conducted by the same authors and presented findings from the same group of participants [71,72]. The data from both of these papers have been used in this review as the aim and findings of each paper were notably different and therefore added value.

Sample sizes ranged from 6 participants to 67, totalling 288 participants across all fourteen papers ($M = 21$). The age of the participants within twelve of the studies ranged from 28 to 78 years. The study by Samms [68] reported the mean age of their participants to be 42 years and the ages of the participants for the remaining paper was provided in categories ranging from 18 to over 70 [69]. The age of the participants was inconsistently reported, making it difficult to collate a mean age of the participants across all papers. The time from their partners' diagnosis to the time the men participated in the studies was reported by thirteen papers and ranged from 35 days to 19 years. Papers included partners of women diagnosed with varying stages of breast cancer from stage one to metastatic breast cancer. Metastatic breast cancer is defined as breast cancer which has spread to different parts of the body.

Hilton, Crawford and Tarko [67] also included a participant whose partner was in the palliative stage of her illness. Two of the fourteen papers reported female partners to be in active treatment for breast cancer at the time of data collection [62,63] which was not explicitly reported by the remaining twelve papers. Treatments experienced by the female partners following their diagnosis included surgery, chemotherapy and radiotherapy. The

types of treatments experienced by their female partners were not reported by six of the fourteen papers reviewed.

Data were collected using one-to-one interviews by thirteen of the papers and focus groups were used by Samms [68]. Although some studies explicitly stated that participants were interviewed alone [65], it was unclear whether participants in the remaining papers were interviewed in the presence of their female partners or alone. Of the fourteen papers, eleven studies used a type of analysis based on thematic grouping, one paper used narrative analysis and two papers used a phenomenological informed thematic approach. Specific details for each paper can be seen in Table 1.

Insert table 1 here

Quality appraisal

To assess the strengths and weaknesses of the selected papers, the Critical Appraisal Skills Programme tool (CASP) [74] was used. Although a range of quality assessment tools are available, the CASP was selected due to its clear and concise structure. The CASP has also been used as a quality assessment tool in a number of previous meta-syntheses [75,76]. The CASP tool enabled each selected paper to be assessed and measured across ten different areas. The selected papers were first screened using two questions which aimed to assess the aims and research relevance of each paper, alongside their appropriate use of qualitative methods. All of the 14 selected papers met the initial screening criteria. Each paper was then assessed against eight areas (see table 2). Each paper was assigned a score out of three, depending on whether the reporting of the area being assessed was weak (1), moderate (2), or strong (3).

Across all 14 of the selected papers, reflexivity was scored as a 'weak' area, as authors failed to describe their epistemological position or explore the potential impact their beliefs and knowledge may have had on the findings presented. Many of the papers provided

detailed accounts of the methodological and analytical procedures used.

The scores assigned to each paper are only one possible interpretation of the information provided and therefore should not be regarded as an objective or definitive score. Although this tool was used to assess the quality of the papers included in this meta-synthesis, papers were not excluded as a result of quality due to potential restrictions and demands placed upon authors during the publication procedure. However, quality ratings were taken into consideration when producing the findings for this meta-synthesis to ensure that identified themes from weaker scoring papers were also supported by stronger rated papers.

Insert table 2 here

Data extraction and synthesis

In accordance with the guidelines by Noblit and Hare [56], the themes from each identified paper were extracted and translated to form new interpretations and metaphors. This method suggests that the findings from varying research papers may generate translations with shared, comparable meanings, opposing translations (refutational translations) or present findings of a particular stance or argument. Noblit and Hare [56] also proposed that the following seven stages should be adopted when conducting a meta-ethnography approach: (1) generate a research question, (2) identify which papers are relevant to answering the proposed research question, (3) read the research papers identified, (4) establish how the papers relate to one another, (5) translate the study's findings into one another, (6) translate the synthesis, and (7) express the findings of the synthesis. By synthesising identified themes from different qualitative studies, new interpretations within an area can be made [77] (see appendix: C). The themes relevant to the aim of this synthesis were extracted from the findings of each paper. The title, description and supporting quotes of each theme were extracted and recorded into a formatted table. This process helped the

author establish familiarity and in-depth understanding of the data. Themes were grouped into commonalities and opposing conclusions which Noblit and Hare [56] refer to as refutational translations. The identified themes were reviewed in supervision to ensure interpretation bias was minimised.

Results and Discussion

Three themes were identified from the fourteen papers synthesised (see table 3 for the distribution of the themes). Each identified theme was present in more than seven of the fourteen synthesised papers. Participants' quotes from the original papers are used to support each of the following themes to ensure participants' experiences from each paper were not lost.

The first theme identified explored the emotional impact of their partners' diagnosis of breast cancer on the participants and how they tried to manage those feelings. This theme occurred in 9 of the 14 papers synthesised. The second identified theme, which was noted in 7 of the 14 synthesised papers, found that male partners attempted to gain further understanding of their partner's cancer as way of reducing the fear and uncertainty they experienced. The third theme, occurring in 8 of the papers, explored how their partner's diagnosis created challenges within their relationships. Breast cancer affected their ability to communicate as a couple due to the difficult context of their conversations and increasingly limited patience for one another. However, relational difficulties following a diagnosis of breast cancer have been widely recognised by previous studies and therefore not explored further in this review [20, 24]. The first two themes were selected for further discussion based on the level of new understandings they brought to this topic area [78].

Insert table 3

Theme 1: “There’s not a whole lot that I can do”: Feeling like a helpless bystander

Participants talked about the emotional impact of their partners’ diagnosis of breast cancer and how they tried to cope with those feelings. Participants reported feeling shocked and surprised by their partner’s diagnosis [61,62,65,68,69,71,73]. Breast cancer was described as an unexpected event that caught the participants “off guard” [71] (p.67). One participant described how “just the word cancer makes you feel like you’ve been punched in the stomach” [61] (p.82). Another participant described how he was trying to feel “secure in the midst of something that isn’t life threatening to me, but it’s life threatening to [my wife]” [68] (p.1354). The partners of the participants in this study had been diagnosed with early stage breast cancer which had been interpreted as life threatening for those diagnosed, but also as a threat to the family unit. Similarly, another participant whose wife had been newly diagnosed with breast cancer explained how “you start saying that she's gonna possibly die. Then you wonder if that happens, what happens to the kids?...It goes on and on and it’s very upsetting” [69] (p.3178-3179). These findings are supported by Kilpatrick et al. [79] who noted the diagnosis stage of the treatment journey to be characterized by crisis, which was reflected in the participants’ descriptions. As one participant explained “... it really hit me. That was my lowest point, I think, in my life, really” [63] (p.402).

Following the initial shock of their partner’s diagnosis, participants reported feeling physically and emotionally stressed [61,62,65,70]. Participants described experiencing a combination of emotional responses such as disbelief, fear, rage, anger, guilt, despair, annoyance, anxiety and sadness [62,65,68,69,71]. The same emotional reactions to that of male partners can be seen in studies exploring women’s experiences of breast cancer, who also reported feeling anxious, overwhelmed and angry [80]. Participants mirrored the emotional reactions of their partners as one participant illustrated “she cried and I also cried”

[65] (p.321). In accordance with family systems theory [19], male partners were not shielded from their partner's emotional response to the diagnosis of breast cancer, but experienced similar distress to that of their partner. These findings are supported by previous research which explored couples' responses to cancer and found that partners experienced psychological distress equal to or greater than that of their partner [81,82]. Feeling unprepared for the diagnosis generated a sense of uncertainty [62,65,70], as one participant whose partner had been diagnosed with metastatic breast cancer illustrated "I didn't know what to do to help her" [70] (p.257). Difficulties in managing uncertainty have similarly been reported as a difficulty for partners and patients throughout the treatment journey, for a number of cancer populations [83,84]. Feeling unprepared and uncertain led participants in this review to feel out of control and unsure of what they could do to help their partner [70].

Participants reported feeling helpless and frustrated in having to stand by and watch the effects breast cancer had on their partners, without being able to fix or solve their difficulties [61,62,69-71]. These findings correspond with previous research which suggests that male partners adopt a problem solving approach when feeling helpless, which fits their need to actively 'do' something in order to feel helpful [50,85,86]. Previous studies describe male partners' attempts to solve their partners' problems without appropriately listening to their needs or empathising with their difficulties [50]. While proactive coping was considered useful, it also led to feelings of frustration. Participants reported feeling "powerless" [62] (p.87), with one participant saying "there's not a whole hell of a lot that I can do, and that's frustrating...and the most difficult part of it all" [61] (p.84).

Approaching care as a set of tasks that needed to be completed has been argued within the wider literature to be congruent with the stereotypical masculine role as the strong person in the dyad, enabling male partners to regain a sense of control [39,87]. The inability to take control of the situation therefore may not have fit with the roles and expectations the

participants in the studies reviewed had held for themselves [62,63]. This may have threatened male partner's self-esteem resulting in a diminished concept of self [88]. As one participant explained "...they say it's a guy thing or a man thing, you want to fix things, you want to put things to right and, of course, I couldn't do that" [63] (p.402). Almost half of the female partners of the participants in that study were in active treatment following their diagnosis of breast cancer at the time this study was carried out [63]. This may have been a time when their care needs were predominantly met by health professionals, which may have contributed to participants' feelings of helplessness. Participants were also noted to refer to their role in the relationship as the protector; as one participant stated "I'm not doing the job that I'm here to do, to help her and protect her" [62] (p.87). Similarly, the partners of the participants in this study were also in active treatment, which again may have contributed to the feeling that they were unable to protect their partners during that time [62].

When unable to control the effects of their partner's illness through the completion of solution driven tasks, participants attempted to control their own emotional responses [73]. As one participant illustrated "I went out on the patio to breathe ... I felt better—the anxiety bugged off...I had to do things I enjoyed, or else I was going to be useless because the anxiety was going to get me." [73] (p.9). This enabled participants to regain an element of control and meet the expectations of their role as the protector. Participants in this paper also reported using leisure activities to "regulate" their emotions to enable them "to keep things, um, running smoothly here" and therefore be supportive to their partner [73] (p.134).

Research by Sabo [89] suggests that the male role of protector and provider encompasses values of emotional reserve and strength, influencing male partners' approach and adjustment to difficult situations. Therefore in regulating their emotions outside of the home, male partners were able to remain congruent to the masculine role as the protector within the home. However, some would argue that as part of the masculine identity, men have

traditionally been taught to refrain from verbally articulating their feelings and may therefore be limited in those skills and abilities [90,91]. Elements of these findings fit with the relationship focused model of coping introduced by Coyne and Smith [92], which suggests that partners participate in two processes; protective buffering in which partners hide their concerns and deny their worries; and active engagement whereby partners attempt to solve problems and seek further understanding of their partners feelings [92]. Although participants in the studies reviewed did not deny their worries, they did report ways in which they attempted to control and regulate their emotions [73], therefore hiding their concerns from their partner (protective buffering). Male partners were also noted to seek further understanding by gathering information from various sources (active engagement) which is discussed further in the second identified theme of this review.

Theme 2: Gathering information: A strategy to reduce fear

Gaining further understanding of their partner's cancer reduced fear and uncertainty experienced by participants [61,62,69,72]. As one participant illustrated "the more you read, the more you understand and the better you feel" [72] (p.80). Fear of the unknown appeared to increase participants' worry and stress [67]. Information was described as "turning a light on in the room" [72] (p.81), making participants experiences feel "less scary" [72] (p.81). Participants sought information from various sources such as health professionals, the internet, and other men whose partners had also been diagnosed with breast cancer [64,67,68,72]. These findings fit with the active engagement element of the relationship focused model of coping, demonstrating partners need to seek out further understanding as a way of helping them to cope with the situation [92]. Learning about their partners' illness and becoming educated about treatment options enabled participants to feel more supportive during decision making processes, helping them feel useful and regain a sense of control at a time when they felt otherwise powerless [62,67].

Some participants felt that it was their role and responsibility to gather and assimilate information for their partners [62]. For example, one participant noted, "as far as ... reading and absorbing the stacks of information we have on breast cancer, that's the kind of thing that I feel like I'm responsible for" [62] (p.92). Another participant explained how he "wanted...to find out more alternatives to it. I wanted to know the statistics to best save her life" [61] (p.84). Gathering information may have therefore been the male partner's way of fulfilling the masculine role as the 'provider' [89]. Similar findings have also noted male partners' need to be included in treatment decision making processes, enabling them to regain a sense of control [28,93]. However, a recent study exploring social support of long-term survivors of female breast cancer in same sex-relationships, from the perspective of the women who had been diagnosed with breast cancer, reported their partners to also research their treatment options and regularly engage them in health focused conversations [94]. Similarly, research exploring the gender differences of men and women newly diagnosed with cancer found that women confided in a greater number of people following their diagnosis than men [95]. It may be that women with breast cancer within the studies reviewed chose to confide in friends and family and may therefore have unintentionally steered male partners into a role in which they needed to seek further information to meet their own needs. Gathering information may have therefore been less about fulfilling the masculine role as the 'provider' but more about adapting to the demands of the illness and attempting to re-establish balance within the family system [19-21,23,24].

However, participants' information needs were not always met by health professionals who at times acted as a barrier to their involvement in their partners' care [64]. Indeed, the information needs of partners have been reported in the wider literature to be often ignored by health professionals [96]. Moreover, partners and family members are also reported to be provided with less information by health professionals than that provided to the

patient [97]. Although understandable when thinking about the limits of patient confidentiality, providing partners with limited information fails to consider male partners and their need for information. The lack of information provided may therefore increase male partners' uncertainty and hinder their ability to uphold the masculine role of 'protective guardian' [98].

Information gained was at times also found to be unhelpful by participants in this review. For example, when faced with conflicting advice or information regarding possible recurrence, participants experienced a greater sense of uncertainty [64,68,69,72]. As one participant explained "the insecurity amongst the professionals, the diverse opinions that we got over some science that I thought was relatively common, that was the biggest shock for me....and the biggest thing I was unprepared for" [61] (p.85). Research suggests that participants may have attempted to support their partners' in making treatment decisions by looking to, and trusting health professionals as the 'experts' who had the 'right' answers to help solve their problem [99].

Although some participants felt that you could "never have too much information" [67] (p.448), others felt "overloaded" [68] (p.1354) with "too much information to the point where you can't analyse it" [68] (p.1354). This would suggest that information provided may feel unmanageable for some, and increase male partner's difficulties during that time. These findings demonstrate the individualistic nature of male partner's information needs and is in keeping with other papers which also suggest that information deliverance should be tuned to the individual [96].

Educating couples on the psychosocial effects of an illness has been described by Rolland [32] as providing couples with a roadmap, forewarning them of potential difficulties and enabling them to regain a sense of control over their lives. For some participants, it was important that they felt included and acknowledged during their partner's treatment journey,

as one participant illustrated "... the consultant was very good, very good because he added me to the conversation, I was part of it all the time ..." [64] (p.68). These findings suggest that male partners should be acknowledged and recognised for the role they play in their partners care and for their own needs.

Strengths and Limitations

The findings of qualitative research are regarded as irreplicable as they encapsulate the sociocultural world of the participants and researcher [59]. The findings of this review are therefore regarded as third level interpretations, made up of the knowledge and beliefs of the participants within each paper, the researchers who gathered and analysed the original data, and the researcher who conducted this meta-synthesis [59]. It is important to note that another researcher, with different values and beliefs, may have produced different findings to that represented in this review. The findings discussed in this review were also selected to represent theoretically compelling and novel understandings of this area of research and therefore do not encapsulate all three themes that were identified by this review process [78].

The assessment of multiple systematic reviews (AMSTAR) checklist was used to further explore the strengths and limitations of this review [100] (see appendix D). The score generated by the checklist categorised this review as being 'moderately at risk' of bias. Although the identified themes were reviewed in supervision to ensure interpretation bias was minimised, the risk of bias could have been further reduced by using an independent researcher to duplicate the selection and data extraction process of this review. A clear audit trail of the search process of this review was recorded to ensure replicability and is regarded as a strength of this review (see appendix B). However, restrictions regarding the type of publications included in this review were adopted (i.e. peer-reviewed journals, English language), which could be argued to be a limitation of this review.

Although this approach has been criticised for the loss of information and depth reported by individual studies, drawing on the findings from a number of papers provides an opportunity to strengthen the theoretical generalisability of that which is reported by one paper alone [55,101]. Papers included in this meta-synthesis explored male partners' experiences from a broad range of countries. This is a strength to this review, as it demonstrates coherent themes of male partners' experiences across a diverse range of cultural perspectives.

Implications for Future Research

It would be helpful for future research to explore health care professionals' experiences of male partners of women diagnosed with breast cancer. This could provide a greater understanding of how health care professionals currently attempt to meet male partners' needs throughout a woman's treatment journey and highlight potential barriers that may be preventing health care professionals from meeting their needs. Future research could also develop and evaluate informational materials tailored specifically to male partners, to support their need to gather information.

This review did not include the experiences of female partners of women diagnosed with breast cancer due to the limited number of studies available. It would be helpful for future research to explore the experiences of female partners of women diagnosed with breast cancer to gain further understanding of their care and support needs.

Relevance to Clinical Psychology Practice

In treating a woman diagnosed with breast cancer as an isolated individual, services fail to recognise the impact breast cancer can have on a partner and therefore fail to meet their needs. Pauwels, De Bourdeaudhuij, Charlier, Lechner and Van Hoof [102] suggested that the perceptions of partners within health care services, as providers of care as opposed to individuals who need support and care for themselves, may influence how they are treated

and how they respond to their own needs. As male partners have been noted to refrain from sharing their concerns, health professionals and their female partners may be unaware of their feelings and therefore overlook their needs [31]. Findings of this review could be used by clinical psychologists to help health professionals become more aware of the emotional impact breast cancer has on male partners. By making health professionals more aware of the process in which male partners seek information as a way of managing their fears and uncertainty, health professionals could signpost male partners to more reputable, appropriate sources of information. Clinical psychologists could also help support male partners fulfil other roles than that of the provider role. For example, clinical psychologists could help male partners to develop their communication skills to enable them to empathise and listen to the needs of their partner, which may facilitate their ability to meet their partners' care needs and therefore reduce their feelings of frustration and helplessness [50]. These findings could also be useful for clinical psychologists working in oncology services who provide individual psychological support to individuals diagnosed with breast cancer. These findings support the need for psychological support services to be available to partners of women diagnosed with breast cancer, who may be struggling to manage their own needs as well as the needs of their partner.

Conclusion

In summary, this meta-synthesis aimed to provide a greater understanding of male partners' experience of their female partner's breast cancer. Synthesis of the fourteen papers included in this review identified three overarching themes. Two of the three identified themes were discussed within this review based on the level of new understandings they brought to this topic area [78]. These themes illustrated how male partners experienced their partner's breast cancer and how they managed those experiences.

Male partners were found to mirror the emotional reactions and responses of their partners. These findings highlight the need for health professionals to regard both the patient and their partner as the client, as similar levels of distress may be experienced by each member of the dyad [103]. Breast cancer should therefore be regarded as a couple's problem as opposed to an individual's problem [20, 32]. Findings from this review also emphasise male partners need to gather information to adapt to the demands of the illness and re-establish balance within the family system [19-21,23,24]. Providing male partners with information in accordance with their individual needs may therefore help male partners meet the expectations of their role, reduce uncertainty and enable them to approach the diagnosis from a more informed position. Learning about their partners' illness enabled participants to feel useful and regain a sense of control at a time when they felt otherwise powerless.

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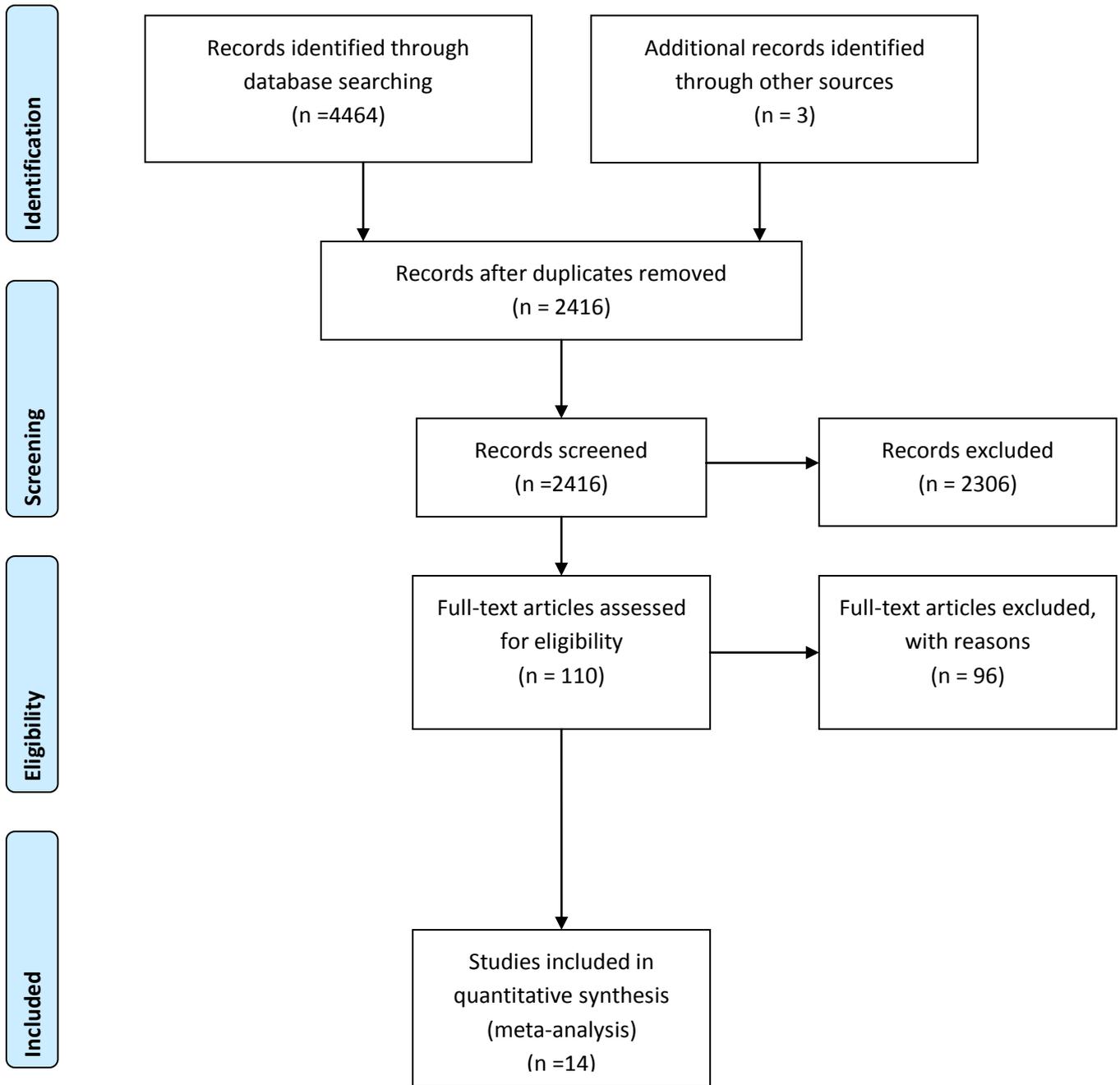


Figure 1. Flow diagram to show how the papers within this meta-synthesis were selected.

Table 1. Details of the included papers

Authors/year	Aim/goal of study	Theoretical orientation	Analysis	Data collection methodology	Sampling frame	Sample Size	Age range (mean)	Relationship status	Female partners diagnosis and treatments	Setting
Harrow, Wells, Barbour and Cable (2008) [60]	To develop an understanding of the everyday impact of breast cancer from the perspective of male partners.	Not specified	A type of analysis based on thematic grouping	Questionnaire and interview.	Purposive	26	30-77	24 Married, 2 partners. Length of time in a relationship: between 1 and 15 years.	Completed treatment for primary breast cancer. Treatments: mastectomy, chemotherapy, radiotherapy, wide local excision. Time from diagnosis ranged from: 7 month to 6 years.	Scotland.
Zahlis and Shands (1991) [61]	To identify the demands that a diagnosis of breast cancer placed on the patient's partners lives.	Not specified	A type of analysis based on thematic grouping	Interview	Purposive	67	28-63 (43.7)	61 Married, 6 partners.	Diagnosed with breast cancer within the previous 2.5 years. Treatments: Mastectomy and lumpectomy. Time from diagnosis ranged from: 35-984 days.	USA.
Zahlis and Lewis (2010) [62]	To describe in the spouses' own words, their experience of their wives' newly diagnosed early stage breast cancer, focusing explicitly on the first 6 months of diagnosis and treatment.	Not specified	A type of analysis based on thematic grouping	Interview	Purposive	48	31-68 (44)	Married Length of time married: between 3 and 32 years.	Diagnosed with local or regional breast cancer within the past 6-months (stage 0-2), in active treatment. Treatments: Lumpectomy/nodal dissection and nonconserving breast surgery, chemotherapy and radiotherapy. Time from diagnosis ranged from: 40-225 days.	USA

Authors/year	Aim/goal of study	Theoretical orientation	Analysis	Data collection methodology	Sampling frame	Sample Size	Age range (mean)	Relationship status	Female partners diagnosis and treatments	Setting
Duggleby, Bally, Cooper, Doell and Thomas (2012) [63]	To explore the hope experiences of male spouses of women with breast cancer.	Not specified	Interpretative analysis	Interview. Second interviews conducted to clarify information and obtain deeper understanding.	Purposive and snowball	11	36-76 (55)	Married, cohabiting Length of time married: between 6 and 50 years.	Diagnosed with varying stages of breast cancer (stages 1 – 3). 5 women were in active treatment.	Canada.
Sandham and Harcourt (2007) [64]	To investigate partners' experiences of breast reconstruction	Not specified	A type of analysis based on thematic grouping	Interview	Purposive	6	43-64 (52)	Partners Length of time in a relationship: 4-39 years.	Undergone breast reconstructive surgery within the previous 2 years.	England
Hoga, Mello and Dias (2008) [65]	To describe the effects of a mastectomy from the husbands' perspective.	Not specified	Narrative analysis.	Interview	Purposive	17	54-84	Married Length of time married to partner: between 21-50 years.	Undergone a total unilateral mastectomy, total bilateral mastectomy or a modified radical unilateral mastectomy. Treatments: chemotherapy, radiotherapy, or both chemotherapy and radiotherapy.	Brazil
Nasiri, Taleghani and Irajpour (2012) [66]	To explore the sexual issues of Iranian men after breast cancer in their wives.	Grounded theory	A type of analysis based on thematic grouping	Interview. Second interviews were conducted with 2 participants to confirm emerging concepts.	Purposive	18	33-70 (51.5)	Married	Undergone unilateral modified radical mastectomy. Treatments: chemotherapy, radiotherapy, or follow-up care . None of the women had received a diagnosis of metastatic breast cancer. Time elapsed from mastectomy: 25 days-6 years.	Iran

Authors/year	Aim/goal of study	Theoretical orientation	Analysis	Data collection methodology	Sampling frame	Sample Size	Age range (mean)	Relationship status	Female partners diagnosis and treatments	Setting
Hilton, Crawford and Tarko. (2000) [67]	To describe how husbands coped when their wives experienced cancer and underwent chemotherapy for breast cancer.	Not specified	A type of analysis based on thematic grouping	Interview	Purposive and snowball	10	39-58 (47.1)	Married	Undergone chemotherapy 6 to 25 months prior to the interview. One female partner was in the palliative stage of her illness.	USA
Samms (1999) [68]	To identify husband's perceived needs related to their wives' breast cancer and their view of how they can be helped to deal with the resultant challenges.	Not specified	A type of analysis based on thematic grouping	Focus group	Purposive	9	(42)	Married Length of time married to partner: between 8-25 years.	Diagnosed with early stage 0, 1 or 2 breast cancer. Mean length of time since initial diagnosis: 2.4 years	USA
Cheng, Jackman, McQuestion and Fitch (2014) [69]	To assess the perceived needs and preferred services of male partners of women newly diagnosed with breast cancer.	Not specified	A type of analysis based on thematic grouping.	Interview	Purposive	27	Ages presented in categories	Married	Newly diagnosed with breast cancer, 6 months post-surgery.	Canada
Lin, Lin, Lee and Lin (2013) [70]	To explore the lived experiences of male spouses of women with metastatic breast cancer.	Not specified	Content analysis	Interview	Purposive	9	31-78 (61)	Spouses	Diagnosed with metastatic breast cancer	Taiwan

Authors/year	Aim/goal of study	Theoretical orientation	Analysis	Data collection methodology	Sampling frame	Sample Size	Age range (mean)	Relationship status	Female partners diagnosis and treatments	Setting
Fitch and Allard (2007) [71]	To explore the perceived impact of a breast cancer diagnosis on male partners of women diagnosed and treated for breast cancer.	Not specified	Content analysis	Interview	Purposive	15	34-71 (53)	Married, cohabiting Length of time married to partner: between 7-45 years.	Diagnosed with breast cancer. Time since initial diagnoses: 0.5-19 years	Canada
Fitch and Allard (2007) [72]	To explore the perceived information needs of male partners of women diagnosed with breast cancer.	Not specified	Content analysis	Interview	Purposive	15	34-71 (53)	Married, cohabiting Length of time married to partner: between 7-45 years.	Diagnosed with breast cancer. Time since initial diagnoses: 0.5-19 years	Canada
Shannon (2014) [73]	To explore men's experiences with leisure and the meaning of those experiences during and following their partners' breast cancer diagnosis and treatment	Hermeneutic phenomenology	Phenomenological analysis	Interview	Purposive	10	46-68	Length of time in a relationship: between 8-35 years	Had a breast cancer experience within the previous five years and were one year postoperative. Treatments: lumpectomy, radiotherapy, chemotherapy, double mastectomy or reconstructive surgery.	Canada

Table 2. Quality appraisal of the selected papers using the CASP appraisal of qualitative research tool [60].

Papers	Research design	Sampling	Data collection	Reflexivity	Ethical issues	Data analysis	Findings	Value of research	Total score
Harrow, Wells, Barbour and Cable (2008) [60]	3	3	3	1	1	2	2	1	16
Zahlis and Shands. (1991) [61]	2	1	2	1	1	2	1	1	11
Zahlis and Lewis (2010) [62]	2	1	1	1	1	2	2	1	11
Duggleby, Bally, Cooper, Doell and Thomas (2012) [63]	3	3	3	1	1	2	2	2	17
Sandham and Harcourt (2007) [64]	2	2	2	1	2	1	2	1	13
Hoga, Mello and Dias (2008) [65]	3	3	3	1	2	2	2	3	19
Nasiri, Taleghani and Irajpour (2012) [66]	2	3	3	1	3	3	2	3	20
Hilton, Crawford and Tarko. (2000) [67]	3	2	2	1	3	1	2	2	16
Samms (1999) [68]	3	2	2	1	1	2	1	2	14
Cheng, Jackman, McQuestion and Fitch (2014) [69]	3	3	3	1	1	1	2	1	15
Lin, Lin, Lee and Lin (2013) [70]	3	3	3	1	3	1	2	2	18
Fitch and Allard (2007) [71]	3	3	2	1	2	2	3	2	18
Fitch and Allard (2007) [72]	3	3	2	1	2	2	3	1	17
Shannon (2014) [73]	3	3	3	1	1	2	3	2	18

Table 3. Distribution of themes

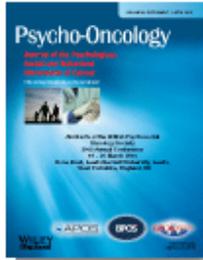
Papers	Theme 1: “There’s not a whole lot that I can do”: Feeling like a helpless bystander	Theme 2: Gathering information: A strategy to reduce fear	Theme 3: The relational impact and struggles of breast cancer
Harrow, Wells, Barbour and Cable (2008) [60]			x
Zahlis and Shands (1991) [61]	x	x	x
Zahlis and Lewis (2010) [62]	x	x	x
Duggleby, Bally, Cooper, Doell and Thomas (2012) [63]	x		
Sandham and Harcourt (2007) [64]		x	
Hoga, Mello and Dias (2008) [65]	x		x
Nasiri, Taleghani and Irajpour (2012) [66]			x
Hilton, Crawford and Tarko (2000) [67]		x	x
Samms (1999) [68]	x	x	
Cheng, Jackman, McQuestion and Fitch (2014) [69]	x	x	
Lin, Lin, Lee and Lin (2013) [70]	x		x
Fitch and Allard (2007) [71]	x		x
Fitch and Allard (2007) [72]		x	
Shannon (2014) [73]	x		

Appendix A

Psycho-Oncology: Journal instructions for authors

Psycho-Oncology

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Appendix B
Table of search terms used

Databases	Search terms combined using the Boolean operator 'AND'				Limits set
	Breast Cancer	Partners	Qualitative	Experience	
1: Psych Info Index terms: Key words: Combined 'index term' search with 'key word' search using the Boolean operator 'OR'	Breast Neoplasms	Human, Males, Husbands, Spouses, Caregivers, Family Members, Couples, Significant Others, Family Relations	-	-	English language Exclude dissertations Peer-review journals
	"Breast Cancer" OR "Breast Neoplasm*"	Caregiver* OR Spouse* OR "Other half" OR carer OR Cohabiting OR Married OR "Significant Other*" OR Partner* OR Family OR Male* OR Men OR Husband* OR Couple*	"Qualitative" OR "Grounded Theory" OR "Interview*" OR "Content Analysis" OR "Interpretative Phenomenological Analysis" OR "Thematic Analysis" OR "Narrative" OR "Focus Group*"	Experience* OR Coping OR Cope OR Perspective* OR Stories OR View OR Manage OR Adjustment OR Understanding OR Perception* OR Perceive OR Need* OR Impact	English language Exclude dissertations Peer-review journals
2. Academic Search Complete Subject terms: Key words: Combined 'subject term' search with 'key word' search using Boolean operator 'OR'	Breast Cancer (exploded term)	Husbands, Marital relations, Significant others, Married people, Spouses in Literature, Spouses, Married men, Couples (exploded term), Men Males, Families (exploded term), Caregivers, Medical care	Qualitative Research, Phenomenology, Interviewing, Social Sciences-Methodology, Grounded theory, Content Analysis, Thematic Analysis, Narrative Enquiry	-	English language Scholarly Peer reviewed Articles
	"Breast cancer" OR "Breast Neoplasm*"	Caregiver* OR Spouse* OR "Other Half" OR Carer OR Cohabiting OR Married OR "Significant Other*" OR Partner* OR Family OR Male* OR Men OR Husband* OR Couple*	"Qualitative" OR "Grounded Theory" OR "Interview*" OR "Content Analysis" OR "Interpretative Phenomenological Analysis" OR "Thematic Analysis" OR "Narrative" OR "Focus Group*"	Experience* OR Coping OR Cope OR Perspective* OR Stories OR View OR Manage OR Adjustment OR Understanding OR Perception* OR Perceive OR Need* OR Impact	English Language Scholarly Peer reviewed Articles

Databases	Search terms combined using the Boolean operator 'AND'				Limits set
	Breast Cancer	Partners	Qualitative	Experience	
<p>3. Web of Science</p> <p>Key words:</p> <p>No Index term function available.</p>	<p>"Breast cancer" OR "Breast Neoplasm*"</p>	<p>Caregiver* OR Spouse* OR "Other Half" OR Carer OR Cohabiting OR Married OR "Significant Other*" OR Partner* OR Family OR Male* OR Men OR Husband* OR Couple*</p>	<p>"Qualitative" OR "Grounded theory" OR "Interview*" OR "Content Analysis" OR "Interpretative Phenomenological Analysis" OR "Thematic Analysis" OR "Narrative" OR "Focus group*"</p>	<p>experience* OR Coping OR Cope OR Perspective* OR Stories OR View OR Manage OR Adjustment OR Understanding OR Perception* OR Perceive OR Need* OR Impact</p>	<p>Document type: Article</p> <p>English Language</p> <p>NOT: "Prostate" OR "Gynecological" OR "Gynaecological" OR "Cervical" OR "Colorectal" OR "Ovarian" OR Colon (in title)</p>
<p>4. EMBASE</p> <p>Subject headings:</p> <p>Key words:</p> <p>Combined subject headings with key word search using OR</p>	<p>Breast Cancer OR Breast Neoplasm*</p>	<p>Spouse, Caregiver, Cohabiting person, Married person, Family, Marriage</p> <p>Caregiver* OR Spouse* OR "Other half" OR carer OR Cohabiting OR Married OR "significant other*" OR Partner* OR Family OR Male* OR Men OR Husband* OR Couple*</p>	<p>Qualitative research OR Qualitative analysis OR Interview OR Grounded Theory OR Content Analysis OR Phenomenology OR Thematic analysis Or narrative</p> <p>"Qualitative" OR "Grounded theory" OR "Interview*" OR "Content analysis" OR "Interpretative Phenomenological analysis" OR "Thematic analysis" OR "Narrative" OR "Focus group*"</p>	<p>Experience OR Coping behaviour OR Adjustment OR Comprehension OR Perception OR</p> <p>Experience* OR Coping OR Cope OR Perspective* OR Stories OR View OR Manage OR Adjustment OR Understanding OR Perception* OR Perceive OR Need* OR Impact</p>	<p>Journal article</p> <p>Human</p> <p>English language</p>

Databases	Search terms combined using the Boolean operator 'AND'				Limits set
	Breast Cancer	Partners	Qualitative	Experience	
<p>5. CINAHL</p> <p>CINAHL headings:</p>	Breast Neoplasms	Men Or Caregivers Or Spouses OR Significant Others OR Sexual Partners OR Married Men OR Male, OR Family	Qualitative Studies OR Phenomenology OR Phenomenological Research OR Grounded theory OR Interviews OR Thematic Analysis OR Content Analysis OR narratives OR Focus Group	-	Peer reviewed articles English language
<p>Key words:</p> <p>Combined 'CINAHL headings' with 'key word' search using Boolean operator 'OR'</p>	Breast Cancer OR Breast Neoplasm*	Caregiver* OR Spouse* OR "Other Half" OR Carer OR Cohabiting OR Married OR "Significant Other*" OR Partner* OR Family OR Male* OR Men OR Husband* OR Couple*	"Qualitative" OR "Grounded Theory" OR "Interview*" OR "Content Analysis" OR "Interpretative Phenomenological Analysis" OR "Thematic Analysis" OR "Narrative" OR "Focus Group*"	Experience* OR Coping OR Cope OR Perspective* OR Stories OR View OR Manage OR Adjustment OR Understanding OR Perception* OR Perceive OR Need* OR Impact	
<p>6. Medline</p> <p>MESH headings:</p>	Breast Neoplasms	Caregivers OR Spouse OR Family OR Marriage OR Male OR Men	-	-	Journal article English language
<p>Key Words:</p> <p>Combined 'MESH' headings with 'key word' search using Boolean operator OR</p>	"Breast Cancer" OR "Breast Neoplasm*"	Caregiver* OR Spouse* OR "Other Half" OR Carer OR Cohabiting OR Married OR "Significant Other*" OR Partner* OR Family OR Male* OR Men OR Husband* OR Couple*	"Qualitative" OR "Grounded Theory" OR "Interview*" OR "Content Analysis" OR "Interpretative Phenomenological Analysis" OR "Thematic Analysis" OR "Narrative" OR "Focus Group*"	Experience* OR Coping OR Cope OR Perspective* OR Stories OR View OR Manage OR Adjustment OR Understanding OR Perception* OR Perceive OR Need* OR Impact	

Appendix C

This table demonstrates how the findings from three of the synthesised papers contributed to the development of theme 2.

‘Gathering information: A strategy to reduce fear’

Paper	Findings	Description of the findings
Zahlis and Shands (1991) [61]	Negotiating the illness experience	Attempts to deal with the illness in the context of the health care system and the world at large. Becoming educated about the illness, arriving at treatment decisions. Pressure to understand the disease so they could help make treatment decisions. Waiting for surgery to be over. Waiting to see if the illness was cured. Frustration regarding how little is known about the treatment as well as problems encountered by physicians.
Zahlis and Lewis (2010) [62]	Mapping out a game plan	Strategies included exploring options, seeking to understand all the information, and finding the best doctor—someone with whom they were both comfortable. Spent time studying statistics, protocols, and treatment options. Questioned the doctors in an effort to understand the disease, its treatment and prevention, and to gain insight into their situation
Fitch and Allard (2007) [72]	Information needs were evident throughout the experience of breast cancer	Experienced worries and had questions. Not knowing about the disease, the treatment options or the anticipated outcome was disturbing for the partners. Equated cancer with death. Unexpected event in their lives. Sense of being unprepared and not having enough information. Assessing information and learning gained through experienced lessened fear. Understanding about recurrence heightened fear.

Appendix D

AMSTAR CHECKLIST (MODIFIED) FOR QUALITY ASSESSMENT OF SYSTEMATIC REVIEWS AND META-ANALYSIS

Study Validity Question	Assessment (Points)
1. Was there duplicate study selection and data extraction? There should be at least <i>two</i> independent data extractors and a consensus procedure for disagreements should be in place.	<input type="radio"/> Yes (1) <input checked="" type="radio"/> Partly (0.5) <input type="radio"/> No (0)
2. Was a comprehensive literature search performed? At least <i>two</i> electronic sources should be searched. The report must include years and databases used (e.g. PUBMED, EMBASE, etc.). Key words and/or MESH terms must be stated and where feasible the search strategy should be provided.	<input checked="" type="radio"/> Yes (1) <input type="radio"/> Partly (0.5) <input type="radio"/> No (0)
3. Were any restrictions applied regarding inclusion of publications (i.e. publication status, language, etc.)? The authors should state that they searched for reports regardless of their publication type. The authors should state whether or not they excluded any reports (from the systematic review), based on their publication status, language etc.	<input checked="" type="radio"/> Yes (0) <input type="radio"/> Partly (0.5) <input type="radio"/> No (1)
4. Was the scientific quality of the included studies assessed and documented? Study quality should be assessed utilizing standard assessment tools for randomized trials (e.g. Cochrane Risk of Bias Tool).	<input checked="" type="radio"/> Yes (1) <input type="radio"/> Partly (0.5) <input type="radio"/> No (0)
5. Was the scientific quality of the included studies used appropriately in formulating conclusions? The results of the methodological rigor and scientific quality should be considered in the analysis and the conclusions of the review, and explicitly stated in formulating recommendations.	<input type="radio"/> Yes (1) <input checked="" type="radio"/> Partly (0.5) <input type="radio"/> No (0)
6. If meta-analysis was conducted, were the methods used to combine the findings of studies appropriate (i.e. was it sensible to combine)? For pooled results, a test should be done to ensure the studies were combinable, to assess their homogeneity (i.e. Chi-squared test for homogeneity, I^2). If heterogeneity exists, a random effects model should be used.	<input checked="" type="radio"/> Yes (1) <input type="radio"/> Partly (0.5) <input type="radio"/> No (0) <input type="radio"/> NA
7. Was the likelihood of publication bias assessed? An assessment of publication bias should be included through graphical aids (e.g., funnel plot) and/or statistical tests (e.g., Egger regression test).	<input type="radio"/> Yes (1) <input type="radio"/> Partly (0.5) <input checked="" type="radio"/> No (0)
8. Was the conflict of interest explicitly stated? Potential sources of support should be clearly acknowledged in both the systematic review and the included studies.	<input type="radio"/> Yes (1) <input type="radio"/> Partly (0.5) <input checked="" type="radio"/> No (0)
Total (Percentage)*	4 (50 %)

Study Quality[†] Moderate Risk of Bias ▼

Section Two: Research Paper

The experience of friendships following a diagnosis of breast cancer

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Abstract

The aim of this study was to explore the experience of friendships following a diagnosis of breast cancer. Using a qualitative design, ten women who had received a diagnosis of primary breast cancer were recruited from breast cancer support groups and interviewed. Data were analysed using interpretative phenomenological analysis. Three super-ordinate themes were selected for further discussion. Receiving a diagnosis of breast cancer provided individuals with an opportunity to learn about the quality of their friendships. Existing processes that take place within friendships may be amplified by a diagnosis of breast cancer, causing individuals to assess and re-evaluate their friendships.

KEYWORDS *Breast cancer; chronic illness; friendship; social support; qualitative*

Introduction

Due to advances in the detection and treatment of cancer, more people are surviving a diagnosis of cancer and therefore living longer with the effects of the illness and its treatment (Erikson, Salsberg, Forte, Bruinooge & Goldstein, 2007; Samson & Zerter, 2003). The term ‘survivorship’ has been used to refer to individuals who have received a diagnosis of cancer and are living with its effects. The National Cancer Survivorship Initiative’s (NCSI, 2010) definition of survivorship includes individuals who are; in active treatment for cancer, in recovery from treatment, regarded as being cured from cancer, or diagnosed with advanced cancer. It has been noted that the increase in the number of survivors of cancer is generating new challenges for health professionals supporting those individuals (Arora, Finney Rutten, Gustafson & Hawkins, 2007). Cancer survivorship has therefore become an important focus within cancer research, directing attention to the longer term emotional and psychological effects of the illness and more specifically the evolving social support needs of people who are living with the long term implications of cancer treatment (Arora et al., 2007; Wong, Ki, Maharaj, Brown, Davis & Apolinsky, 2014).

Breast cancer accounts for 23% of all new cancer cases and is the most common type of female cancers worldwide (Jemal, Bray, Center, Ferlay, Ward & Forman, 2011).

Although men can also be diagnosed with breast cancer, this study will only focus on women who have been diagnosed with breast cancer. Specific prevalence rates of female breast cancer vary across different countries, however worldwide incidence rates are reported to be in excess of 1.68 million (World Health Organisation, 2012). Survival rates of breast cancer also vary due to differences in the awareness of the illness, and screening and treatment programmes available. However, the number of women surviving the diagnosis and living longer with the effects of the illness and its treatments is increasing, with approximately two thirds of women in the UK surviving breast cancer more than twenty years post diagnosis

(Cancer Research UK, 2011; Jemal, 2011). Nevertheless, the consequences from breast cancer treatments – which may include surgery, radiotherapy, chemotherapy and hormone therapy - are reported to be overwhelming, as many women are left with a number of difficulties including ongoing pain and swelling (Pedersen, Sawatzky & Hack, 2010; Polinsky, 1994). Furthermore, a qualitative and descriptive study exploring thirteen women's experiences of symptoms following the treatment of breast cancer noted participants to report a number of unexpected and ongoing symptoms such as reduced energy levels, pain, and impaired movement in their limbs (Rosedale & Fu, 2010).

Moreover, in addition to the physiological effects of breast cancer, women may also experience ongoing psychological difficulties. For example, women diagnosed with breast cancer are reported to be at greater risk of developing depression and severe anxiety (Burgess et al., 2005; Deshields, Tibbs, Fan & Taylor, 2006; Mehnert & Koch, 2008). Burgess et al (2005) explored the prevalence of anxiety and depression in a sample of 222 women diagnosed with early breast cancer, interviewing participants eight weeks post diagnosis, followed by subsequent interviews for up to five years. Using a psychiatric structured interview schedule, symptoms that corresponded with the diagnostic criteria of anxiety and depression from a version of the Diagnostic and Statistical Manual of Mental Disorders were elicited (DSM-III-R: American Psychiatric Association, 1987). Of the 170 women who provided complete data, nearly half of those participants presented with symptoms which met the criteria for a diagnosis of anxiety, depression or both in the first year post diagnosis, which then reduced to 15% five years post diagnosis (Burgess et al., 2005). Participants with longer term symptoms of anxiety and depression were also associated with a lack of confiding intimate relationships, demonstrating the need for interventions to focus on the improvement of women's social support needs (Burgess et al., 2005).

Many women also report feeling different from their previous selves as a result of the diagnosis and treatment of breast cancer, affecting their outlook on life and the relationships with those around them (Arman, Rehnsfeldt, Lindholm & Hamrin, 2002; Shapiro, Angus & Davis, 1997). Breast cancer has therefore been theorized as a chronic illness as those diagnosed often experience lifelong physiological and psychological difficulties and also changes in their social relationships (Boehmke & Dickerson, 2006; Polinsky, 1994). The conceptualisation of breast cancer as a chronic illness allows insights to be drawn from theoretical and empirical work in that field. For example, one of the most influential approaches to the understanding of chronic illness is the work of Bury (1982, 2001), who conceptualised chronic illness as a biographical disruption. Bury (1982, 2001) argues that when an individual is diagnosed with a chronic illness, the assumptions they hold about their life and their future are challenged. When faced with a chronic illness, an individual's life trajectory is therefore disrupted and thoughts of suffering and death are forced to the forefront of their mind (Bury, 1982). Moreover, the disruption caused by the diagnosis of a chronic illness is not only viewed by the individual but also recognised and influenced by those around them in their social context (Bury 1991). Following a biographical disruption, Bury (2001) also described a process of biographical repair by which individuals attempt to regain a previous sense of self, or develop a new identity when living with a long term illness.

Furthermore, using Bury's (1982, 2001) framework, Mathieson and Stam (1995) reported the diagnosis of cancer to not only demonstrate biographical disruption but also alter an individual's identity. Individuals diagnosed with a chronic illness such as cancer, therefore, often need to renegotiate their position within their social networks to account for the changes they have experienced as a result of their illness (Bury, 2001). Again, this process does not take place in isolation as an individual is reported to make sense of their experiences in the context of those around them (Adams, 2008). This is supported by

Brennan (2001) who highlights the need to recognise the disruptions caused by cancer within an individual's social world, drawing attention to studies exploring social support.

Indeed, research investigating the effects of social support demonstrates the interaction between women diagnosed with breast cancer and their close relationships, providing insight into their social context. Social support has been defined as a multidimensional concept, incorporating the support individuals receive from family, colleagues, health professionals and friends (House, Umberson & Landis, 1988). Furthermore, social support consists of emotional, informational, and material support, adding to the complexity of this broad concept (Landmark, Strandmark & Wahl, 2002).

A number of studies have reported social support to have a positive effect on women diagnosed with breast cancer. For example, a study exploring social support with 84 women who were considered to be in recovery from breast cancer found social support to reduce participants' anxieties and help them cope with the diagnosis and treatment phases of their illness (Dirksen, 2000). Similarly, women diagnosed with breast cancer who reported a greater number of people in their social network, with whom to discuss their difficulties, were found to have a greater chance of survival (Maunsell, Brisson & Deschênes, 1995). These findings demonstrate the benefits of social support in helping women cope with their diagnosis and the potential impact it can have on a woman's illness trajectory.

However, social support is not always helpful for women diagnosed with breast cancer. Research suggests that support from friends and relatives of women diagnosed with breast cancer can at times be overly optimistic and overprotective (Chantler, Podbilewicz-Schuller & Mortimer, 2005; Figueiredo, Fries & Ingram, 2004; Peters-Golden, 1982). A study by Arora et al (2007) also noted the timing of social support to be important for women diagnosed with breast cancer. Surveys exploring the helpfulness of the support received

showed that despite needing and wanting more long term social support, women experienced a reduction in social support within a year of their diagnosis (Arora et al., 2007).

Research suggests that the types of relationships within an individual's social support network may provide different forms of help and support for women diagnosed with breast cancer. For example, friends have been perceived by women diagnosed with breast cancer as helpful in terms of providing them with emotional support (Arora et al., 2007). Similarly, Bloom (1982) suggests that social support including that from friends is helpful for women with breast cancer as it reduces the amount of effort needed to cope with their diagnosis. Moreover, a study exploring the effects of social support on the survival of 133 women diagnosed with primary breast cancer highlighted a positive relationship between friendships and survival rates (Waxler-Morrison, Hislop, Mears & Kan, 1991). Using a multivariate analysis of the size of the participants' social networks, the number of supportive persons in their lives, the amount of contact they had with friends and the number of friends whom they regarded as supportive participants' social contexts were found to be important in terms of survival (Waxler-Morrison et al., 1991). Interviews with 18 women from this study found that they relied heavily on their friends for practical support in terms of transport to and from hospital appointments and help with childcare duties. It was also reported (Waxler-Morrison et al., 1991) that, for some, friendships changed as a result of their diagnosis as some friends struggled to manage their own discomfort of being around someone with a life threatening condition. Yet, how those changes were experienced by the individuals diagnosed with breast cancer was not explored. These findings suggest that friends, as an element of an individual's social support network, may provide a unique type and quality of support to a woman diagnosed with breast cancer that could usefully be explored further.

As more people are surviving a diagnosis of cancer and therefore living longer with the effects of the illness and its treatment, the evolving social support needs of those

individuals needs to be explored (Arora et al., 2007; Erikson, Salsberg, Forte, Bruinooge & Goldstein, 2007; Samson & Zerter, 2003; Wong, Ki, Maharaj, Brown, Davis & Apolinsky, 2014). Previous studies of women diagnosed with breast cancer have incorporated the exploration of friendships alongside the study of family members and health professionals, therefore capturing friendships within the broader concept of social support (Arora et al., 2007; Chantler, Podbilewicz-Schuller & Mortimer, 2005). However, research suggests that social support received from friends may provide women with a different type of support (Arora et al., 2007). A greater understanding of changes within the quality and nature of a woman's friendships is needed in order to understand how this discrete aspect of social support affects those diagnosed with breast cancer.

Research focusing specifically on women's experiences of their friendships following a diagnosis of breast cancer has, to the author's knowledge, not been conducted. In order to enable health professionals to develop interventions that incorporate the specificities of women's support needs, it is important to gain further understanding of women's friendships (Burgess et al., 2005; Waxler-Morrison, et al., 1991). Consequently, the aim of this study was to explore women's experiences of their friendships following a diagnosis of breast cancer. Using a qualitative approach, this study sought to understand how friendships were experienced and understood, what changes took place within those friendships and what sense was made of those changes. Rich data exploring individuals' experiences of friendships and what sense they make of those experiences could provide further understanding of how individuals renegotiate their position within their social networks to account for the changes they experience (Bury, 2001; Smith, 1996). Further understanding of social processes that may take place following a diagnosis of breast cancer could help individuals to manage changes experienced throughout survivorship.

Method

Design

To explore women's experiences of their friendships following a diagnosis of breast cancer, a qualitative methodological research design using interpretative phenomenological analysis (IPA) was adopted. This methodological approach was selected as the most suitable for exploring individuals' lived experiences (Smith, Flowers & Larkin, 2009). Through rich accounts of individuals' experiences, IPA allows the researcher to explore how an individual is thinking about and managing a complex health issue, enabling meaning to be drawn from participants' experiences while staying true to their own language (Chapman & Smith, 2002; Smith, 1996; Smith, Flowers & Larkin, 2009).

Procedure

Research Question.

The research question for this study was developed through observations made in clinical practice and through consultation with women who attended a breast cancer support group. Women who attended a breast cancer support group talked about how their friendships had changed following their diagnosis and how breast cancer had helped in their consideration of their own friendships. This prompted the researcher to think about how that may have been experienced.

Recruitment procedure.

A total of ten community based, patient-led breast cancer support groups across the North West of England and North Wales were contacted with regards to this study. The number of individuals who attended each group ranged from approximately eight to fifteen women. Information packs were e-mailed to the support groups, which were then distributed to its members via e-mail (see ethics section: protocol appendices B-E). The researcher was invited to attend one support group meeting to further explain the aims, rationale and target

sample of the study to its members. Individuals who met the inclusion and exclusion criteria of the study at that meeting were provided with a printed information pack.

Participants expressed their interest to take part in the study by contacting the principal researcher directly by phone, e-mail, or by returning a 'consent to contact' form (see ethics section: protocol appendix D). Participants were contacted by the principal researcher to ensure the inclusion criteria were met and to establish a suitable location to carry out each interview. During the initial contact with potential participants, questions were asked to illicit further information about their diagnosis. One woman who offered to participate in this research had received a diagnosis of metastatic breast cancer, indicating that the cancer had spread to different parts of her body, and therefore did not meet the inclusion criteria of this study.

A total of twenty women volunteered to participate in this study. Ten women were purposively selected from seven of the recruiting support groups. A maximum of two participants were selected from each recruiting support group to provide a range of participants from each group. The remaining ten women were contacted by phone or letter to thank them for their interest in this study (see appendix: B).

Participants

Ten women were purposively recruited from seven breast cancer support groups across the North West of England and North Wales, between September and December 2014. As the first year of diagnosis can be the most challenging time for an individual and her family, it was important that participation in this study did not pose any added pressure for participants (Stanton, Danoff-Burg & Huggins, 2002). Participants in this study had therefore received a diagnosis of primary breast cancer between January 2011 and August 2013, ensuring an appropriate gap between the date of diagnosis and their participation in this study.

Women who had received a diagnosis of metastatic breast cancer were excluded from this study, as they may have faced different challenges in terms of their treatments and prognosis. The rationale to exclude women with metastatic breast cancer from this study was supported by previous research. For example, a qualitative study exploring the experiences of women who used online support groups following their diagnosis of metastatic breast cancer reported their experience of breast cancer to feel different from those who had been diagnosed with primary breast cancer given the uncertainty they felt with regards to their future (Vilhauer, 2011).

The age of the participants ranged between 49 and 68 years ($M = 57$ years). Four of the women remained in employment, while the remaining six participants were retired from work. Three of the participants lived alone, five lived with their husband and two of the participants lived with their husband and children. The surgical treatments the women experienced following their diagnosis included a lumpectomy (five participants), a wide local excision (one participant), a mastectomy (three participants) and a double mastectomy (one participant). Three of the women also had a surgical procedure to remove their lymph nodes. Following surgery, eight women received chemotherapy; nine women received radiotherapy; and eight women received a combination of both chemotherapy and radiotherapy treatments. With the exception of long term hormone therapy, all but one of the participants had completed active treatment and was under review from the local hospital. One of the participants was awaiting reconstructive surgery.

Further details of the participants can be seen in table 1.

Insert table 1 here

Interviews.

Data were collated using semi-structured interviews, which were guided by a semi-structured interview schedule that was created by the principal researcher (see ethics section:

protocol appendix G). Broad questions regarding participants' diagnosis and treatment were asked at the start of the interview to set the context of the participants' experiences and help them to become more familiar with the interview process. The questions then narrowed in focus to explore the different aspects of participants' experiences of friendships. The interview questions were broad in nature, so as not to impose an understanding of the topic area on the participants' experiences (Smith, Flowers & Larkin, 2009). In concordance with an IPA approach, participants were provided space and time to explore and reflect on areas they deemed important (Smith, Flowers & Larkin, 2009).

Interviews were conducted over a two month period. Four women chose to be interviewed at their local cancer support centre, and six women were interviewed in their home. Lone worker policies were adhered to throughout. The purpose and process of the study was revisited prior to each interview taking place. Written consent and demographic information was also collated from each participant at that time (see ethics section: protocol appendices E & H). Interviews were participant led in order to develop a rapport and trusting relationship with the participants. The interview schedule (see ethics section: protocol appendix G) was used as a flexible guide to generate discussion and maintain the overall focus of each interview. The duration of the interviews ranged from 42 to 123 minutes ($M = 70$ minutes). Each interview was recorded using a digital Dictaphone.

Ethical concerns.

Ethical approval for this research project was obtained through the researcher's host academic institution (see ethics section: appendix B). At the start of each interview, participants were informed of confidentiality and its limits during the interview process. Participants were made aware that if the contents of the interview were considered to reveal a risk to themselves, or someone else, that the researcher would need to share that information with the appropriate professionals or agencies. During the interview process, a small number

of participants became tearful. The researcher provided participants with space and time to help them feel as comfortable as possible when expressing their emotion. The researcher asked participants how they were feeling at various times during the interviews and reminded participants that a break could be taken at any time. Participants were also reminded that they could withdraw their data from the study within two weeks of their interview date.

Data Analysis

Interviews were transcribed verbatim by the principal researcher. Transcriptions were a direct representation of the participants' words and did not include emphasis, intonations or pace of speech. Identifiable information was removed from each transcript prior to analysis to protect participants' anonymity.

Data were analysed using IPA. As transparency is an important measure of qualitative research, supporting documentation for each stage of the analytical process is provided (Smith, 2011; Yardley, 2000).

Each interview was listened to and read several times to establish familiarity with the data and acquire a holistic understanding of the participants' experiences. Initial notes pertaining to significant and interesting observations were made during this process. Detailed comments relating to the linguistic style, conceptual and descriptive content of each interview were recorded in the left margin of each transcript. Higher level emergent themes were noted in the right margin of each transcript and collated to establish clusters of themes for each participant (see appendix: C). Emergent themes were reviewed against the original data to ensure that identified themes remained true to the participants' accounts. A table was created for the elicited themes for each participant, along with a description of each theme and supporting quotes from the transcript. This process was repeated for each transcript in turn. Emergent themes from each transcript were collated and higher order themes were

constructed to establish convergent messages and meanings across the data set (see appendices: D -I).

Two transcripts were reviewed to explore the principal researcher's initial interpretations of the transcript data. Super-ordinate themes were also reviewed in supervision to ensure themes were representative of the data and further strengthen the trustworthiness of the interpretations (Elliot, Fischer & Rennie, 1999; Rodham, Fox & Doran, 2015; Smith, Flowers & Larkin, 2009). Participants' quotes have been used throughout to ensure that the findings stayed true to their experiences.

Super-ordinate themes, that were evident for at least half of the participants in this study, were considered to be recurrent and therefore represented in the findings of this study (Smith, 2011). The presence of the themes across the data set can be seen in table 2.

Insert table 2 here

Epistemological stance

The epistemological stance underpinning this study is that of critical realism which suggests that although data can inform us of a reality, it is not a direct reflection of an individual's reality (Harper & Thompson, 2011). This study involves the researcher making sense of participants' attempts to process and make sense of their experiences and therefore does not attempt to ascertain an objective truth.

Reflexivity.

As findings in IPA research are co-constructions of the participants' experiences and the researcher's interpretations of their experiences, I completed a reflexive diary to reflect upon my understandings and interpretations throughout (see appendix: J; Breakwell, Hammond, Fife-Shaw & Smith, 2006).

I approached this study with the assumption that friends would be there to help the participants in any way that they could and that support of any kind would be welcomed by

the participants. However, these findings demonstrate that a number of participants lost contact with some friends following their diagnosis, and that the support provided by friends and the support needed from friends did not always complement each other.

Many of the participants talked about not wanting to scare me when talking about their experiences of breast cancer. Being interviewed about a predominantly female illness by a woman may have affected their responses. Participants may have held back during the interview process as a way of protecting me from their difficult experiences. I managed this by reassuring the participants during the interviews and encouraging their contributions.

Findings and Discussion

In line with previous IPA papers, the findings are presented and discussed in the context of existing literature (Mistry & Simpson, 2013; Williamson, Simpson & Murray, 2008). It is important to note that participants' quotes have also been edited to improve the readability of the findings and to remove identifiable information. Edited quotes are represented using the following [...]. Pseudonyms have also been assigned to each participant to maintain anonymity.

Analysis of the data identified four major themes. The first theme explored how breast cancer acted as a platform where the expectations and the quality of the participants' friendships were tested. The second identified theme described how breast cancer affected the proximity between the participants and their friends. The third theme explored how breast cancer caused the participants to re-evaluate their time and how it was spent with friends. The fourth theme described how breast cancer provided the opportunity to develop friendships with those who had been through a similar experience. Friendships based on the shared experience of cancer provided a level of understanding that participants could not gain from other friendships. The value and benefit of support received from those who have been through a similar experience has been widely recognised by previous studies (Cope, 1995;

Lugton, 1997; Sherman, Rosedale & Haber, 2012). As the fourth theme does not generate novel or new understandings to this topic area, it was not included in the findings of this study (Yardley, 2000).

Theme 1: “You learn who your friends are”: Cancer acted as a platform to assess the quality of friendships

Breast cancer tested participants’ expectations of their friendships, causing them to re-evaluate their quality and value. Participants used various terms to categorise their friendships such as “close” (Mary), “distant” (Anne), “genuine” (Penny) and “inner circle” (Lilly). Participants described having “different layers” (Sue) of friendships from acquaintances to very close friends. These categories or layers of friendships appeared to be placed on a hierarchy with close friends at the top and more distant friends at the bottom. The different categories of friendships within those hierarchies were linked to expectations placed on those friendships.

While some friends met participants’ expectations following their diagnosis, other friends did not. As Sue explained, “people that you think are good friends, erm they don’t return the phone calls and you just don’t get to see them and they just drift away”. Brennan (2004) argues that assumptions can be made by an individual diagnosed with cancer with regards to how a friend might react and how those assumptions do not always fit with the reality of a friend’s response. Participants described feeling upset by friends who did not meet the expectations of their friendships. As Mary illustrated: “it was upsetting I think...we thought we meant more to them, than we obviously do”. Lack of contact and support from those who were thought to be close friends was interpreted as evidence that their friendship may have been valued differently by those involved. Individuals are reported to view their friendships as being mutual, in that they assume their friendships are valued in the same way

(Freeman, 1992). However, receiving a diagnosis of breast cancer appears to highlight the disparity between the categorisation of the friendship of each individual within the dyad.

One participant described how she had previously supported a close friend through a difficult experience and therefore expected that same level of support to have been reciprocated. For example, she explained how "...when you've been there for somebody, to think that they would be there for you...because like I say I've been there for her" (Tracey). Individuals are reported to assume that the friendship they have provided to another would be equal to that of the friendship they would receive (Bell, 1981). Again when these expectations were not met and support was not reciprocated, participants questioned the value of that friendship. These findings are supported by research which suggests that women expect their friendships to maintain balance and be reciprocal in nature (Moremen, 2008). However, when this balance within a friendship is disrupted and one individual feels as though they are not getting back what they had previously put into a relationship, the stability of that friendship is challenged.

In contrast to the expectations participants held of close friends, fewer expectations, if any at all, were held of those who were regarded as more distant friends. Consequently participants reported to have been surprised and therefore moved by the support received from distant friends. As one participant described;

Others who you may be weren't as close and you didn't realise they thought as much of you if you like, that they've now sort of come forward so I suppose yes there are people who you maybe wouldn't have expected necessarily to hear from who you have heard from you know...It's nice to think that people thought that much of you.
(Sarah)

Although similar acts of care and support were provided by friends across the different levels of friendships, the way in which those acts were evaluated by the participants

appeared to be strongly affected by their expectations. For example a visit from a close friend appeared to be an anticipated expression of care that was expected from that relationship. Yet a visit from a distant friend was more of a surprise to the participants as it had been unexpected from that level of friendship. These findings also demonstrated a disparity in the categories of friendships, as some distant friends appeared to have placed the participants in a higher category of friendship than participants had anticipated. Lydon, Jamieson and Holmes (1997) suggest that friendships develop between individuals that are regarded as acquaintances, when one of those individuals reaches out to the other which is then reciprocated over time. Breast cancer may therefore have enabled distant friends to reach out to the participants and therefore provided an opportunity in which friendships could develop.

Breast cancer acted as a platform where the expectations and the quality of friendships were tested. As one participant noted “oh I think you get to know who they, who you would perhaps say are the, your true friends...” (Ailsa). This was echoed by a number of participants who described breast cancer as an experience that helped them “learn” (Mary) more about the quality of their friendships. Therefore based on the actions of their friends, participants re-evaluated the positioning of their friendships within their hierarchies. As Anne explained “so they’re on my not so close friend list”. Another participant commented “...I thought I had more friends but really some of them were just fleeting visitors in my life” (Sue). This demonstrates how individuals whom Sue had previously thought of as ‘friends’ were downgraded within her hierarchy to ‘fleeting visitors’.

Theme 2: Proximity of friendships: Keeping friends at a distance or pulling them in close

Participants talked about the importance of the proximity of their friends during the treatment phase of their illness, with some wanting to maintain distance and others wanting to

pull friends in closer. Being held in mind by friends enabled participants to recognise that friends were there for them if and when they needed them.

Participants talked about sometimes feeling overwhelmed by support during their treatment and managed this by controlling the amount of face to face contact they had with friends. As one participant explained “I felt overloaded really and I mean that sounds awful because people are obviously wanting to do what they can and they’re concerned and whatever...there’s only, so much you can deal with on a daily basis” (Ailsa). Although recognised as an expression of care, the physical presence of friends was not always what participants wanted or needed at that time. Women described being physically unwell and busy with hospital appointments, as Tracey explained “you’re tired and you’re, you’re feeling ill, you don’t want to be mithered [bothered]”. Another participant noted “I don’t know if I could’ve coped with a lot more people coming round to see me all the time” (Anne). Although well intentioned, visits from friends during the treatment stage were perceived to be an exhausting, added stressor with which many participants felt unable to cope. These findings are supported by a review of literature which reports that social support can actually be perceived as stressful and therefore increase the risk of negative health outcomes (Burg & Seeman, 1994). The emotional efforts participants needed to cope with their own feelings and the feelings of their friends during that time may have proved too difficult and therefore managed by avoiding contact with friends (Hochschild, 1979; 1983).

For some participants, visits from friends were regarded as an unusual situation. As Mary reported saying to her friend “you don’t have to come see me, I’m not used to you coming to see me every day”. She further described a situation where she returned home to find her house full of friends and reported “...I looked at everybody and I said ... if I get that many people here when I’m diagnosed I’m going to have a hell of a wake” (Mary). Friends being in her home prompted her to think about the seriousness of her illness and the threat it

posed to her mortality. These findings echo with Bury's (1982) biographical disruption framework which suggests that when faced with a chronic illness, death is forced to the forefront of an individual's mind.

Feeling prepared and in control over the physical proximity of friendships was important. As one participant described, "...if you're not wearing your wig or whatever...do you want somebody just appearing?" (Janet). For Janet, it was important that she could prepare for visitors by putting on her wig. Another participant talked about how friends telephoned first to ask her if she was well enough for visitors. As she illustrated "nobody sort of came round without ringing first and saying, 'are you up to having visitors?'" (Ailsa). These findings suggest that participants may not have wanted to be seen as being 'unwell' by their friends even though they knew they were being treated for a serious illness. Being unwell may not have fit with the identity that they wanted to portray to their friends and was therefore hidden from their friends. Research notes that some individuals diagnosed with cancer report interactions with those outside of the family to be strained, as friends and acquaintances can display similar levels of mental anguish to the individual diagnosed with cancer (Dunkel-Schetter, 1984). Participants may have therefore wanted to maintain a physical distance, as a way of protecting themselves from the reactions of their friends.

While some participants minimised face to face contact, others pulled friends in closer and increased the amount of contact they had with friends. Participants who wanted more contact were transparent in that need and encouraged this form of support from their friends. As one participant explained "so really every day somebody did pop round ... and drop in which was great because it did take my mind off it and make me feel more normal" (Penny). This participant encouraged friends to visit and talk about "normal" (Penny) things which distracted her from her illness. Visits from friends may have helped some participants

maintain a sense of normality, when normality was otherwise disrupted by breast cancer (Bury, 2001).

Even though participants may not have wanted to see their friends, it was important to know that they were still there for them and holding them in mind. Contact in the form of emails, text messages, cards, and flowers showed participants that friends were thinking of them and cared about them. As one participant explained "...somebody who cares enough to pick up the phone or pop a card in the post and just that they care how you are, do you need anything?... Just little touches, doesn't need to be a grand gesture" (Sue). Another participant explained: "I knew if I picked the phone up, if she was able she would drop everything and come... she would be there for me... no matter what" (Janet). It was important that participants felt able to rely on their friends and trust that their friends would be available if and when they needed them. "Just knowing that they were there" (Lilly) was reassuring and enough for some participants. Friends therefore acted like a safety net in that participants did not always need or want to see them but needed to know that they were there. These findings were similar to a previous study (Woodgate, 2006) which explored the perspectives of social support for young people diagnosed with cancer. Woodgate (2006) found that the psychosocial-emotional presence of others was reported to be more important than their physical presence. This highlights the value of friends holding participants in mind and 'being there' for them, even if they are not always there in the physical sense. This process may have been facilitated by social media technologies which enabled participants to maintain virtual contact with their friends as a number of participants reported to communicate with their friends by "text" (Lilly) and "e-mail" (Ailsa; Vallor, 2012). For some, informing friends of their diagnosis was "a lot easier" by e-mail "than telling somebody face to face" (Anne). It has been argued that on-line communications may enhance existing friendships as they provide individuals with more choice in 'how' they

present themselves and 'when' they respond (Briggle, 2008). Communication by text and e-mail may have therefore provided participants with a greater sense of control within their friendships during that time.

Theme 3: Time as a currency: Paying friends back with time

Following a diagnosis of breast cancer, time and how that time was spent with friends was re-evaluated based on the time and effort they had received from friends during their illness. Friends provided participants with emotional and practical support in a number of different ways. As Lilly explained "I had a lot of friends coming, you know, just for a chat and a, a coffee ... I had friends round here washing my hair ... anyway that they could really" (Lilly). Another participant said "...I had one friend who did my ironing for nine months" (Andrea).

The time provided by friends and the support given was recognised and "really appreciated" (Penny) by participants. Similarly, Lilly explained that she had "... appreciated the time...you know lives are busy aren't they...?". Time was therefore evaluated in the context of friends' lives and valued highly from friends who were perceived to have little time to spare.

Participants were more comfortable talking about the time and effort they had received from friends by emphasising how it would be repaid in the future. For example one participant noted "it's what I would've tried to do for them" (Andrea). Similarly, Lilly explained "...I would be there for them you know if God forbid anything happened...". Time and effort were therefore regarded as resources that had been exchanged between the participants and their friends, and would be reciprocated in the future (Foa, 1973).

Participants described ways that they had supported their friends since their diagnosis and therefore already begun to reciprocate the support they had previously received. For example, Sarah said "you try to respond in the way they've been with you really". The

support received appeared to have been banked by the participants, ready to be repaid to their friends as and when needed. These findings are supported by Sprecher (1992) who suggests that there are two forms of exchange orientation in close relationships: worry about obtaining less than what had previously been invested into a relationship, and worry about obtaining more from a relationship than could not be returned. Participants therefore wanted to offer the same support in terms of time and effort that they had received to maintain an equal balance within their friendships (Moremen, 2008).

When faced with breast cancer participants were forced to re-evaluate how they spent their time. As one participant explained "...it sort of makes you aware of your erm, mortality...we don't really have very long on this earth..." (Sue). The assumption that their time was unlimited had therefore been challenged by the diagnosis of breast cancer (Bury, 1982). The re-evaluation of time caused participants to reconsider how their time would be best spent: as one participant described:

I think because you realise life's too short really... You know, that none of us know what's round the corner, and I think in that respect you need to have the chance to let people know yes, ... you do like them and you are friends with them and you would do anything for them. (Sarah)

Participants talked about giving friends their time as a way of demonstrating a friend's importance and as a way of showing friends how much they meant to them. Participants also withdrew time from friends who had not been supportive to them during their treatment. As time was not offered to participants by those friends when they needed it the most, participants did not want to give them their time and reinforce a one-sided exchange (Moremen, 2008). For example, Sue illustrated "well I don't want time wasters in my life because our time on this planet is limited... people who aren't prepared to make it a two-way thing ...". A diagnosis of breast cancer caused participants to review their friendships, as it

had made them more aware of unequal friendships. Similarly, one participant also stated "... life's too short, erm, to spend time with people like that, I think I'd rather spend the time I've got ... with the true friends that were there even when I was a bit miserable" (Penny). As those friends had not been willing to spend time with her when she was 'miserable' and unwell, Penny believed them to be undeserving of her time now that she felt happier. She went on to further explain how "they're only after the fun times it's not about friendship then is it?" (Penny). Penny's concept of a 'true' friendship was someone who would be there for her through the good times and the bad. When friends were not able to be there for her through the difficult times, it caused her to question how those friends fit with her concept of friendship. Time was therefore regarded as a precious commodity following a diagnosis of breast cancer and should not be wasted on people who did not deserve it.

Strengths and Limitations

The research question for this study was co-constructed with the 'experts' in this area (Britt, 2013) through consultation with women who attended a breast cancer support group. A further strength of this study was that participants were able to choose the time and location in which their interview was carried out therefore increasing participants' accessibility to this study. This may have also helped participants to feel more relaxed during the interview process, as they were able to select a setting most suited to their needs.

The diagnosis of breast cancer coincided with retirement for a small number of participants in this study. Retiring from work may have also been a moment of significant change and an important transition in participants' lives. Including work status as a recruiting criterion could have strengthened the homogeneity of the sample. The homogeneity of this sample could have been further strengthened by including age as a recruitment criterion, as the experiences of friendships may have been different for participants in their 40s from those in their 60s. It may have also been helpful to have included treatments

received as a recruitment criterion as two of the participants in this study did not receive chemotherapy. This may have affected their physical wellbeing and therefore their experience of friendships.

During analysis, it would have been helpful to carry out second interviews with participants to seek further meaning and clarification of their responses. However, as time was reported to be very precious for the participants it did not feel appropriate to take up more of their time. This study provides a clear analysis trail, ensuring transparency of the analysis process and strengthening the findings of this study. Supervision was also used to review initial interpretations of transcript data and identified themes to further strengthen the trustworthiness of the interpretations (Elliot, Fischer & Rennie, 1999; Rodham, Fox & Doran, 2015; Smith, Flowers & Larkin, 2009).

Future Research

Participants in this research were recruited through breast cancer support groups and may therefore have been dissatisfied in some way by the support received from their existing friendships. It may be useful for future research to explore the experiences of women who do not attend breast cancer support groups, to see how their experiences of friendships differ.

It may also be helpful for future research to explore the experiences of the friends who were reported to have distanced themselves from the participants or who were described as being unsupportive following the participant's diagnosis, to gain further understanding of how they had experienced their friends' diagnosis. However, accessing this population could prove challenging as those deemed to be unsupportive may feel embarrassed by how they responded to their friends' illness. It may be more appropriate to gather data from this population using a survey, to enable individuals to anonymously explore potentially difficult emotions.

Summary of the Findings

The aim of this study was to explore the experience of friendships following a diagnosis of breast cancer. Using a qualitative design, ten women who had received a diagnosis of primary breast cancer were recruited from breast cancer support groups and interviewed. Data were analysed using interpretative phenomenological analysis. Three super-ordinate themes were selected and discussed based on the level of new understanding they brought to this area (Yardley, 2000). Breast cancer acted as a platform where the expectations and the quality of friendships were tested. Breast cancer also affected the proximity between the participants and their friends. Regardless of the distance, it was important that participants felt held in mind by their friends through small gestures of care. This helped participants know that their friends were there for them, should they need them. Receiving a diagnosis of breast cancer also caused participants to re-evaluate their time and how it was spent.

Conclusion

The support offered by friends following the diagnosis of breast cancer provided participants with an opportunity to learn more about the quality and value of their friendships. Normal processes that take place within friendships appeared to have been amplified by the diagnosis of breast cancer, causing participants to assess and re-evaluate their friendships. Breast cancer therefore shines a light on friendships, magnifying the disparity between the categorisation of friendships, and makes imbalanced friendships appear more prominent (Freeman, 1992; Moremen, 2008).

Survivors of cancer are said to occupy a 'liminal' space, in that they are able to pass through the illness but are unable to return to the space they occupied before their diagnosis (Navon & Morag, 2004). Participants described how they had faced a life threatening illness, which forced them to re-evaluate how they spent their time and with whom. They continued

to associate themselves with cancer by attending cancer support groups, maintaining cancer within their lives and as part of their new identity (Mathieson & Stam, 1995). Participants also reported experiencing changes within their friendships following their diagnosis. Such changes may not be shared by friends, therefore forcing individuals to renegotiate their altered self within their social world (McKenzie & Crouch, 2004). These findings therefore support Bury's (2001) concept of biographical repair as participants renegotiated their social positioning following a diagnosis of breast cancer.

Implications for Clinical Practice

These findings provide further insight into how women experience friendships following their diagnosis, which could help health professionals to better support women by helping them to make sense of their experiences throughout survivorship, and facilitate the process of biographical repair (Bury, 2001). Having a greater understanding of how breast cancer may impact on friendships may provide women with a greater sense of control, helping them to think about what support they would want from their friends and how they could communicate that need. By asking questions about friendships, health professionals adopt a holistic approach to a woman's care needs and acknowledge that such changes may occur.

The ways in which breast cancer may affect a woman's friendships could be added to information provided to women following their diagnosis to highlight the potential changes they may experience following their diagnosis. Clinical psychologists could also use the findings of this study to develop and evaluate interventions tailored to friendships, to raise awareness of the potential changes women may experience and how those changes could be managed throughout survivorship.

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TABLE 1. Participant details

Participants	Age	Ethnicity	Date of diagnosis	Support group	Surgical treatment	Chemotherapy and/or radiotherapy	Awaiting further treatment	Living status	Working status	Length of interview (minutes, seconds)
Mary	57	British	September 2012	A	Double mastectomy	Chemotherapy	No	Lives with husband	Retired	81.5
Lilly	45	White British	May 2011	B	Lumpectomy	Chemotherapy and radiotherapy	No	Lives with husband and children	Working	47.58
Ailsa	68	White British	April 2012	C	Mastectomy	Radiotherapy	No	Lives with husband	Retired	55.21
Sue	63	White British	January 2011	C	Lumpectomy Lumpectomy and removal of lymph nodes	Chemotherapy and radiotherapy	No	Lives alone	Retired	42.24
Janet	65	White British	July 2013	D	Wide local excision and removal of lymph nodes	Chemotherapy and radiotherapy	No	Lives alone	Retired	123.59
Anne	57	White British	March 2013	E	Lumpectomy and removal of lymph nodes	Chemotherapy and radiotherapy	No	Lives alone	Retired	78.17
Sarah	62	Scottish	August 2013	F	Lumpectomy and removal of lymph nodes	Radiotherapy	No	Lives with husband	Retired	59.24
Tracey	54	White British	August 2012	G	Lumpectomy	Chemotherapy and radiotherapy	No	Lives with husband	Working	50.02
Penny	54	White English	December 2012	G	Mastectomy	Chemotherapy and radiotherapy	No	Lives with husband	Working	70.50
Andrea	49	White British	May 2011	D	Mastectomy and removal of lymph nodes	Chemotherapy and radiotherapy	Yes: Reconstructive surgery	Lives with husband and children	Working	99.28

TABLE 2: Distribution of themes

Participants	Theme 1:	Theme 2:	Theme 3:	Theme 4:
	“You learn who your friends are”: Cancer acted as a platform to assess the quality of friendships	Proximity of friendships: Keeping friends at a distance or pulling them in close	Time as a currency: Paying friends back with time	“It’s like, if you’d not had a baby... I don’t think you really know what it’s like”: Developing friendships through the shared experience of breast cancer
Mary	X	X		X
Lilly	X	X	X	X
Ailsa	X	X	X	
Sue	X	X	X	X
Janet	X	X		
Anne	X	X	X	
Sarah	X	X	X	X
Tracey	X	X		X
Penny	X	X	X	X
Andrea			X	X

Appendix A

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Book:

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Contribution to a Book:

Hartley, J. T., & Walsh, D. A. (1980). Contemporary issues in adult development of learning. In L. W. Poon (ed.),

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Appendix B

Letter of Thanks



*Lancaster University
Doctoral Programme in Clinical Psychology*

Dear X,

Thank you for offering to take part in my research about friendships following a diagnosis of breast cancer. As I have now interviewed ten women about their experiences, I will not be carrying out any further interviews.

Thanks again for getting in touch though, I really appreciate it

Kind regards,

Nicola Edwards
Trainee Clinical Psychologist
n.edwards@lancaster.ac.uk

Appendix C

Transcript excerpt to demonstrate notations and emergent themes

Participant 7: Sarah

Initial Notations	Line N.O.	Original Transcript	Emergent Themes
<p>Breast cancer brought her closer to some friends</p> <p>Colleagues: not thought of as friends. Category?</p> <p>Unexpected reaction/support offered</p> <p>Was not previously regarded as a 'close' friendship</p>	<p>748</p> <p>749</p> <p>750</p> <p>751</p> <p>752</p> <p>753</p> <p>754</p> <p>755</p> <p>756</p> <p>757</p> <p>758</p> <p>759</p> <p>760</p> <p>761</p> <p>762</p> <p>763</p> <p>764</p> <p>765</p>	<p>I: Erm, When you talked about, the, your friends reactions of your work colleagues friends, you described it as being unbelievable, can you tell me a bit more about that</p> <p>R: Erm, I think the <u>closeness</u> with some of them, you know what I mean</p> <p>I: Yes</p> <p>R: And maybe you had, <u>I'd always been friends</u> with them but it was, and we'd maybe go for the occasional drink, it wasn't a <u>close friendship</u> they were just <u>working colleagues</u> you know what I mean. But they were, <u>really really</u> nice do you know what I mean, you know I think, <u>I wasn't expecting them not to be nice</u> that sounds silly but erm, more sympathetic I think than I thought they would have been maybe</p> <p>I:I was going to say what did you expect then</p> <p>R: I don't know really, I don't know what, I don't know what you expect really in that situation</p> <p>I: yes</p> <p>R: But maybe, maybe not, not all, but maybe there's the few you, I didn't expect it from you know</p> <p>I: Yes</p>	<p>Cancer brought distant friends closer</p>

Initial Notations	Line N.O.	Original Transcript	Emergent Themes
<p>Friends- effort, saw a lot of her</p> <p>Hugs; expression of care, not expected</p> <p>Work friends thought more of her than she had thought of them- different category?</p> <p>‘Just’</p> <p>Categorisation of friends</p> <p>Surprised by their reaction</p>	<p>766</p> <p>767</p> <p>768</p> <p>769</p> <p>770</p> <p>771</p> <p>772</p> <p>773</p> <p>774</p> <p>775</p> <p>776</p> <p>777</p> <p>778</p> <p>779</p> <p>779</p> <p>780</p> <p>781</p> <p>782</p> <p>783</p> <p>784</p> <p>785</p> <p>786</p>	<p>R: the reaction do you know what I mean. Like there was the, the the school secretary, she was lovely and I was friends with her and she would do, she did loads of work for me I was always in and out getting something and, erm, when I went in there it was ahh big hugs and everything which I wasn’t expecting really</p> <p>I: Rights</p> <p>R: No, do you know what I mean sometimes. Yes</p> <p>I: What was that like if you’d not expected that sort of response</p> <p>R: Erm, it was nice in a way to think that people thought that much of you if you like, you know because you didn’t, you don’t think they do you’re just, work colleagues do you know what I mean</p> <p>I: Yes</p> <p>R: Yes so, and as I say there was the odd person who were just acquaintances with who were very nice you know but you didn’t, didn’t expect it really (interview interrupted by dog barking at the postman)</p> <p>R: Yes so, and as I say there was the odd person who were just acquaintances with who were very nice you know but you didn’t, didn’t expect it really, you know</p> <p>I: Yes, acquaintances</p> <p>R: Just through work and things you know</p>	<p>Expectations of friendships based on categorisation of friendships</p>

Major theme

Appendix D

A table to illustrate the formation of a major theme

This table shows the emergent themes and supporting quotes that contributed to the formation of a major theme for participant 2 ‘Lilly’. This major theme contributed to the super-ordinate theme 3 of the findings: ‘Time as a currency: Paying friends back with time’

Major theme	Emergent themes	Supporting quotes
<p>Time and effort as a reciprocal currency within friendships</p>	<ul style="list-style-type: none"> • Friends gave her time- showed they cared, made her feel important • Time is precious • Makes time with friends- a priority now • Gives time to her friends to show how important they are to her • Care shown in the amount of effort given • Gives friends time because that’s what she values, rewards them with time • Pattern of friendships changed as a result of cancer (increased effort) • Time as a currency, pays them back with time • Friendship as a reciprocal process • Important to see friends as life is short • Changed friendships – more accommodating now, increased flexibility • Banked support would pay friends back • Would reciprocate the effort- would pay them back • Friends valued part of her life- shows them that value with time • Friends appreciate her more now as nearly lost her to cancer 	<p>“I think it’s the same for them as well you know so, erm, I felt quite important actually them all coming round and, erm, yes, I appreciated the time and I know, you know lives are busy aren’t they you know mines hectic at the moment but you know if somebody phoned me and said, you know I need to talk to somebody I’d be there like a shot”</p> <p>“So yes I mean it was, I guess I know that she I would’ve done the same for her if there’d been you know if she’d...Been the other way around you know tried to, yes...”</p> <p>“Erm well we see each other more now, we do a lot more things together now, erm, although we did do things before but, yes, we’re in contact more now I would say. I see you know I see my I go I go out and see my friends at least I see at least one set of friends a week “</p> <p>“Erm, I think it’s made me appreciate life a bit more, erm, I do things now that I wouldn’t have dreamed of doing erm, and I want to do more things, you know it’s sort of, I think, it I think it opens up your eyes and things, and makes you think ... I just I just do more with them now [friends] whereas like I said before I you know could maybe 2 months without even seeing them but now I you know will make a point of, I’ve got different circles of friends of seeing them quite regular, on a regular basis or going away with them”</p> <p>“but the same for me for them really, I’m always going to be there for them”</p> <p>“Ah it meant a lot to me obviously erm, definitely, yes they looked after me, yes I would be there for them you know if God forbid anything happened yes”</p> <p>“I I rely on them much as what they rely on me really because you know life’s not been easy for them a lot as well so they’ve all got a story to tell and erm, yes, ... there’s four of us that stuck together for god knows how many years”</p>

Appendix E

A table to illustrate the major themes used to develop theme 1: “You learn who your friends are”: Cancer acted as a platform to assess the quality of friendships.

Participant	Emergent themes	Major theme(s) identified for each participant
Mary	<ul style="list-style-type: none"> • Level of friendships linked to intensity of initial response • Different groups and categories of friendships • Unexpected reaction from friends due to levels of friendships 	Expectations of friendships based on levels
	<ul style="list-style-type: none"> • Cancer acted as a platform to show the quality of friendships • Friends responses changed the value placed on friendships • Distant friends reclassified 	Cancer enabled her to assess the quality of her friendships
Lilly	<ul style="list-style-type: none"> • Expected to lose some friends • Friends exceeded her expectations • Expectations of her friends fit with her reality 	Expectations of friendships
	<ul style="list-style-type: none"> • Proven their friendships, given her evidence re: quality • Evaluation of friendships (stronger, extremely important) • Show vulnerability to friends and they would still be there, made them stronger • Cancer tested the strength of the friendships • Friendships developed- made them stronger • Actions demonstrated the quality of friendships 	Cancer acted as a stage in which the quality and strength of her friendships could be observed
Ailsa	<ul style="list-style-type: none"> • Cancer brought her closer to some friends and created distance with others • Friendships changed due to lack of care shown by some friends during treatment • Different levels of friendships • Re-evaluate levels/categories of friendships 	Re-evaluation of friendship levels

Participant	Emergent themes	Major theme(s) identified for each participant
Ailsa	<ul style="list-style-type: none"> • Levels of friendships determined how she felt about their responses • Upset when friends she had expected to be supportive were not • Upset when friends who she thought were close, did not get in touch • Friendships as a reciprocal process- upset when doesn't happen as broke an unwritten contract 	Expectations of friendships based on levels, levels re-evaluated based on friends actions
Sue	<ul style="list-style-type: none"> • Cancer deepened friendships, develop quality • Levels/layers of friendships • Loss of friends- showed that they were not true friends • New friends made during treatment with cancer fulfilled a need at the time, not enough to create a lasting friendship • Presence, effort and time= assessment of quality, showed they care, richness of friendships • Assessment of levels of friendships based on time and experience • Received unhelpful support from more distant friends 	Layers of friendships
	<ul style="list-style-type: none"> • Cancer provides a platform to show/test friendships • Cancer provided an opportunity for friendships to prove themselves • Some avoided her as if cancer was contagious- scared by cancer • Friends unable to reciprocate care= loss • Cancer created distance with some friends • Loss of friendships felt hurtful • Lack of effort and time= lack of care • Cancer too difficult for some people to be around • Cancer was a test of friendship • Loss of friends- showed that they were not true friends 	Cancer as a platform in which the quality of friendships were tested
Janet	<ul style="list-style-type: none"> • Past experiences of support from friends- contributed to expectations • More surprising to receive care from those not deemed close • Support naturally occurring from friends 	Expectations of friendships based on past experiences and levels

Participant	Emergent themes	Major theme(s) identified for each participant
Anne	<ul style="list-style-type: none"> • Support only unconditionally accepted from close friends • Felt guilty if accepted support from friends not so close to- lack of reciprocity • Categories/levels of friendships • Only showed vulnerability to friends really knew • Unhelpful advice offered by distant friends • Support received from distant friends interpreted as guilt (that they had not made an effort) • Expected vs unexpected support • Role of friendships was to offer support- not her role to ask • Valued the offer of support- limited herself to how much accepted 	<p>Expectations of support and the type of support she was able to accept was established by pre-existing levels within her friendships</p>
	<ul style="list-style-type: none"> • Process of learning about friendships • Movement of friendships between levels based on actions • Cancer- platform to show quality of friendships • Cancer maintained contact with people not expected to • Movement of friends between levels based on actions • Cancer put friendships under the spotlight • Cancer rekindled old friendships 	<p>Cancer put friendships under the spotlight: re-establishing the quality and levels of the friendships</p>
Sarah	<ul style="list-style-type: none"> • Classification/levels impact on expectations • Unexpected reaction from some due to level of friendship • Expectation based on friendship levels • Evaluation of friends- surprised by reaction -not what she had expected • Evaluation of friendships • Levels of friendships • Unexpected support due to friends age and level of friendship- valued highly • Levels of friendships linked to expectations of friendships. 	<p>Expectations of friendships based on perceived levels/categories of friendships</p>

Participant	Emergent themes	Major theme(s) identified for each participant
Tracey	<ul style="list-style-type: none"> • Made allowances for family members who distanced themselves during treatment but not for friends- expected more • Upset when expectations from friendships not met • Expected support from a friends- more upsetting when not received • Best friend had invested a lot into the friendship, expected a return on that investment • Upset when support from a friend not reciprocated as she had supported her- not got back what she put it, unexpected • Support received made her question a friendship • Levels of friendships - best friend came with expectations • Re-evaluations of level of friendship lost due to actions • Friends tell each other their problems- reciprocal process 	Expectations of friendships based on friendship level
Penny	<ul style="list-style-type: none"> • Contrast in expectations of friendships and levels of support • Expectations based on levels of friendships • Closeness to new friends unexpected • Expectation of friends did not fit with reality • Expected friends to be supportive • Levels of friendships 	Expectations of friendships based on assessed levels of friendships
	<ul style="list-style-type: none"> • Tested friendships after treatments, see what she means to them • Testing friendships now to assess impact of cancer • Friends move between levels of friendships based on actions • Cancer acted as a platform to show quality of friendships 	Cancer tested the quality of her friendships

Appendix F

A table to illustrate the supporting quotes used to develop theme 1:

“You learn who your friends are”: Cancer acted as a platform to assess the quality of friendships.

Participant	Supporting Quotes
Mary	<ul style="list-style-type: none"> • <i>“When you’re diagnosed you do think about death...so much so I gave one of my closest friend who was our bridesmaid 37/8 years ago, I gave her the songs I wanted, I know that sounds awful, I wanted the right songs”</i> • <i>“I I’ve got friends in all sorts of do you know what I mean... Then I’ve got very very good friends, that I’ve had for years and I’ve got nursing friends from the hospice and counselling friends”</i> • <i>“So she, she did get upset with me on the phone because we’ve known each other for a long time”</i> • <i>“One of my friends, yes, one of my, who was a very very close friend, I , I gave, I put it down to the fact that she couldn’t face me. Erm, we were very close, the four us you know husbands and, and wives gone on holiday lots together, erm, she changed, erm, and I and I and I don’t know why. Erm, She suddenly stopped ringing, erm, didn’t phone. I went into hospital, she didn’t come to see me. Erm, and even, I tried to give her an olive branch, ...I rang and left a message on her answer phone, she still didn’t ring”</i> • <i>“It was upsetting I think, and and I think ...we thought we meant more to them, than we obviously do. They are the only couple that erm, have just managed to just cut themselves off from us, totally, totally. They did come and see me, gosh 2 months ago, erm, but then that was it.... And yet my husband has phoned X, the husband, so he will have seen a missed call on his, it was only just to say hi how are you, but I just think maybe they just, I don’t know, I honestly don’t know if maybe they feel guilty, because they’ve let it go too long”</i> • <i>“Whether she can’t face me, I wouldn’t have put her down as that because she’s a very kind person, erm, maybe she just wants to cut herself off</i> • <i>“you learn who your friends are don’t you”</i>

Participant	Supporting Quotes
Lilly	<ul style="list-style-type: none"> • <i>“I think it’s made them stronger”</i> • <i>“Yes, erm, they’re quite, obviously they’re quite strong aren’t they, that you know they were strong before, I think it just made it you know, made that, you know, I’ve got close circles of friends and just made it stronger really”</i> • <i>“... I suppose it felt as though, that they were you know that they were good friends really that I could rely on them to erm, you know, take up the time to do that”</i> • <i>“ like I say the best thing that they done was didn’t run so, that was all I could err wish for”</i> • <i>“I think you know I’ve got friends and then I’ve got, you know as you do I’ve, you have err an inner circle of friends and then a bit of an outer circle and then a bit more friends that you know, and even the ones that you know who the ones that I don’t really see, they were quite supportive too”</i>
Janet	<ul style="list-style-type: none"> • <i>“I’ve had a lot of support from my close friends”</i> • <i>“... she’s always been a good friend”</i> • <i>“... the few friends I do have are very precious to me”</i> • <i>“...you know I have, good, solid, friendships that mean a heck of a lot to me...”</i> • <i>“we’re not that close but, but we are very clo, we both supported each other through our divorce”</i>

Participant	Supporting Quotes
Ailsa	<ul style="list-style-type: none"> • <i>“I did have a couple of people who were, I thought close to me, and knew I wasn’t well but didn’t ring me or get in touch”</i> • <i>“People I saw on a fairly regular basis, used to go out for a meal with maybe once a month, a group of us and there were two people in that group that never rang at all...It was quite hurtful really ... I just thought well that’s perhaps the kind of person she is, maybe she can’t deal with it”</i> • <i>“No, but then I think that’s, I mean this was somebody I worked very closely with for probably ten years, she was my deputy you know”</i> • <i>“Yes we still meet up but I think it’s changed perhaps the...The erm, the way I feel about her, yes”</i> • <i>“Oh I think you get to know who they, who you would perhaps say are the, your true friends don’t you”</i> • <i>“The ones that erm, and some people surprise you I think, people perhaps that you thought, wouldn’t be as concerned end up being a good friend you know one particular person that I worked with, not particularly close to erm, ended up being very supportive and coming to see me and she brought me, she brought me things like books and, because it wasn’t always particularly flowers that you wanted it was something to keep you occupied really...I think people surprise you don’t they and how erm, as I said the people that you think perhaps were your closest and your best friend’s...Don’t necessarily, erm, become that, it’s sometimes somebody else who’s stepped in instead”</i> • <i>“... you get to know people better don’t you and I’ve certainly got to know her better from that erm, but I think you get to know people better anyway because it’s how they react which is what we were saying before”</i> • <i>“...I suppose that’s the one person who’s become more of a friend since the diagnosis”</i> • <i>“Well I, I mean I think really it’s more to do with the people who, get in touch with you isn’t it and the people who continue to get in touch with you and the people that perhaps you would’ve expected to have got in touch who don’t, you know, so I think that was really, it’s so it’s people who can err related to you but others obviously feel that they can’t but there was only a couple of those”</i>

Participant	Supporting Quotes
Sue	<ul style="list-style-type: none"> • <i>“well you do find out who your friends are”</i> • <i>“... I thought I had more friends but really some of them were just fleeting visitors in my life”</i> • <i>“... you do find out who your friends are as people just disappear off the erm off the map...Erm or people that you think aren't good friends, erm they don't return the phone calls and you just don't get to see them and they just drift away...well I've been quite erm what's the word I want, I've just accepted it because that is them isn't it, if they can't cope with the fact that I've had a serious illness that's their problem not mine</i> • <i>“well the people that I know now are my very good friends erm, they want to know how I, they know we'll we'll ring each other up or the girl I'm meeting now, I used to work with her and we we kept in touch throughout and, hi X [participants name] how are you doing today ah I'm not so bad or oh I'm not very good today it's been an effort to get out of bed you know that kind of thing”</i> • <i>“Yes, and you kind of pick up on who you can rely on and people know that they can rely on me, so it's a deeper interaction with people”</i> • <i>“Well I think new people will come into my life and some of them will go out and some of them will get into my dotage, some of them will pop their clogs. I just see life going on and some friendships have become deeper”</i> • <i>“I think some friendships have come deeper”</i> • <i>“...but you really don't know how people are going to react in a crisis until there is one”</i> • <i>“One of the girls I used to work with erm, is a bit life and soul, I thought there might have been more from her but I was sort of cut out of her life yes...Erm, I don't get e-mails or phone calls or anything anymore, and if I meet her she'll say oh hi X [participants name], how are you doing and off she goes, doesn't really, not really that interested anymore so I think it was all a bit superficial”</i> • <i>“Erm, it does hurt a bit but life goes on and if people aren't a true friend, why bother with them. If it's got to be, what am I trying to say here, erm, if it can't be a deep friendship so all the emotions count whether you're happy or whether you're a bit down”</i> • <i>“Yes... I mean there's a couple of people that I haven't really known as long as I my own school friends but we've developed quite a deep friendships, umm, because there's different degrees I mean there's your acquaintances I mean, my son reckons I know everybody in X [town where she lives] because of the job I used to do, half the time I don't know who they are but I pretend, and say oh hello how's the family you know thinking oh who's this, so I mean there's different layers from acquaintances down to people that you've known a long time or people that you're closer to”</i>

Participant	Supporting Quotes
Sarah	<ul style="list-style-type: none"> • <i>“I mean there was one or two of them to be fair who, who I mean they’re young I can’t believe it there’s a young girl like, the young girl who lives in ... she’s only, she’s only she’ll only be, she’s 29 this week actually, and she was unbelievable, she would text me regularly every week, she’d erm, keep me up with all the gossip that was going on everywhere”</i> • <i>“but then as I say colleagues from other ...who were, were friends and acquaintances but... Not close that we, we went went out or anything, they’ve been fantastic, they’ve been coming up here to see me a couple of times you know and erm, they’ve been, been lovely”</i> • <i>“Erm, I think the closeness with some of them, you know what I mean...And maybe you had, I’d always been friends with them but it was, and we’d maybe go for the occasional drink, it wasn’t a close friendship they were just working colleagues you know what I mean. But they were, really really nice do you know what I mean, you know I think, I wasn’t expecting them not to be nice that sounds silly but erm, more sympathetic I think than I thought they would have been maybe.. but maybe there’s the few you, I didn’t expect it from you know”</i> • <i>“Like there was the, the ..., she was lovely and I was friends with her and she would do, she did loads of work for me I was always in and out getting something and, erm, when I went in there it was ahh big hugs and everything which I wasn’t expecting really...Erm, it was nice in a way to think that people thought that much of you if you like, you know because you didn’t, you don’t think they do you’re just, work colleagues do you know what I mean”</i> • <i>“there’s one or two as I say colleagues who’ve retired who who came up here have never been to my house before, we’ve been friends, we’ve been out never been to my house up here, and that’s nice because that’s developed you know...In that respect, and, and I think and you’re likely to hold on to those, friendships, but then you were friends with them before it wasn’t that you weren’t friends with them”</i> • <i>“... it made it closer with some people because maybe, you were always friends with them but, and and you were close but you didn’t realise how close if you, if you like, and something like that just, you know, makes you let people know how you feel if you like”</i> • <i>“but I suppose there’s been others who you may be weren’t as close and you didn’t, realise they thought as much of you if you like, that they’ve now sort of come forward so I suppose yes there are people who you maybe wouldn’t have expected necessarily to hear from who you have heard from you know... Erm, yes it’s it’s very it’s nice you know, it is nice to, to think that people thought that much of you that as I say they’d get in touch and, you know do something or, go out for a drink or whatever, yes”</i>

Participant	Supporting Quotes
Penny	<ul style="list-style-type: none"> • <i>“Some of them have become better, the ones that were really there for me and, and spent a lot of time with me when I wasn’t much fun, are the ones that I really value a lot because because because before I was ill, I was always, I suppose the life and soul of the party and, probably fun to be around... they’re the ones that I really value now because I think well they actually care about the person I am”</i> • <i>“So, so yes it’s not something I expected, I never thought I would want to be a, this sounds really selfish, I never thought I would want to be around a load of cancer sufferers erm, but, but they’re not cancer sufferers are they they’re just friends who happen to have cancer”</i> • <i>“the good friends were were fantastic so no, the good friends I wouldn’t have asked any more of the good friends...but there are a few friends that, I was disappointed with that, that didn’t, really keep in touch but, but then afterwards realised they weren’t really friends that were really worth, they were just there for the good times really them, so they’re the ones I’ve sort of let go a bit”</i> • <i>“there’s, a few I don’t feel the same about but the good, the good friends were, were very good”</i> • <i>“Rather than old friends, I always thought old friends were the best which they are in a lot of ways...But some of the new friends are fantastic in ways that old friends are not and that’s what I didn’t expect, I didn’t expect to get so much support from people I’ve only known for two years which is nothing is it two years it’s nothing”</i> • <i>“it’s really surprising that erm some of the, some of the friends I thought would be there weren’t and some of the friends that I didn’t think would be were, err I was really surprised by the ones that were excellent...and came with me to my appointments and popped round in the day time, weren’t necessarily were the ones that I would’ve expected to happen really, erm, so you you don’t know you just don’t know I think it really clarifies who your genuine friends are and who aren’t and and if I’d had to guess before I was ill I wouldn’t have always guessed right”</i> • <i>“I wouldn’t have predicted in all cases which which ones would be there and which ones wouldn’t”</i> • <i>“because they’re only after the fun times it’s not about friendship then is it”</i> • <i>“which friends, the true friends and the the good friends are fantastic friends...and also that friendship isn’t about who you’ve known the longest erm, because I mean the best friend from age four is still my best friend I mean so some of the long friendships are still there but some of the new friendships that I only met less than two years ago the girls here, but in two years some of them have become like best friends that I can imagine being friends with forever, not I wouldn’t have thought previously it was possible to make close friendships within two years I you know I would’ve thought it would take a lot longer than that... because most of my friends I’ve known at least twenty years you know if not all my life erm, so I wouldn’t have expected to make deep friendships so quickly as I have here so that’s surprised me”</i>

Participant	Supporting Quotes
Anne	<ul style="list-style-type: none"> • <i>“I’ve got the benefit of having you know lots of friends that would’ve been willing to come with me”</i> • <i>“...I think you need a friend you feel fairly confident in and, like on one of the ones, I was really glad that my friend actually had been there, she erm, this was a different friend from the first friend but this friend had actually been erm, erm, a cancer nurse so that she knew and could help explain things if I needed to, you know, if I needed anymore explanation”</i> • <i>“this time I I’d took another friend it a a male friend with me because we we we we’re really close friends”</i> • <i>“there was, there was one friend that slightly upset me, as she popped round and she said oh I called in since I’ve I’ve on my home from erm going to Sainsbury’s and I thought, I can’t get to the shops why haven’t you asked me before you went ...and I thought you stupid person... I thought why didn’t you think...so they’re on my not so close friend list”</i> • <i>“I mean there was, there was erm, a younger girl from .. and erm, she she was only in her 20’s and she knocked on one day and she said I’ve been to the shops and I thought of all the things that were easy and convenient and bought me a huge bag of groceries that I hadn’t asked for at all but you know, like instant porridge and instant this and just was, oof goodness me you know...that’s really nice...she just sort of arrived on the doorstep with it...Oh it was just wow.... You just feel a bit overwhelmed you know”</i> • <i>“I was quite pleased in one sense that I hadn’t you know, we made the effort again but I think, I think if I hadn’t have had the cancer those friendships would’ve drifted and maybe now you think ohh should I contact them you know it’s two years since I left work sort of thing. ...I think, I think it’s just maybe you know they had a fear that they might have lost that friendship totally, you know they might have had a fear cancer death sort of thing I don’t know”</i> • <i>“I guess, yes probably because you you got to know people a little bit better and different...Erm, I mean it it’s not something I sort of measure really like you know...how deep a friendship is sort of ... apart from the one that went down because she didn’t tell me she was going to Sainsbury’s”</i>

Participant	Supporting Quotes
Anne	<ul style="list-style-type: none"> • <i>“... I think maybe it’s just highlighted different friends and the different ways they approach things. So you know you you know which ones you can rely on for lifts and which ones you go to for food and who’d come and look after you when you’re sick sort of thing so I’ve learnt a bit more I can put them in different categories ... and how they would react to things...I mean it, it might make it easier to know who to turn to if any support was gained in the future”</i> • <i>“I ended up sort of keeping more contact with work people than I expected to really as a result of it”</i> • <i>“I then decided some of them, with some of my closer friends, I was happy for them to come”</i> • <i>“Some of my distant ones felt they, almost felt they should come and see me ...It was like a funny sort of reaction, ooh we’ve got to see you quick you know, you think I am not going anyway, I am not...you don’t want to end up being like their conscience you know, ooh she’s got cancer ooh we must make the effort to see her now and you think well why haven’t you made the effort the rest of the time”</i> • <i>“... you know you your, your close friends that doesn’t happen to but some of your others that, they suddenly think, we really must make that date, I’ve got to see you before you start your treatment and you think, why ...”</i> • <i>“... I think some friendships that without the cancer might have almost folded you know particul, I I’ve got one friend in mind who I worked with years ago and then you know I met her once after I think between leaving work and having the diagnoses and then you know became very important, I think more so for her to re-establish that friendship”</i> • <i>“... and to, put more effort into seeing each other again, and I think, I think I also sort of was aware you know”</i> • <i>“friends that are working full time...just are under so many stresses, so I think I did sort of then look more for friends who are either retired or had more time really”</i>

Participant	Supporting Quotes
Tracey	<ul style="list-style-type: none"> <li data-bbox="405 264 2031 368">• <i>“... I mean I’ve got another best friend from who’ve known since I was five, five years old she was there for me, she was really good X [friend] ...Erm, she came to visit me, took me to her house I stayed at her house, and same with my sister, one of my sister-in-law’s I stayed at her house, she was the one that, I didn’t want to come back home to face my operation, so yes, my best friend from five years old she was really good”</i> <li data-bbox="405 400 1167 427">• <i>“I knew X [friend] would be there for me.. Yes, yes, yes 100%, yes”</i> <li data-bbox="405 464 2031 635">• <i>“I had a friend that I I’ve never seen since I was diagnosed with cancer, she’s never contacted me at all...and I’d I’d always been there for her because she’d had a lot of anxiety and depression in her life and panic attacks ... and couldn’t get out of the house and things like that and I used to go and visit her in when, from when I used to live next to her and I moved so I used to go and visit her and you know listen to her and talk to her and see if she wanted anything from the shops and things, and I’ve known her like over 20 years and when I was diagnosed with cancer, ... never heard or seen her at all, not even a phone call”</i> <li data-bbox="405 671 2031 775">• <i>“...she’s known me a long time, just like I say, it would’ve been nice just a little card with ...You know, just to acknowledge that she’s thinking of me, I didn’t want pity, I didn’t want you know... It’s just erm, when you’ve been there for somebody, to think that they would be there for you...just just an acknowledgement, just and acknowledgement to say that she’s thinking of me, because like I say I’ve been there for her”</i> <li data-bbox="405 807 2031 866">• <i>“all the ones that I knew would be there were there it’s just X wasn’t there, whether that’s her way of coping she couldn’t see me like I say I don’t know but I haven’t yet asked her that so I can’t really...”</i> <li data-bbox="405 903 2031 962">• <i>“like I say she is an understanding girl...and she, she’s quite good at listening, erm, and like I say she’s had a few problems herself in life so she sort of understands how other people ...don’t understand what you’re going through”</i> <li data-bbox="405 999 2031 1058">• <i>“she is a good listener and I am for her ...so you know what I mean, we we tell each other our problems and she’s quite understanding you know so, erm, it sort of that eased me a bit”</i> <li data-bbox="405 1094 2031 1198">• <i>“X (friend) who I always thought was a good friend I don’t think she is a good friend... that’s my one, person, who I’m quite annoyed with...Who I’m very annoyed with really, and when I find time to go and see her and see what her excuse was I will but at the moment ...I’m busy getting on with my life at the moment”</i> <li data-bbox="405 1238 2031 1297">• <i>“My friend XX [friend] I didn’t expect her to be the way she she was, my other friend X [friend] who who’s a really good listener yes, she was how I expected, I’ve got another friend X, she was coming to visit me you know”</i>

Appendix G

A table to illustrate the supporting quotes used to develop theme 2:

Proximity of friendships: Keeping friends at a distance or pulling them in close

Participant	Supporting Quotes
Mary	<ul style="list-style-type: none"> • <i>“we’d slip down to the boat and then have 4 or 5 days there and it was, it was nice to get away from the house because as much a people mean well you don’t want to go through the same story, you know...Time after time so much so that X [husband] used to just, third chemo she’s OK, and just send out you know a message to everybody”</i> • <i>“I came home and I’d got a house full here, and I walked in and I looked at everybody and I said good God I said, if I get that many people here when I’m diagnosed I’m going to have a hell of a wake aren’t I”</i> • <i>“ so other friends, like I said that day they all, loads of them came up here, erm....Well, weird, it was kind, it was a bit ghoulish I thought... Because a lot of the people that came up didn’t often call.”</i> • <i>“I’ve got one friend, other than when she’s on holiday, from the day I was diagnosed she has phoned me everyday”</i> • <i>“I’m not dying you know, you don’t have to come see me, I’m not used to you coming to see me everyday”</i> • <i>“Well then you become, you become centre of attention then don’t you”</i> • <i>“I didn’t want loads of visitors to be honest because I didn’t know how I was going to be”</i>
Sarah	<ul style="list-style-type: none"> • <i>“ah they would phone up regularly they’d say you know, we’re going out come and have a drink with us or we, or she or we’ll come up and see you, and they’d all come up to see me you know...and they, and I said to them, you shouldn’t be doing all of this you’re so young you two, you’re, they were so lovely you know, I couldn’t, we, I just thought we were so lucky to have people like that in, that were in our department that were so caring, I mean X’s lovely even now, she’s, I I still hear from them all the time”</i> • <i>“it’s that link isn’t it you know and she would e-mail me and I’d, I’d e-mail her if she wasn’t at the do to say we’d missed you blah blah blah and she’s e-mail saying yes you know, I’m feeling alright you know or whatever, so I suppose you had, you do have, you have that if you like where it’s sort of, kept you in touch”</i>

Participant	Supporting Quotes
Lilly	<ul style="list-style-type: none"> • <i>“Just knowing that they were there”</i> • <i>“I just felt as though, that they were there for me”</i> • <i>“I’d be there texting them and they’d say you know how are you feeling today you know, crap I’m in bed all day or you know, so, yes, they were there”</i> • <i>“Erm, I think because them being so close but yet so far do, I don’t, you know it’s that sort of. I suppose is that’s sort of, knowing that you can, you know erm, rely on them enough you know like I said they are like my family but they’re that sort of distant away that they didn’t sort of worry as much as what my family would”</i> • <i>“they’re that just bit more distant than your immediate family aren’t they”</i> • <i>“Erm, probably just, just to know that they were there to be honest, erm and to know that I could, you know I was stuck or if I was feeling a bit shit I could phone them and gas off to them and let off steam to them, you know I only had to pick up the phone and say you know can you come round and they were here”</i> • <i>“just knowing that they were there really”</i> • <i>“I can rely on them, if I need them they’re going to be there”</i> • <i>“they were phoning or they were ringing and you know and err came, you know some even come round, friends who I don’t see err, you know from you know I don’t go out with them or I don’t socialise with them but friends who knew about me yes, came”</i>

Participant	Supporting Quotes
Ailsa	<ul style="list-style-type: none"> • <i>“I felt overloaded really and I mean that sounds awful because people are obviously wanting to do what they can and they’re concerned and whatever...there’s only, so much you can deal with on a daily basis”</i> • <i>... the other thing I think you feel is in the day, if you’re not wearing your wig or whatever is do you want, do you want somebody just appearing, you might want to put your wig on or put a scarf on...That’s how I felt anyway, I didn’t want anybody coming...Unannounced”</i> • <i>“I mean obviously they sent flowers and cards erm, rang up but again that was a bit, erm, too much really, erm, but yes the usual things really, lots of flowers”</i> • <i>“...lots of texts and e-mails on the days I was going for my chemo and whatever from my friends...Oh it was very nice, it was, it showed they were thinking of me and showed they were supporting me”</i> • <i>“...at the beginning when I first of all got the diagnosis and you’re having to tell people...It becomes too much, erm because you’re upset and you’re having to repeat the same story really”</i> • <i>“and then she’d she sent me a text you know on my when she’d gone she sent me a text you know on my thing and she’s and she oh and then she came back the next day with some flowers because she said I know you’re feeling low and, this is to cheer you up so, it’s that sort of thing I think that, is helpful”</i> • <i>“it was nice, sent me cards people you know and I thought ooh gosh you know I’ve got a card from such a body and, erm so yes that was nice it was nice”</i> • <i>“... I think you can be overloaded as well...you can be overloaded with with, well that was going back to the question of you know all the phone calls and things ...Which is nice but it’s an overload of too much... You know you can only deal with so much little things you know”</i> • <i>“I mean obviously they sent flowers and cards erm, rang up but again that was a bit, erm, too much really, erm, but yes the usual things really, lots of flowers”</i>

Participant	Supporting Quotes
Ailsa	<ul style="list-style-type: none"> • <i>“he would sort of ferry the phone calls you see and he’d say things like oh well she’s she’s just gone up for a bath and she’s fine but she’s going to have an early night and, but she’s fine and if she feels up to it she’ll ring you back in the morning or whatever he said and leave it at that”</i> • <i>“ Erm, and I perhaps also erm knowing when to perhaps back off a bit as well isn’t it, that sometimes you need the space because you feel so tired, so you know, that you can’t really see people because you haven’t got the energy you know the tiredness comes over you”</i> • <i>“nobody sort of came round without ringing first and saying are you up to having visitors you know do you want me to pop round and you know if if you don’t that’s fine so no no nobody sort of knocked on the door and said I’m here to see you, no”</i>
Sue	<ul style="list-style-type: none"> • <i>“...somebody who cares enough to pick up the phone or pop a card in the post and just that they care how you are, do you need anything? ... Just little touches, doesn’t need to be a grand gesture”</i> • <i>“it was just nice to know that somebody cared enough to say oh well I’ll come with you”</i> • <i>“ they were excellent erm, I could ring them and say oh I’m having a good day do you fancy going to such a place and do you want to nip round and have lunch with me you know that sort of thing”</i> • <i>“They were there when I needed them and they offered, that was very very important”</i> • <i>“Yes, well it was both because it worked both ways, it was the fact that it, it meant a lot that they were thinking about me and...Oh I wonder how she’s doing today I’ll give her a call, you know that that sort of thing was very nice”</i> • <i>“I know that I could ask them if I wanted anything and somebody would be there but they also offered, they didn’t wait to be asked”</i> • <i>“Erm, it’s, how does it feel, erm very reassuring, you know this this person isn’t putting on an act for me she’s not trying to say everything’s going to be alright, she’s listening to me, erm, and although she doesn’t know she understands that I don’t want to jump about today and I’m a bit frightened”</i>

Participant	Supporting Quotes
Penny	<ul style="list-style-type: none"> • <i>“so really every day somebody did pop round erm, and drop in which was great because it did take my mind off it and make me feel more normal”</i> • <i>“there wasn’t really a day went by that I didn’t really have a friend to visit I think we’d all, again sort of organising a rota really so they’d take me out for coffee or whatever or to the pictures and so the first year it was as if, erm, they were all looking out for me making sure, I’d you know, I’d got someone everyday really which was great”</i> • <i>“I did not want to be at home on my own, I could think of nothing worse than being in the house on my own all day”</i> • <i>“I suppose if I’m honest when I was ill I probably did want to see people more than usual really I suppose if I’m really ...without being too needy”</i> • <i>“some would come round with homemade soup and that for me, erm, there’d always be somebody that would go with me to my appointments, I never went to a chemo appointment on my own, erm and the radio appointments, they worked out this transport rota so they were really good in a practical way really”</i> • <i>“yes because it broke, it broke the day up, they’d have been nothing worse than, than thinking I’ve got eight hours to fill before you know my husband and children came home... With nothing to, to take my mind off things, but because friends did pop round it was, it was great you know”</i>

Participant	Supporting Quotes
Janet	<ul style="list-style-type: none"> • <i>“I know I was frightened I will admit that, erm, my friend... came with me because I’m on my own my children live away, erm so ...came with me to each appointment and she’s been an absolute brick bless her”</i> • <i>“...she’s been with me to all my appointments and follow-ups and everything”</i> • <i>“because I don’t know how I would’ve managed without, two in particular, X and X, erm, because my daughter was abroad and still is but bless her she rang up erm as soon as she heard, and wanted to fly home and I said look X, no, I’m in good hands, erm, it’s treatable, erm, and it’s not you, I couldn’t justify her flying over at that stage because there was all the professionals around me as I say X and X [friends] ...”</i> • <i>“...maybe it’s e-mail that’s enabled these links you know the modern links erm...”</i> • <i>“... it’s very comforting and reassuring that there are people around who are genuinely concerned”</i> • <i>“... I’m sure if I were to pick the phone up...some of them would even you know come and keep me company if I’d ask them”</i> • <i>“and then the ones slightly further afield erm, have been, they’ve been very emotionally supportive but at a, a step removed”</i> • <i>“...because they’re not quite my inner circle of friends but they’re still concerned you know ...there are still, there are still a wide circle of people who are generally interested”</i> • <i>“By, I could tell, it, if I tell you how I felt erm, as they were trolleying me into my first operation, I said to the staff, ooh I feel as if I’m floating on an air, on a, a mat, a mattress or I don’t know what exp, I feel as if I’m floating on a cloud of good will ...That’s my, and that’s how I felt there was so much good will...From everybody you know, sort of my colleagues at work, erm, my the meet up group of people, erm, everybody was wishing me well erm, and it it it was it was just amazing, I just had never experienced that before I mean obviously that group, none of them got in touch at all”</i> • <i>“... even though they didn’t sort of say it in so many words but I felt they were rooting for me to make a good recovery erm, I find it very difficult to, put into words but, as I say that comment I felt as if I was floating on a..well almost on a cloud of good will...”</i>

Participant	Supporting Quotes
Janet	<ul style="list-style-type: none"> • <i>"... I actually sat in a service where their preacher mentioned me oh I could've crawled into a whole of embarrassment..."</i> • <i>"I knew if I picked the phone up, if she was able she would drop everything and come... she would be there for me, you know no matter what"</i> • <i>"... my just world fell apart and X said well that's why I came I'm I'm there to listen and ask the right questions erm, which is true because I mean she did actually, ask things of the consultant when we were in the clinic.."</i> • <i>"I keep saying I don't know how I'd managed without them but it, it's deeper than that I suppose we've, it's been a journey that we've travelled together"</i> • <i>"and they were both there for me and I know that, erm, if I'd have asked for more support they would've given it to me erm"</i> • <i>"I keep going it it's this good will, which is a much wider circle"</i> • <i>"I mean they've not been over and in my face and cooking and, but, I suppose one thing is they've allowed me to talk freely and openly about how I'm feeling"</i>
Anne	<ul style="list-style-type: none"> • <i>"... really nice so you know they gave me a love, you know they'd made it themselves a pillow and they gave me some like erm perfume free cosmetics and just a two... You know half a dozen little things, so that was a real encouragement to me"</i> • <i>"I think just people, you know, being there I mean in one sense sometimes I look back and think that was a really lonely year because I was by myself a lot, but then on another way I think, I don't know if I could've coped with a lot more people coming round to see me all the time you know"</i> • <i>"I mean, yes, the friend that I went with he said oh if you're panicking in the night phone up and I'll, and I'll come round"</i> • <i>"I think it was on my third chemo ... she said look I'm happy to come and just spend the night"</i>

Participant	Supporting Quotes
Anne	<ul style="list-style-type: none"> • <i>“I didn’t know how I was going to be”</i> • <i>“there was, there was one friend that slightly upset me, as she popped round and she said oh I called in since I’ve I’ve on my home from erm going to Sainsbury’s and I thought, I can’t get to the shops why haven’t you asked me before you went ...and I thought you stupid person...I thought why didn’t you think...so they’re on my not so close friend list”</i> • <i>“... I did a lot of erm e-mail type communications, so, the, I had, I had one of those, ooh I don’t know three or four different circulation lists, one of them there’s a group of friends that don’t live close that we always go on holiday with twice a year, .. and then I also had like a circulation peop, of people that I worked with”</i> • <i>“I think, because the majority I probably told via e-mail that’s a lot easier than telling somebody face to face, when you tell somebody face to face they, people don’t know what to say...and you might as well have said, I’m I’m dead you know because their reaction is so...you know if it’s, people yes, people just don’t know how to handle it”</i>
Tracey	<ul style="list-style-type: none"> • <i>“you’re tired and you’re, you’re feeling ill, you don’t want to be mithered [bothered]”.</i> • <i>“Just to say I’m thinking of you, I can’t keep in touch every day and what have you or come down and see you but I’m thinking of you”</i> • <i>“you know, a stamp on an envelope... and a little card thinking of you, she didn’t even have to write anything it in, just put from X [friend]...”.</i> • <i>“I just couldn’t thank her enough, she was my rock you know”</i> • <i>“I mean even friends that I’ve worked with years and years ago you know, things like that, they all text me you know, thinking of you think you’re OK”</i>

Participant	Supporting Quotes
Tracey	<ul style="list-style-type: none"> • <i>“like I say I didn’t want people visiting me but just to get a little text out of the blue thinking of you hope you’re OK today, be strong... those little, little gestures mean a lot ...Especially when you’re sat in the house in the house you know, lost your hair and, feel ill ... Look like shite ...I looked terrible and I didn’t want people, I did, I didn’t want people to sort of come in and feel shocked and, or feel sorry for me in that way you know...I just...I was quite happy with a text message”</i> • <i>“...You know it’s, it’s nice to think that people out there are thinking of you”</i> • <i>“I don’t want to be felt sorry for or anything like that, it’s just nice to know ...that people are you know, if you needed them they’re there”</i> • <i>“She was sort of my backbone, so I can’t forget her, and she’s, she’s my I’ve known her since I was five, she’s the type of friend where I can pick up the phone, may not see her six months...and we’re just, nor, you know”</i> • <i>“... you know you just want to get on with it ...Just a nice feeling to know that they’re thinking of you”</i> • <i>“she came she came to erm, to see the specialist with me wrote up, sat in the background my notes...very reassuring very very very reassuring very good”</i> • <i>“Erm, I just phoned her up and I just said erm, I’ve meaning to tell you I’ve been diagnosed with breast cancer and straight away anything that you need anything she was down the next day, you know, just phone me I’ll come to all, because I I said that when I’m when I’m going to see the specialist I’m coming out and it’s not going through and it’s not sinking in with X [husband] because he’s distraught about it so it’s just going in one ear and out the other..So her and my brother used to come and take notes for me, write it down for me so I could relate to it”</i> • <i>“Just to say I’m thinking of you, I can’ keep in touch every day and what have you or come down and see you but I’m thinking of you”</i> • <i>“She was there, she went to the hospital, she came to the hospital with me and my husband, she took notes down because it was just going in one ear and out the other but she’s very good at writing notes, she’d, she’d her job is social services so she’s quite good at”</i> • <i>“whatever I needed all I had to do was to pick up the phone and she was, she was there straight away for me. She’d come to to my house, take me to wherever I wanted to go”</i>

Appendix H

A table to illustrate the supporting quotes used to develop theme 3:
Time as a currency: Paying friends back with time

Participant	Supporting Quotes
Lilly	<ul style="list-style-type: none"> • <i>“I think it’s the same for them as well you know so, erm, I felt quite important actually them all coming round and, erm, yes, I appreciated the time and I know, you know lives are busy aren’t they you know mines hectic at the moment but you know if somebody phoned me and said, you know I need to talk to somebody I’d be there like a shot”</i> • <i>“So yes I mean it was, I guess I know that she, I would’ve done the same for her if there’d been you know if she’d...Been the other way around you know tried to, yes...”</i> • <i>“Erm well we see each other more now, we do a lot more things together now, erm, although we did do things before but, yes, we’re in contact more now I would say. I see you know I see my I go I go out and see my friends at least I see at least one set of friends a week”</i> • <i>“Erm, I think it’s made me appreciate life a bit more, erm, I do things now that I wouldn’t have dreamed of doing erm, and I want to do more things, you know it’s sort of, I think, it I think it opens up your eyes and things, and makes you think ... I just I just do more with them now [friends] whereas like I said before I you know could maybe 2 months without even seeing them but now I you know will make a point of, I’ve got different circles of friends of seeing them quite regular, on a regular basis or going away with them”</i> • <i>“but the same for me for them really, I’m always going to be there for them”</i> • <i>“Ah it meant a lot to me obviously erm, definitely, yes they looked after me, yes I would be there for them you know if God forbid anything happened yes”</i> • <i>“I I rely on them much as what they rely on me really because you know life’s not been easy for them a lot as well so they’ve all got a story to tell and erm, yes, ... there’s four of us that stuck together for god knows how many years”</i> • <i>“... I think it’s the fact of staring death in the face to be quite honest and that’s how I put it...”</i>
Ailsa	<ul style="list-style-type: none"> • <i>“I don’t know because I don’t know how I’d feel if she was poorly... Would I be, would I think ooh I’m not going to bother sending her a card you see I don’t know that sort of crossed my mind you see”</i> • <i>“I think it makes you realise that, you know we have finite time on this earth”</i>

Participant	Supporting Quotes
Sarah	<ul style="list-style-type: none"><li data-bbox="421 339 1742 368">• <i>“I could spend 18 months having this treatment and I said if it comes back in 5 years I’ve just wasted I think that time”</i><li data-bbox="421 403 2022 523">• <i>“If something had happened now I would pick up the phone and say, or send them and e-mail saying how are you, you know, what’s going on, do you need anything, as opposed to just, drifting along so I suppose those things have, there’s the odd ones that have been strengthened because of it...I think because you realise life’s too short really... You know, that none of us know what’s round the corner, and I think in that respect you need to have chance to let people know yes, you you do like them and you are friends with them and you would do anything for them”</i><li data-bbox="421 558 2022 646">• <i>“So I, sort of tried to boost her up now you know I text and say it’s OK you know blah blah blah we’ll get on with it and she says oh its, thank you for that and it’s nice to be reassured and I think you try to respond in the way they’ve been with you really...You know being positive and, and erm, I had I had I don’t know, they were amazing”</i><li data-bbox="421 681 1413 710">• <i>“She’d make the effort or I’d do the same you know so yes, in that respect it’s different”</i><li data-bbox="421 745 2022 804">• <i>“I mean, I think it makes you, maybe do more with your life you know like I want to see places and go places, but but at the same time have like a bucket list or anything silly like that”</i>

Participant	Supporting Quotes
Sue	<ul style="list-style-type: none"> • <i>“...it sort of makes you aware of your erm, mortality, and we don’t really have very long on this earth...”</i> • <i>“well I don’t want time wasters in my life because our time on this planet is limited and you know people who aren’t prepared to make it a two-way thing who are, if you’re not being fun anymore they don’t want to know...and I don’t think it’s necessarily a conscious thing but ...Whereas at one time they might have popped round, they they find something else to do you know oh sorry I haven’t seen you for ages but I’ve been really really busy and I’ve got this on and I’ve got that on whereas at one time you know they would’ve made an effort”</i> • <i>“Umm yes, I mean erm a couple of friends did offer to come and help me with my cleaning but I can’t get excited about housework”</i> • <i>“some people just seemed to naturally know the right thing to say and erm, a couple of the girls I worked with it was oh dear and that was about it, it’s the things, don’t know what to say, erm a couple of people I got a nice big hug from and an oh I am sorry ... is there anything I can do to help”</i> • <i>“practical stuff I got from family, friendship came from friends”</i> • <i>“Erm it was really the emotional thing that I wanted because most of the practical stuff came from the family because I’ve got three children”</i> • <i>“Well it’s just, it’s comforting and they did normal stuff with me, like we’d go out for lunch or go out for a walk, just things like that”</i>
Anne	<ul style="list-style-type: none"> • <i>“It’s knowing how much to accept help all the time you know, so it was really nice that people did offer. I mean several other people from church said you know is there anything we can do etc etc, and I mean to to one person I said, because it it was Summer time I was going through chemo I said erm, I actually I’d just like somebody to go for a walk with, rather than you doing something, just a bit of company to go out with you know”</i> • <i>“One of the people from church the one who was a cancer nurse in the past erm she did say shall I do a rota so that people from church didn’t, different people from church can take you for your treatment, and in the end I thought I’d rather I go with people that I really know than people I don’t know quite so well, and I went, people took me definitely the first week”</i> • <i>“whereas with not having family you know it’s been the friendships that have been sort of my main source of err support and strength”</i> • <i>“It felt like she shared that little bit of the journey and somebody else shared that little bit of the journey you know”</i> • <i>“I’ve got a lot of friends, so lots of close but I wouldn’t say I had somebody that was sort of my number one friend you know, so it’s good having all these different ones to, do different things really”</i> • <i>“The day after I had chemo she’d always come round with a fish pie or something like that, because we came to the conclusion that that was the easiest thing for me to eat...Ah it was lovely”</i>

Participant	Supporting Quotes
Penny	<ul style="list-style-type: none"> <li data-bbox="421 336 1209 368">• <i>“They’re only after the fun times it’s not about friendship then is it?”</i> <li data-bbox="421 400 2020 491">• <i>“My friends organised a rota because I had to go for erm, 28 sessions of radiotherapy Monday to Friday erm for four weeks in ... which is quite a trek from ... so my friends worked out a rota so somebody would drive me every day so that was fantastic so so I really appreciated the practical help”</i> <li data-bbox="421 523 1601 555">• <i>“I don’t need to spend time with them anymore I’ve got other better closer friends that were there for me”</i> <li data-bbox="421 587 2020 678">• <i>“I think life is too short to spend time with people just because they’ve suggested it, now I pick and choose and think... Well do I really want to spend all day with a shallow friend or with a, a genuine friend and so, so there are a few that what I would call shallower friends I’ve, lost touch with”</i> <li data-bbox="421 710 2020 801">• <i>“I just think it’s a bit false really because I think well, that’s not really friendship is it, they only want to be around the, the fun times, they don’t want to be around the miserable times so, I think life’s too short, erm, to spend time with people like that I think I’d rather spend the time I’ve got with, with the true friends that were there even when I was a bit miserable”</i> <li data-bbox="421 833 2020 924">• <i>“I’d rather know that people are there for me and I’d rather them show it in a practical way erm, like some brought cakes round and that sort of things or we’d go out for you know lunches or meals and and that’s what I really needed from my friends”</i> <li data-bbox="421 956 2020 1083">• <i>“Whereas other friends, didn’t bother when I wasn’t a bundle of fun and I was going through chemo and being sick and sort of stayed away, erm, and to be honest it’s quite a few of those friends that have sor, now that I’m back at work wanted to pick up again, oh lets go for lunch now and and I can’t be bothered now there’s some people I, I’ll probably not going to see again because they didn’t want to bother with me when I needed them and I was ill, and it’s only now they think I’m back to being a fun person again that they want to come out with me and I think well actually no”</i> <li data-bbox="421 1131 2020 1233">• <i>“So there are a few friends that’ll be, only wanted to be around me for the fun times and didn’t want to be around me for the miserable times and, and they’re the ones that, I’m not really returning their calls I’m putting them off, there’s the few that you know are now saying oh lets meet up for lunch and I think well they didn’t want to meet up for lunch when I was ill, so I’d rather meet up for lunch with those that did meet up with me when I was, when I wasn’t fun”</i>

Participant	Supporting Quotes
Andrea	<ul style="list-style-type: none"> <li data-bbox="421 413 1066 443">• <i>“I would feel I could do the same for other people, yes”</i> <li data-bbox="421 475 1335 505">• <i>“I think they just tried to to be there and and be the help that they could I think”</i> <li data-bbox="421 537 2027 663">• <i>“No I think the other friends are still there because we’ve been through other things together and other experiences which have, pulled us together but there are certain things that they, just don’t thoroughly understand I think because they haven’t and that doesn’t make them less of a friend...it’s just different, erm, yes so, they’re still there you know, and a lot of friends did come and help out you know I had one friend who did my ironing for 9 months, and she’s going to do my ironing when I have my reconstruction for 6 months”</i> <li data-bbox="421 695 2027 758">• <i>“Well I mean a lot of people would bring meals around for us but I don’t know whether that’s just... because when you’re in, when you’re visiting in hospital it can be quite a hard push to you know, well seen as I never did any cooking before it was quite hilarious”</i> <li data-bbox="421 790 2027 884">• <i>“a lot of people did bring meals round you know because I couldn’t, because the chemo, chemotherapy affected, I lost all my fingernails, which isn’t a very common side effect and two toe nails, I lost I couldn’t erm, I used to wear white gloves a lot to, to try to protect them, but I couldn’t erm you know cut vegetables or cook because you had no, when you’ve got no nail you haven’t got any pressure in your”</i> <li data-bbox="421 916 2027 1042">• <i>“I could just sit in the chair and not do anything or, erm, they would always make sure, you know if we were having a a group of ladies together if one of them was ill, they often would stay away which I felt a bit bad about but they didn’t want me to you know, catch anything, I did have to be hospitalised twice during chemotherapy with temperatures and low neutrophils and things, so, yes so yes so I was often cold and I still don’t like my feet to be cold so I would still take my slippers to a lot of people’s houses when I would go”</i> <li data-bbox="421 1074 2027 1200">• <i>“Others they’d just come round and see you and bring you a book or bring you some nice juice because I couldn’t erm, yes your taste buds go off erm, yes so, you know someone was always, would always be around if I was having the the chemo that the, the kids or, whatever because, yes in theory you could lose them but you’re never quite sure erm, you know and, to know that some of them would be there especially, especially for my daughter to have someone to talk to because we’d told the school because we weren’t sure how they were going to react”</i> <li data-bbox="421 1232 2027 1286">• <i>“I think when you’ve been honest with someone it can enable them to be more honest and open with you...when you’ve shared something of yourself with somebody, that is more personal, it, can mean they also can do the same when they’re in a similar situation”</i>

Participant	Supporting Quotes
Andrea	<ul style="list-style-type: none"> • <i>“we’re still you know I’m still close friends especially with one of them erm, you know she’d been through things since you know you, try to be there for her as well”</i> • <i>“I think it changes you in that, if I think should I or shouldn’t I do something that I’ve maybe wanted to do for a while, I’m more likely to say yes just go for it ...because you don’t know how long you’ve got, so you don’t want to live a life of oh I wish I’d had”</i> • <i>“I think I’m more likely to say yes lets go for it, than I would’ve been...So whether that’s friends or family, you know I might you, you know take that opportunity because you don’t know...how long you’ve got you know, I mean we still don’t know how long I’ve got...you know, a moment I’d, as far as they are they are aware I don’t have any cancer in my body”</i> • <i>“...and people to help out practically, so, whether that was by cooking meals or inviting my family over while I was in hospital or whatever because you know picking up from school by the time you’ve got home to cook tea to get out for visiting time”</i> • <i>“I think other people you know that maybe you weren’t expecting things from you know they might bring you cake round or whatever ... you know they would come and do what they thought was helpful and...you know or maybe a book that they’d found helpful”</i> • <i>“...you know if I wasn’t feeling well they [her children] could just go through to each other’s through this little door, literally it was a door...between the two and they could be there for each other and they could just go and play outside erm you know didn’t, wasn’t”</i> • <i>“It was an over an hour there and back, and then so then probably for eight or nine of the sessions friends drove me ...you know none of them wanted petrol, I did offer them petrol you know usually I’d pay for the coffee on the way back or something coffee and cake and ooh can’t have coffee and cake on the way back, erm, yes but they were they were prepared to do that to take that time out, it meant leaving about half past 7 quarter to eight in the morning for my appointment, you know and the earliest we would be back would be half past ten so it was you know a good chunk of their day”</i> • <i>“(driving to radiotherapy) it was really nice because I felt that you got to know them a little bit better ... and it was nice, it was I think it was a time to get to know people differently when you’re travelling for a couple of hours in a car”</i> • <i>“...organised the rota that was you know, that was OK right like, who can do which days and, erm, yes and that was good that was very helpful”</i> • <i>“Erm, but I think, I hope that if someone else was going through something...they would feel that they could talk with me...so it’s opened those lines of communications because none of my immediate friends here had been through it at that point”</i> • <i>“I would try to be the same if someone was going through you know, what can I do for you, I probably wouldn’t volunteer to do somebody’s ironing you know, but you know I probably would you know say I’ll come, you know what can I do can I have, you know can I take a meal round for you”</i>

Appendix I

A table to illustrate the supporting quotes used to develop theme 4:

“It’s like, if you’d not had a baby... I don’t think you really know what it’s like”: Developing friendships through the shared experience of breast cancer.

Participant	Supporting Quotes
Lilly	<ul style="list-style-type: none"> • <i>“It’s probably different actually because the other, the group of friends like the ...group, they know what exactly what I’ve gone through although my friends probably you know, have got an idea what I went through but they know, you know they went through the chemo they went through the radio, they went through the cancer diagnosis so, yes, they probably erm, although I’m not as close to them as I am with my my own friends, they know, you know when we get together we talk, we talk about effects and different things, different treatments and stuff, peop what people are going through and stuff so yes, it is a different set of friends all together”</i> • <i>“... I think it’s it means a lot to all of us, the nine of us when we get together because we feel as though you know we fought it at the same time really so, yes...talk about it with them...my other friends, I wouldn’t necessarily talk about it unless it was brought up in a conversation”</i> • <i>“...we’ve all gone through it, they und they understand probably a bit better than my friends who haven’t gone through it and they understand that you know a lot a lot of us are taking the Tamoxifen and, we’re all having the flushes and the night sweats and things like that so you can, relate, you can you know it’s like a topic of conversation you know rather than talking to a, who somebody who doesn’t understand”</i> • <i>“ we got I get a lot out of talking to somebody who’s going through it or was going through it at the time or, erm, and I thought and and X did as well and she got a lot out of it and thought there must be other people out there who need to talk to somebody who’s gone through it other than you know you go to talk to a doctor or a breast care nurse, they, although they’ve got a clue of what you’re going on about or they haven’t actually experienced that and I think talking to somebody who has experienced it is a lot better than”</i> • <i>“...obviously you’re on the same wavelength”</i> • <i>“they’re good friends they’re good they’re good girls they’re good ladies and we like I said we we’ve kept in touch now and we’re three years down the line and we still go out”</i> • <i>“ we’ve started a choir, erm, so and I’ve got new friends through that, you know the people coming”</i>

Participant	Supporting Quotes
Mary	<ul style="list-style-type: none"> • <i>“I made a very good friend ... we keep in touch a lot...So you do kind of make friends, make new friends, in the ... erm, especially if you’re having your chemo on the same day, even though she lives in ..., we’ll still, we’ll still meet up”</i> • <i>“it’s a special friendship I think, when you’ve gone through the same thing and hair loss, and and and everything”</i> • <i>“Well it, you kind of bond”</i> • <i>“the special friendship, I think it’s because you know what they’re going through and they know what you’re going through”</i> • <i>“I think it was because we were going through the treatment together. Erm, She knew how I was feeling, I knew how she was feeling, she was quite poorly during chemo, she didn’t cope with the chemo like I coped with it”</i> • <i>“Special in a, in a, in a different kind of way to your own friends”</i>
Sarah	<ul style="list-style-type: none"> • <i>“Well it’s definitely the cancer there’s no, you know, the common bit because it would be you know what kind of treatment did you have, how are you finding this, how are you finding that, and I think that was the sort of erm, bit and not just the cancer but the effect like erm, you know she’d be, she’d say and I’d say how’s X coping with it, you know it wouldn’t be just you, how’s other people coping with it you things like that and I think, yes, I mean you always did have something in common before that but no, the this is definitely in that respect, you know”</i> • <i>“Ah it’s, it is does help to talk to somebody who you knows been through the same situation it definitely helps you have you know some understanding of the, of what’s gone on”</i> • <i>“it was lying in there one day I thought that hmm yes you’re the only one, you’re the one who’s got to cope with this you’re on your own here you know, and I think erm, and then you know those people have gone through exactly the same thing you know”</i> • <i>“even though there’s the cancer’s not the same, it’s that link isn’t it you know and she would e-mail me and I’d, I’d e-mail her if she wasn’t at the do to say we’d missed you blah blah blah and she’d e-mail saying yes you know, I’m feeling alright you know or whatever, so I suppose you had, you do have, you have that if you like where it’s sort of, kept you in touch”</i> • <i>“...it it probably strengthened it in, in that respect, in the respect that you, you had some understanding of what...hers was much worse, but what her her family would be going through and, you know, things like that ...”</i>

Participant	Supporting Quotes
Tracey	<ul style="list-style-type: none"> • <i>“there’s a good little gang of us come, and it’s my little lifeline”</i> • <i>“... we just either talk about our problems, we don’t, we have a laugh, we have a cry, everything. So I have a little social life with them all here”</i> • <i>“Well I think because we’ve all been through, not necessarily breast cancer, other people have had other cancers or or or other thing, erm, it’s like a little escape route for us all, we say you know we can we can we can have good banter or we can sometimes one of them will come in feeling fed up and lonely and depressed and sit down and have a good cry”</i> • <i>“You don’t realise, there’s so many other people that are going through what you’re going through, and everybody copes with it different, some people, like I’ve got a friend that I used to work with ... I met up with her and she’d just been diagnosed with breast cancer you know and I was saying to her ooh is she like me you know in shock, couldn’t eat and then she says oh no no I was fine with it...See you’re listening to other people’s stories as well, how different people cope with things”</i> • <i>“You know, I’ve got good good friends and, and like I say...some new ones”</i> • <i>“we just talk about all what we’ve gone through or you know or, or erm, like erm, ooh I still get pain do you still get pain... you know your hair loss, how what tablets people are on now, just general chit chat about it all”</i>
Sue	<ul style="list-style-type: none"> • <i>“when you’re in hospital you might strike up a friendship with somebody in the next bed but you go home and never give them a second thought but they’ve been a friend for a short term, you’ve fulfilled a need for each other”</i>
Andrea	<ul style="list-style-type: none"> • <i>“I think it’s different, I mean they go through different things ...it’s like if you’d not had a baby... you can’t, I don’t think you really know what it’s like”</i> • <i>“whereas now I would say I had a wider group of erm, friends in that I’ve got friends who’ve been through, cancer and that’s, I don’t think you usually make friends with someone with whom you have nothing in common”</i> • <i>so this is a different commonality that I have with other people erm, and we can be there for for you know each other so if you’ve got something you know I always know that there’s someone that I can ask about anything</i> • <i>“so then you’ve got to know a few other people I mean that’s only been going 18 months so I, how, deep that friendship goes I don’t know I mean”</i>

Participant	Supporting Quotes
Andrea	<ul style="list-style-type: none"> <li data-bbox="421 240 2033 331">• <i>“anyway but she’d been through it and she so as soon as, we sent out an e-mail to a lot of friends to tell them that this is the situation and then, you know, she responded and said look you know I went through this a... you know a year ago, you know and if you want to be in touch and I still, if I have any questions I still go back to her”</i> <li data-bbox="421 363 2033 427">• <i>“you know, I didn’t know her very well, before that you know I’d only met her I’d been to a wedding...and met her a couple of times so I didn’t know her that well, but this, sort of, common bond”</i> <li data-bbox="421 459 2033 491">• <i>“after I was diagnosed but like she was also there you know I felt I, there were questions I could ask her”</i> <li data-bbox="421 523 2033 555">• <i>“but it was useful to have people around who’d been through some of the same things as you”</i> <li data-bbox="421 587 2033 651">• <i>“so I would phone her up and I would just say, oh I just feel, like this and I hadn’t found the support group at that point...erm and she was just there on the end of the phone”</i> <li data-bbox="421 683 2033 746">• <i>“whereas the ones through the support group it’s, our common bond with cancer, so it’s a different basis for which, we’re friends...so I suppose that’s, that’s the big difference I think”</i> <li data-bbox="421 778 2033 842">• <i>“I guess you have a bond with people that you’ve been through something that’s personal, that they’ve also been through the same thing so you have that, you, just, you have something in common”</i> <li data-bbox="421 874 2033 938">• <i>“erm, and it’s good to have somewhere you can ask, your questions or have a think because other frie, I mean other friends who haven’t been through cancer, don’t know what it’s like...they can read about it but until you’ve experienced it you don’t know, so</i> <li data-bbox="421 970 2033 1034">• <i>“there was no reason for me to know these people erm, but now, they are my friends because we’ve been something similar and you can be there for each other”</i> <li data-bbox="421 1066 2033 1083">• <i>“I think it’s broadened my friends and made me have other friends that I wouldn’t normally have got to know”</i>

Participant	Supporting Quotes
Penny	<ul style="list-style-type: none"> <li data-bbox="421 316 2024 371">• <i>“this group here... who’ve become really like best friends now because they actually, we all understand that, that that you are actually a changed person really, you’re no you’re not really ever over it because you can never quite do what you could do before”</i> <li data-bbox="421 408 2024 528">• <i>“whereas friends think you can, they don’t realise they think oh you’re just depressed and that’s all, but it’s not because the pain you know the treatment affects all your joints so you know sometimes I can barely walk and I, I’ve lost both both arms are really damaged, one with lymphedema one with erm vein damage so both of my arms are really weak erm and I have awful joint joint pain so that stops me doing a lot of things I could do before, I used to go rambling, I can’t I can’t ramble now”</i> <li data-bbox="421 564 2024 620">• <i>“...we’ve all got cancer so everybody else in the group has got joint pain and days when they can barely you know, get out of bed and, and occasionally you know, periods of depression that that then lift and are OK again”</i> <li data-bbox="421 657 2024 713">• <i>“it’s only really the new friends I’ve made here that in some ways have become I won’t say better friends but more understanding friends than than the lovely friends I had before who are still lovely”</i> <li data-bbox="421 750 2024 782">• <i>“...But don’t understand but the friends here understand because they’ve all been through the same and are still going through the same thing”</i> <li data-bbox="421 850 2024 938">• <i>“a lot of us have made really good friendships and, you know out of, out of ... we now go out you know we go the classes together, we’re on walking groups together or you know meals out or whatever so we’ve made some really good friendships ... we’ve all made like different friendship groups within this group that I think will last forever”</i> <li data-bbox="421 975 2024 1007">• <i>“I I think these friends will last my whole life I think, I do, because, because we were all in the same boat”</i> <li data-bbox="421 1043 2024 1099">• <i>“I think I get more support, from these new friends, erm I think we all go with each other you know, like one’s got a hospital appointments and we’ll all go with her and if someone’s admitted to hospital you know, we’ll all visit”</i> <li data-bbox="421 1136 2024 1192">• <i>“I think, I think there’s more actual support from the centre friends, cancer friends, erm, than from other friends really because they seem to think that, ooh you’re over it now, you know you’re better now”</i>

Participant	Supporting Quotes
Penny	<ul style="list-style-type: none"> • <i>“I knew they’d understand because they would’ve felt like that themselves and they had, the, most of them had been feeling exactly the same feelings at different times through the treatment...So that made me feel more normal that, that most of them gone gotten over it and erm, and and I mean even now everybody has the odd bad week but then there’s always a good week so that just made me more confident then that we’re all not going to feel like this forever”</i> • <i>“I never thought I would want to be around a load of cancer sufferers erm, but, but they’re not cancer sufferers are they they’re just friends who happen to have cancer”</i> • <i>“in two years some of them have become like best friends that I can imagine being friends with forever, not I wouldn’t have thought previously it was possible to make close friendships within two years I you know I would’ve thought it would take a lot longer than that”</i> • <i>“we’re not pretending we’re all honest with each other”</i> • <i>“you’re not worried about being judged erm, you can be honest and say exactly how you feel”</i> • <i>“whereas the friends I’ve met since, the, I’ve only known them since I’ve had cancer, we’ve all been through the chemo together so we’ve all been thrown together and bought wigs together and bought beds together and all the rest of it, erm, you don’t have to pretend to them because they’ve only known you since you had cancer anyway, so you don’t have to pretend to be the person you were before”</i> • <i>“... friends at this group we’re understanding so you know, help each other more without, without having to say, ooh can you do that for me you know what I mean”</i> • <i>“you don’t feel as if you’re supporting them when I’m sure we are, you feel as if they’re supporting you, do you know what I mean, I’m sure it works all the way round”</i> • <i>“...some of the new friends are fantastic in ways that old friends are not and that’s what I didn’t expect, I didn’t expect to get so much support from people I’ve only known for two years which is nothing is it two years it’s nothing”</i>

Appendix J

Excerpt from my reflexive diary

The interview today felt rushed. The participant said that she was meeting a friend for lunch and that she only had 45 minutes to spare. I felt that the interview was hurried along and that she did not want to expand on some of her answers due to time. The participant was tearful during the interview. I realised it had touched on area of her life that she had tried to forget and put behind her. I felt like I was being intrusive. I wonder if she had planned to meet her friend to limit the length of the interview and as a way of keeping herself safe. Maybe she had planned to meet a friend who could provide her with some comfort?

Section Three: Critical Appraisal

A critical appraisal of the process of researching women's experiences of friendships

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Thesis Summary

The aim of the doctoral thesis was to explore women's experiences of their friendships following a diagnosis of breast cancer. Ten women, who had received a diagnosis of primary breast cancer, were purposively recruited from seven breast cancer support groups across the North West of England and North Wales. A qualitative design using semi-structured interviews was adopted. Data were analysed using interpretative phenomenological analysis ([IPA], Smith, Flowers & Larkin, 2009). Three super-ordinate themes were selected and discussed based on the level of new understanding and novelty they brought to this area (Yardley, 2000). The first theme explored ways in which breast cancer tested women's expectations of their friendships, causing them to re-evaluate their quality and value; the second theme related to the importance of the proximity of their friends during the treatment phase of their illness; and the third described how time with friends post active treatment was re-evaluated based on the time and effort they had received from friends during their illness.

Receiving a diagnosis of breast cancer provided individuals with an opportunity to learn about the value and quality of their friendships. The findings of this study demonstrate how existing processes that take place within friendships may be amplified by a diagnosis of breast cancer, causing individuals to assess and re-evaluate their friendships. Breast cancer therefore highlights flaws within friendships, magnifying the imbalance within friendships (Moremen, 2008). These findings support Bury's (2001) concept of biographical repair as individuals are forced to renegotiate their social positioning following a diagnosis of breast cancer, based on their experiences of those around them.

The Aim of this Critical Appraisal

The aim of this critical appraisal is to discuss and reflect upon issues that arose while completing the research for this doctoral thesis. This critical appraisal explores obstacles and dilemmas I faced during the different stages of the research process, discusses limitations of the research and considers potential implications for future research in this area. As the findings in IPA research are regarded as co-constructions of the participants' experiences and the researcher's interpretations of participants' experiences, this critical appraisal will draw on entries from the reflexive diary I completed throughout this research process (Breakwell, Hammond, Fife-Shaw & Smith, 2006).

Inspiration behind the Research

Three years ago my husband's friend Tom died of oesophageal cancer at the age of 27. Tom's illness and his friendship had a significant effect on my husband and continues to underpin his 'life is too short' approach to living. Seeing how a friend's diagnosis of cancer can affect a friend, I began to think about how friendships may be experienced by those diagnosed with cancer. I gained further understanding of this area while on placement in a psychology service for oncology patients. I worked with many women who had been diagnosed with breast cancer, who often talked about the importance of their friendships and the roles they had played in their recovery. However, I was unable to find research that explored women's experiences of friendships following a diagnosis of breast cancer.

Developing the Research Question through Consultation

In order to be respectful to those involved in research and to increase its relevance, I attended a breast cancer support group to consult with the 'experts' in this area and gain advice with regards to the direction of this study (Britt, 2013). This also aligned with my values and beliefs that research should be carried out 'with' individuals as opposed to 'on' individuals.

Many of the women in the support group talked about how their friendships had changed following their diagnosis of breast cancer and how they had lost friendships and established new friendships as a result of their diagnosis. A number of women described how breast cancer had also helped them discover who their friends were. This prompted me to think about how breast cancer had done that and what processes had taken place for them to reach that point. However, this was not the experience of all group members present at that meeting. As one group member informed me that “breast cancer doesn’t change friendships in any way really, divorce does though. You should do it on divorce”. I was grateful for that group member’s contribution as it strengthened the importance of asking broad questions regarding the experience of friendships so as not to impose an understanding or assumption on participants’ experiences (Smith, Flowers & Larkin, 2009). Attending the support group therefore helped me firm up the scope of my research and develop my research question.

Recruitment Process

Many of the women with whom I had previously worked with while on placement in the oncology service explained how busy they had been during the treatment stage of their illness and how many demands had been placed on them throughout that time. Research notes that patients can be extremely affected by the side effects of cancer treatments (Pedersen, Koktved & Nielsen, 2013). It was also frequently reported that it was not “until the dust had settled” that they began to reflect on their experiences and think about their life as a cancer survivor. This is supported by previous research which regards the time after treatment as a transition period in which individuals shift from patient to survivor (Arnold, 1999). Based on my previous experience and the research discussed, I felt that it would be more appropriate to contact individuals to participate in this research who had completed active treatment for cancer in the form of radiotherapy, chemotherapy and surgical

procedures following their initial diagnosis. I therefore decided to recruit participants through support groups rather than through hospital services.

I initially approached five breast cancer support groups in September 2014. Due to the initial lack of response, I contacted a further five support groups one month later. Upon reflection, approaching additional support groups was unnecessary as more than twenty women in total offered to participate in this study. I had misinterpreted the initial lack of response from the support groups as a lack of interest in this research and failed to acknowledge the frequency of their group meetings. Many of the groups met on a monthly/bimonthly basis and had therefore not been given enough time to receive and process the information I had sent out. Many of the groups also reported to have been getting ready for Christmas and had been busy with choir rehearsals and the planning of Christmas events. When carrying out research in the future, I aim to be mindful as to how the time of year may impact on recruitment, give potential participants more time to read and consider information and approach research with more patience.

During the initial contact with potential participants, I asked questions to illicit further information about their diagnosis, in order to ensure that the inclusion and exclusion criteria for this research had been met. I felt very uncomfortable asking individuals I had never met before about their medical history. Although it felt quite intrusive, the women informed me of their experiences without any hesitation. This made me think about their previous experiences of being asked about their diagnosis, for it to have been discussed without hesitation.

One woman who offered to participate in this research had received a diagnosis of metastatic breast cancer, which meant that her primary diagnosis of breast had spread to different parts of her body, and therefore did not meet the inclusion criteria of this study. She explained that there had also been other things that she was not able to participate in due to

her metastatic diagnosis. I was concerned how declining her offer of participation and exclusion from this research may have been received. It would have been helpful and potentially less disheartening to have been able to sign post her to a further study that was more suited to her diagnosis.

Data Collection

Providing Space and Interjecting

During the first interview, I found it difficult to ask exploratory questions to elicit further detail from the participant's responses. I felt nervous in wanting to 'get it right' and therefore used the interview schedule as a rigid structure rather than a flexible guide (Smith, Flowers & Larkin, 2009). I listened to the first interview with my supervisor and reflected on the approach I had adopted. We talked about the importance of asking exploratory questions to elicit meaning and gain further understanding of the participants' experiences. I recognised that it was my responsibility as the researcher to guide the participants and help them explore their interpretations and meaning in order to produce representative findings.

Guidance suggests that it is important to recognise the potential power imbalance between the researcher and the participant (The British Psychological Society [BPS], 2010). In wanting to reduce that power imbalance I, at times, refrained from interrupting participants during the interviews when they talked about things that were not relevant to the aim of this research. Although I potentially made more work for myself adopting this approach (i.e. transcribing long interviews), I feel that it helped me build a rapport and trust with the participants who were then able to provide detailed responses to later questions regarding their friendships. I also felt extremely grateful that they had given me their time and volunteered to participate in this research and therefore felt that I needed to repay them with my time by listening to what they wanted to say. This concept of repaying the participants

with my time mirrored the findings of this research – i.e. concluding that time is regarded a currency that is reciprocated and exchanged between individuals (Foa, 1973).

The Importance of ‘Giving Back’

Many women stated that they had never previously talked about some of the topics that were discussed during the interviews and a number of women were tearful throughout the process. When asked if they wanted to continue, the women talked about wanting “to help” and “give back” and appeared to approach the process as something they ‘had to do’ rather than something that they may have ‘wanted to do’. I was respectful of their decision to continue and privately acknowledged my discomfort and worry that I had upset them by revisiting such difficult experiences. However, in volunteering to participate in this research, I felt that the women had something important to say and that my role was to provide them with the space for their experiences to be heard. Women diagnosed with breast cancer are recognised as being an active, committed group of individuals, who have a voice in determining what research priorities are funded in this area (Marshall, 1999). The extensive amount of research with women diagnosed with breast cancer also reflects their dynamic and active approach (Braun, 2003).

Participants’ approach to research may have also been linked to Bury’s (1982) concept of biographical disruption, in that the diagnosis of breast cancer brought thoughts of death and mortality to the forefront of their minds. Taking part in research may have been a participant’s way of doing more with their time, which they may have perceived to be limited. Many women reported to think about cancer and death on a daily basis and therefore ever present in their lives (Mathieson & Stam, 1995).

The Impact of the Environment

The interviews varied in length from 42 minutes to 123 minutes. Upon reflection, interviews that took place in the cancer support centres were shorter ($M = 54$ minutes) than

interviews that had taken place in participants' homes ($M = 81$ minutes). It is also important to note that participants who were interviewed in the support centres were the same participants who became upset during the interview process. Approaching the interviews as a formal, time limited appointment, may have been used as a strategy to ensure limits and boundaries were maintained. This may have also helped the participants feel safer when discussing personal details with someone they had never met before. Those individuals may have also foreseen the process as something that would be upsetting and therefore chose to be interviewed in an environment where they could seek comfort and reassurance from their friends following the interview. When planning this research, I thought about ways in which I could protect my safety and adhered to lone working policies throughout. I had not anticipated that participants may have also been concerned about their emotional safety which could have influenced the location of each interview.

Analysis

Data were analysed using interpretative phenomenological analysis (IPA). I followed a step-by step approach to analysis and demonstrated an audit trail of this process to strengthen the findings of this research (Smith, 2011; Yardley, 2000). I reviewed two transcripts during supervision to explore my initial interpretations of the data. I also used supervision to review super-ordinate themes to ensure the identified themes were representative of the data and further strengthen the trustworthiness of my interpretations (Elliot, Fischer & Rennie, 1999; Rodham, Fox & Doran, 2015; Smith, Flowers & Larkin, 2009).

I listened to each interview three times and read each interview twice to immerse myself in the data and acquire a holistic understanding of the experience of each participant. Although the accounts of some of the participants were at times upsetting to hear, I felt

uplifted when listening to positive experiences of support they had received from their friends.

Participants' experiences of friendships prompted me to think about my own concept of friendship and reflect upon the support I had provided to friends over recent months. Due to the demands of the doctoral training course, I had not seen as much of my friends as I would have previously. I began thinking about the experiences of the friends who had not been there to support the participants through their illness and wondered what may have been going on in their own lives, which may have prevented them from being able to support the participants in this research.

While my friends have often commented on my lack of availability over recent months and have been honest with me about their experiences of my friendship, I was surprised when participants felt unable to be honest with their friends about their experiences. Participants did not explain their feelings to friends who had been unsupportive or ask them questions to gain further understanding. Many participants talked about distancing themselves from unsupportive friendships by avoiding telephone contact and making excuses not to meet with them. These observations are supported by research which explored friendships of women over the age of 55 which found that strain and conflict within friendships were reported to have been avoided, as they ignored problems and distanced themselves from strained relationships (Moremen, 2008). Rather than exploring the difficulties within their friendships, the women in this research approached strained friendships by ignoring and distancing themselves from unsupportive friends. Although research suggests that receiving a diagnosis of breast cancer increases women's empathy for others, I felt at times that the participants in this research struggled to empathise with those they had previously considered to be their friends (Horgan, Holcombe & Salmon, 2011). Again this made me think about my own concept of friendship and how my expectations

regarding honesty and openness within a friendship may have at times been different from the participants in this research.

Participants also talked about concealing their emotional distress and putting on a performance for some friends, to maintain a sense of “normality” (Cowley, Heyman, Stanton & Milner, 2000). One participant in particular talked about hiding her true feelings from ‘old’ friends that she had known for a long time, while being honest with ‘new’ friends she had more recently met at the cancer support centre. The participant often talked about how her ‘old’ friends did not understand how she was feeling and did not provide her with the support she needed. Whereas the ‘new’ friends who had been through a similar experience, were reported to know implicitly how she was feeling. During the analysis process I found myself feeling defensive at times for the participant’s ‘old’ friends, who were unaware of how she was feeling and therefore unable to provide her with the support that she wanted and needed. Although she talked about feeling like two different people, she also talked about how important it was that she could feel like her old self, rather than “a cancer patient”. Research exploring the narratives of those attending cancer support groups found that some individuals felt the need to draw on the support of those who have been through a similar experience, seeking support outside of their established social circle (Yaskowich & Stam, 2003). This participant may have used the support of those from the cancer support group to meet that need, enabling her to maintain her ‘old’ self with her ‘old’ friends. This also chimes with previous research which found that individuals diagnosed with cancer are forced to balance the old self and new self (Mathieson & Stam, 1995). In this instance, ‘old’ friends and ‘new’ friends were used to help the participant distinguish between her two selves.

During analysis, I also found myself wanting to find out more from certain aspects of the interviews and noted a number of questions on each transcript during the analysis process.

With that in mind, it may have been helpful to have revisited the participants for a second interview to seek further clarification and meaning of their responses.

Limitations

For a small number of women in this study, their diagnosis of breast cancer coincided with their retirement from work. Retirement may have also been experienced as a moment of significant change which could have also affected participants' experiences of friendships. Including work status as a recruitment criterion could have further strengthened the homogeneity of the sample.

It may have also been helpful to have included age as a further recruitment criterion, as the ages of the women in this sample ranged from 49-68 years. The experiences of friendships for a woman at the age of 49 may have been different to that of a woman aged 68 years. Again, including age as a further criterion may have also further strengthened the homogeneity of this sample.

Future Research

Participants in this research were recruited through breast cancer support groups and may in some way have been dissatisfied by the support received from existing friends and therefore forced to seek further support from a group. It may be useful for future research to explore the experiences of women who do not seek further support from a support group, to see if their experiences of friendships differ from the experiences of the participants in this research.

It would be helpful for future research to explore the experiences of those who were reported to have distanced themselves from the participants or who were described as being unsupportive. It would be helpful to discover what may have been going on for them at that time and how they had experienced their friend's diagnosis.

Conclusion

Completing this study has strengthened my thoughts regarding the importance of consultation in research. I feel that the consultation I carried out at the start of this research process helped guide the direction and relevance of this study. I aim to draw on 'the experts' further to guide future research projects and support clinical practice. Many of the reflections discussed throughout this critical appraisal were based on excerpts from my reflexive diary. Completing the reflexive diary and seeking guidance in the form of supervision throughout this process has helped shape the decisions made at the various stages of this research. It also enabled me to acknowledge my strengths and weaknesses as a researcher, aiding my development. I aim to develop my skills further as a qualified clinical psychologist by remaining actively involved in research.

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doi: 10.1177/13591053030086006.

Section Four: Ethics Section

Nicola Edwards

Lancaster University

Word Count: 2597

All correspondence should be sent to:

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Lancaster University

Lancaster

LA1 4YG

**Faculty of Health and Medicine Research Ethics Committee (FHMREC)
Version 7**

Lancaster University

Application for Ethical Approval for Research

<p>1. Title of Project:</p> <p>The experience of friendships following a diagnosis of breast cancer.</p>
<p>2. If this is a student project, please indicate what type of project by ticking the relevant box:</p> <ul style="list-style-type: none"> • DClinPsy Thesis
<p>3. Type of study</p> <ul style="list-style-type: none"> • Involves direct involvement by human subjects

Applicant information
<p>4. Name of applicant/researcher:</p> <p>Nicola Fedyszyn¹</p>
<p>5. Appointment/position held by applicant and Division within FHM</p> <p>Trainee Clinical Psychologist</p>
<p>6. Contact information for applicant:</p> <p>E-mail: [REDACTED] Telephone: [REDACTED] Address: Clinical Psychology, Division of Health Research, Lancaster University, Furness College, Lancaster, LA1 4YT</p>
<p>7. Project supervisor(s), if different from applicant:</p> <p>Name: [REDACTED] E-mail: [REDACTED]</p> <p>Name: [REDACTED] E-mail: [REDACTED]</p>

¹ Please note: Nicola Fedyszyn was my maiden name. The ethics committee were made aware that my name changed to Nicola Edwards during this research.

8. Appointment held by supervisor(s) and institution(s) where based (if applicable):

[REDACTED]

[REDACTED]

9. Names and appointments of all members of the research team (including degree where applicable)

Nicola Fedyszyn: Principal researcher
 [REDACTED] Thesis supervisor
 [REDACTED] Field supervisor

The Project

NOTE: In addition to completing this form you must submit a detailed research protocol and all supporting materials.

10. Summary of research protocol in lay terms (maximum length 150 words).

When diagnosed with cancer, people are faced with crisis and uncertainty and often draw on their friends for support (Brennan, 2004). Research exploring the effects of social support on the survival of women diagnosed with breast cancer found friendships to be important in terms of survival rates (Waxler-Morrison, Hislop, Mears & Kan, 1991). Bloom (1982) suggests that social support from friends is helpful for women with breast cancer as it reduces the amount of effort they have to make in order to cope. However some people diagnosed with cancer have described their interactions with those outside of the family as strained, as they can display similar levels of distress to themselves (Dunkel-Schetter, 1984). Research exploring friendships following a diagnosis of breast cancer is lacking. Further understanding could help individuals to make sense of their experiences. Using a phenomenological approach, this research seeks to explore how friendships are experienced following a diagnosis of breast cancer.

11. Anticipated project dates

Start date: August 2014 End date: May 2015

12. Please describe the sample of participants to be studied (including number, age, gender):

- The sample for this research will consist of between four and ten women who have received a diagnosis of breast cancer within the last three years (between January 2011 and December 2013). I have chosen women diagnosed within this time period, to ensure that participants are able to reflect on experiences gained within a similar time frame to further increase the homogeneity of the participants.
- Participants will be sought using purposive sampling methods to increase the homogeneity of the sample, required for IPA research.
- Participants will be recruited from cancer support groups within the North West of England and North Wales.

Inclusion criteria:

- Women who have received a diagnosis of breast cancer within the last three years (between January 2011 and December 2013).
- Women who are over the age of 18.

Exclusion criteria:

- Women who have received a diagnosis of breast cancer outside of the specified time frame.
- Women who have received a diagnosis of metastatic breast cancer².

13. How will participants be recruited and from where? Be as specific as possible.

- Participants will be recruited from cancer support groups in the North West of England and in North Wales.
- The recruiting support groups are run by charity organisations or led by the patients themselves. The support groups are not funded by the NHS and do not run meetings on NHS property. I felt that it would be more appropriate to recruit participants outside of the hospital setting. Participants diagnosed with breast cancer within the last three years may still be attending hospital appointments for treatment and/or further testing, and I therefore did not feel that it was appropriate to contact them about research at that time.
- Approval from the research and development department of each charity organisation will be sought prior to recruitment.
- During the first month of the recruitment phase of this research project, I will contact the first five support groups. This will be extended to further groups if the recruitment target is not met. I will contact the support groups by e-mail or by telephone. I will also attend the support groups to explain the aims, rationale and target sample of the research to the group members.
- Individuals attending the support group that meet the inclusion criteria set for this research will be provided with an information pack. The information pack will consist of a letter to the potential participant, an information sheet, a 'consent to contact' form, a consent form and a pre-paid self-addressed envelope. Participants will opt-in to the research by completing a 'consent to contact' form or by contacting me directly through my University e-mail address or phone number.
- I will also ask each support group if it would be possible to display a poster explaining the aims of the research and how they could contact me for further information.
- I will explain that a number of participants will be purposively selected from a range of the recruiting support groups.

Participants will be recruited from the following support groups:



² Metastatic breast cancer: Breast cancer that has spread to different parts of the body.



14. What procedure is proposed for obtaining consent?

- Participants in this research will be required to opt-in, using the contact details on the information sheet, or by returning the opt-in consent slip provided in the information pack.
- Written consent will be sought at the time of the interview, prior to the interview taking place.

15. What discomfort (including psychological), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks.

- The questions asked at interview may be regarded by some as intrusive in nature, as I will be asking participants about their personal experiences and feelings around a potentially sensitive topic. Participants could become upset or distressed during the interview process. I will try to make participants feel as comfortable as possible and provide them with the adequate space and time needed during the interview process.
- The interview questions may raise things about their friendships that they had not considered before, which participants may find distressing.
- Participants will be reminded that they do not have to answer all the questions asked if they do not want to and that they can take a break if they need to.
- Participants will be reminded of the limits of confidentiality at the start of each interview. If a participant discloses information which poses a risk to themselves, or a risk to others, I will inform the participant that confidentiality will need to be broken. I will then explain that the information will need to be shared with appropriate professionals/agencies and with my project supervisor. Where possible, the participant will be informed at each stage of the process.
- Taking part in this research may be an inconvenience to the participant as the interview will take up approximately an hour of their time.
- Participants have the opportunity to withdraw their data within two weeks of taking part. Once the interview data has been anonymised and put into themes it might not be possible for data to be withdrawn, though every attempt will be made to do so. Participants will be reminded of this at the time of the interview.
- Each participant will be given an information sheet outlining the details of this research, and the role I will be adopting as the principal researcher. This information defines my role as a researcher, and states that I will not be acting in a therapeutic capacity. It states that I cannot offer therapeutic advice or consultation at any point during the research process. If participants begin to seek therapeutic advice, I will remind participants of my role as a researcher.
- Participants in this research may be experiencing difficulties as a result of their current situation, and may request information about professional support. If this situation occurred, I would sign post participants to their G.P. or provide the phone number for the Macmillan cancer support line.

16. What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, details of a lone worker plan).

Risk to Investigator:

- There may be unknown risks to the researcher when conducting interviews, as the researcher will have no prior information about the participants in this study.
- Interviews will be carried out in community centres or in the participants' homes (to increase accessibility to participate in this research).
- Lancashire Care Foundation Trust, and Lancaster University lone worker policies will be adhered to.
- I have been trained in de-escalation and breakaway techniques.

Before each interview I will make sure:

- My mobile phone is fully charged.
- My car has enough petrol to get there and back.
- My car is parked in a way that facilitates a quick exit (i.e. turn car around if necessary before the interview).
- I will inform my 'buddy' of:
 - The date, time, and location that the interview will be taking place.
 - The first name and contact number of the interviewee, and state how long the interview will last.
 - My personal and work phone number, car make and registration.
 - An emergency contact
 - The name of the research supervisor for this project

I will:

- Call my 'buddy' before the interview to let them know I have arrived at the location and what strength of signal I have on my phone.
- Let my 'buddy' know what time I am expected to complete the interview (allowing for an unexpectedly long interview).
- Inform the interviewee that the interview will last approximately x amount of time, and I will have to call my colleague to let them know if we need more time.
- Start the recording as soon as possible, and end it as late as possible in the interview process.
- If the interviewee has any pets that make me feel uncomfortable, politely ask if they can be put in another room during the interview process.
- Try to sit as near to the exit as possible.
- Keep my phone out, but on silent so that I am able to see if my 'buddy' is trying to make contact.
- Call 'buddy' after the interview has finished and let them know that I am safe in my car, with the doors locked.
- If the interview takes more time than expected, text buddy or call 'buddy' to let them know the expected completion time.
- If I feel that I am in any danger at any point during the interview- I will make my excuses and leave. If I need to, I will call my 'buddy' and ask them if my next appointment has arrived to help facilitate my exit from the situation. If I feel that I am in danger and I can't get out, I will text or call my buddy using the code word Mavis to let them know that I am in trouble. For example 'could you let Mavis know I'm running late for our appointment'.

- If my 'buddy' is unable to make contact with me at the time agreed (on either phone number), they should call the interviewee and ask to speak to me.
- If my 'buddy' is not been able to make contact with me through these means, they should contact the project supervisor.
- If my 'buddy' cannot make contact the research supervisor or remains concerned, they should contact the police.

17. Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study.

There will be no direct benefits for those taking part in this research.

18. Details of any incentives/payments (including out-of-pocket expenses) made to participants:

Participants will be refunded any travel expenses incurred up to a maximum of £10.

19. Briefly describe your data collection and analysis methods, and the rationale for their use:

- A phenomenological approach will be used to gather the data for this research, as this was deemed to be the most suitable approach when exploring individuals lived experiences (Smith, Flowers & Larkin, 2009).
- Data will be analysed using interpretative phenomenological analysis (IPA). IPA enables individuals to explore their experiences, and the meaning they place upon those experiences, in their own terms (Smith, Flowers & Larkin, 2009). IPA is most suitable for exploring phenomena, relationships, or events that are deemed to be important to the individual, and aims to explore how the individual makes sense of their experiences (Smith, Flowers & Larkin, 2009).
- Data will be collated using semi-structured interviews with between four and ten participants. A small sample has been noted to provide an adequate perspective of individuals' experiences due to the homogenous, purposive sampling methods adopted in research IPA (Smith & Osborn, 2003). Interviews allow rich detailed accounts of an individual's experiences to be explored (Fade, 2003).
- I will transcribe each interview recording as a way of familiarising myself with the data.
- I will review one interview recording and one analysed transcript with my research supervisor and field supervisor, to strengthen the validity and coherence of the interpretation (Smith, Flowers & Larkin, 2009). I will regularly meet with my research supervisor and field supervisor to minimise potential biases and attempt to increase the validity of the analytic process.
- Findings in IPA research are co-constructions of the participants' experiences and the researchers' interpretations of their experiences; I will complete a reflexive diary to reflect upon my understandings and interpretations throughout (Breakwell, Hammond, Fife-Shaw & Smith, 2006).
- Each interview will last approximately one hour, and will be carried out on a one-to-one basis.

20. Describe the involvement of users/service users in the design and conduct of your research. If you have not involved users/service users in developing your research protocol, please indicate this and provide a brief rationale/explanation.

- I attended the breast cancer support group in Wrexham, North Wales. I discussed the aims of the research, potential recruitment strategies and the contents of the interview schedule.
- I discussed the aims of the research with two clinical psychologists working within oncology psychology services in the North West of England.

21. What plan is in place for the storage of data (electronic, digital, paper, etc.)? Please ensure that your plans comply with the Data Protection Act 1998.

- Paper copies of information (i.e. consent to contact forms, demographic information, participant consent forms) will be scanned and stored electronically on a secure, password protected electronic University file within 2 hours of receiving the documents. All paper copies of information will then be shredded using a criss-cross shredder.
- Electronic information (i.e. consent to contact forms, demographic information, participant consent forms, interview transcripts) and audio digital recordings of the interviews will also be stored on a secure, password protected electronic University file. Electronic information will be stored by the University for 10 years after the research has finished as stated in the Lancaster clinical psychology doctorate guidance. Audio recordings will be deleted by myself after the project has been marked.
- After the 10 years, all electronic data will be destroyed and/or deleted by the Lancaster clinical psychology doctorate training programme administration team.
- Interview transcripts will be anonymised. During the analysis process, paper copies of anonymised transcripts will be stored in a locked filing cabinet. Following the analysis process, all paper copies of anonymised transcripts will be shredded using a criss-cross shredder.

22. Will audio or video recording take place?

- Audio

If yes, what arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files be destroyed?

- I will audio record each interview using a digital recorder with the participants consent.
- After each interview, I will download the audio recording onto a secure, password protected electronic University file as it is not possible to encrypt the portable device.
- Audio recordings of the interviews will be deleted from the digital recorder immediately after each file has been uploaded to a secure, password protected file space.
- Audio recordings will be deleted from the password protected electronic University file after the project has been marked.

23. What are the plans for dissemination of findings from the research?

- A post-study summary of the research findings will be sent out to the participants that took part in this research.
- I will present the findings of this research at:
 - The Lancaster University thesis presentation day
 - The support groups involved in the recruitment process.
 - The Liverpool Oncology Psychology Service
- I will also submit the findings of this research for publication to a relevant academic journal.

24. What particular ethical problems, not previously noted on this application, do you think there are in the proposed study? Are there any matters about which you wish to seek advice from the FHMREC?

- As I live in the [REDACTED], and have completed a placement at a local oncology psychology service, I may receive a 'consent to contact' form someone I know. In this instance, I would contact the potential participant and explain that I would be carrying out the interview and ask them how they would feel about that. If the participant would like to continue as a participant, I would arrange a date and time to carry out the interview.
- At the start of each interview I will describe what confidentiality is and its limits. If a participant discusses something that is deemed to be of risk to themselves or someone else, I will discuss this with the participant and explain that I will need to share that information with the appropriate professionals/agencies. I will keep the participant informed at every stage of the process, unless that has the potential to increase the level of risk. I will also discuss this ethical area with my project supervisor.

Applicant: Nicola Fedyszyn

Signature:

Date: 20.07.2014

Project Supervisor: [REDACTED]

Signature:

Date: 20.07.2014

*I have reviewed this application, and discussed it with the applicant. I confirm that the project methodology is appropriate. I am happy for this application to proceed to ethical review.

Appendix A

Thesis Protocol: Version 7

Title

The experience of friendships following a diagnosis of breast cancer.

Details

Name of applicant: Nicola Fedyszyn, Trainee Clinical Psychologist

Name of research supervisor: [REDACTED]

[REDACTED]

Name of field supervisor: [REDACTED]

Care.

Version number: 7

Introduction

When diagnosed with cancer, people are faced with crisis and uncertainty and often draw on their friends as a form of support (Brennan, 2004). Although friends may provide less support than family members in terms of time, it has been suggested that satisfaction is higher with the support provided by family members (Neuling & Winefield, 1988). This suggests that support from friends may hold a different value and meaning to an individual than support received from other sources.

Moreover, research exploring the effects of social support on the survival of women diagnosed with breast cancer found friendships to be important in terms of survival rates (Waxler-Morrison, Hislop, Mears & Kan, 1991). Women in this research were reported to rely heavily on their friends for practical support such as driving to hospital appointments and looking after their children. It was also

reported that, for some, friendships changed as a result of their diagnosis as some friends struggled to manage their own discomfort of being around someone with a life threatening condition. However, a more detailed assessment of how this was experienced and how the women in this research made sense of those changes was not explored.

Bloom (1982) suggests that social support from friends is helpful for women with breast cancer as it reduces the amount of effort they have to make in order to cope with their diagnosis. Therefore social support from friends enables individuals to manage better the stresses associated with the illness. However some people diagnosed with cancer have described their interactions with those outside of the family as strained, as they can display similar levels of distress to themselves (Dunkel-Schetter, 1984). Research also suggests that friends of an individual diagnosed with cancer can feel helpless and frightened by the diagnosis (Davison, Pennebaker, & Dickerson, 2000). How this is experienced by the individual diagnosed with cancer is not fully understood.

Research exploring the narratives of individuals attending cancer support groups found that some individuals turn to the support of those who have been through a similar experience (Yaskowich & Stam, 2003). This research found that some people diagnosed with cancer can be left feeling isolated in their social world, as those around them do not know what to say or do (Yaskowich & Stam, 2003). Therefore some people look for support outside of their established social circle, forming new friendships with people from a cancer support group (Yaskowich & Stam, 2003). Research exploring how friendships are experienced by individuals who have been diagnosed with cancer and what changes take place within those friendships is lacking.

Brennan (2004) states that assumptions can be made by an individual diagnosed with cancer with regards to how a friend may react in a certain situation, and how those assumptions do not always fit with the reality of a friend's response. Therefore individuals faced with a life changing event such as cancer, may find that their friend's react in an unexpected way. How this is experienced and how individuals manage the nature of the responses of their friends is not yet fully understood. Further understanding could help individuals to make sense of their experiences, and therefore help support people through their cancer journey.

This research will focus on the experiences of women who have been diagnosed with breast cancer as this is a common type of cancer diagnosed in women (Brennan, 2004). The diagnosis of breast cancer and the burden of the treatments following a diagnosis can be overwhelming (Pedersen, Sawatzky & Hack, 2010). Many women who survive breast cancer are left with pain, numbness, swelling, worrying thoughts that the illness will return, and anxieties regarding follow-up medical appointments (Polinsky, 1994). Breast cancer has been described as a chronic illness as those diagnosed often experience lifelong psychological effects, follow-up treatments and appointments, changes in employment and changes in social relationships. Breast cancer also tends to affect women at an age when they have a number of established friendships. How the aforementioned difficulties contribute to the experience of those friendships has not yet been explored.

Consequently, research exploring friendships following a diagnosis of breast cancer is lacking. Using a phenomenological approach, this research seeks to explore how friendships are experienced following a diagnosis of breast cancer,

how they are understood by the individual, what changes take place within those friendships and what sense is made of those friendships.

Method

Design

A phenomenological approach will be used to gather the data for this research as this is the most suitable approach when exploring individuals' lived experiences (Smith, Flowers & Larkin, 2009). Data will be analysed using interpretative phenomenological analysis (IPA). IPA enables individuals to explore their experiences, and the meaning they place upon those experiences, in their own terms (Smith, Flowers & Larkin, 2009). IPA is most suitable for exploring phenomena, relationships or events considered to be important to the individual and aims to explore how the individual makes sense of their experiences (Smith, Flowers & Larkin, 2009).

Data will be collated using semi-structured interviews with between four and ten participants. A small sample has been noted to provide an adequate perspective of individuals' experiences due to the homogenous, purposive sampling methods adopted in research using IPA (Smith & Osborn, 2003). Semi-structured one-to-one interviews allow rich detailed accounts of an individual's experiences to be explored, and enable additional clarification questions to be asked (Fade, 2003).

Each interview will last approximately one hour, and will be carried out on a one-to-one basis. Participants will be recruited from cancer support groups in the North West of England and North Wales.

Sample

Participants will be sought using purposive sampling methods to increase the homogeneity of the sample, required for IPA research. The sample for this research will consist of between four and ten women who have received a diagnosis of breast cancer within the last three years (between January 2011 and December 2013). I have chosen women diagnosed within this time period, to ensure that participants are able to reflect on experiences gained within a similar time frame to further increase the homogeneity of the participants. Participants will be purposively selected from a range of the recruiting support groups.

Inclusion criteria:

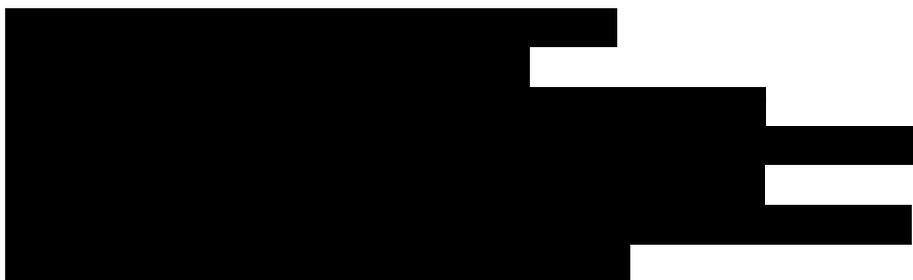
- Women who have received a diagnosis of breast cancer within the last three years (between January 2011 and December 2013).
- Women who are over the age of 18.

Exclusion criteria:

- Women who have received a diagnosis of breast cancer outside of the specified time frame.
- Women who have received a diagnosis of metastatic breast cancer³.

Recruitment Strategy

Participants will be recruited from the following cancer support groups in the North West of England and in North Wales;



³ Metastatic breast cancer: Breast cancer that has spread to different parts of the body.



During the first month of the recruitment phase of this research project, I will contact the first five support groups to avoid over-recruitment. This will be extended to further groups if the recruitment target is not met. I will contact the cancer support groups by e-mail (see protocol appendix A) or by telephone. I will attend the cancer support groups to explain the aims, rationale and target sample of the research to the group members. Approval from the research and development department of each charity organisation will be sought prior to recruitment.

The recruiting support groups are run by charitable organisations or led by the patients themselves. The support groups are not funded by the NHS and do not run meetings on NHS property. I felt that it would be more appropriate to recruit participants outside of the hospital setting. Participants diagnosed with breast cancer within the last three years may still be attending hospital appointments for treatment and/or further testing, and I therefore do not feel that it is appropriate to contact them about research when at a hospital.

Individuals attending the support group will be provided with an information pack. The information pack will consist of a letter to the potential participant, an information sheet explaining the research project in further detail, a 'consent to contact' form, a consent form and a pre-paid self-addressed envelope (see protocol appendix B, C, D, E). Participants will opt-in to the research by completing a 'consent to contact' form (see protocol appendix D), or by contacting

me directly through my Lancaster University e-mail address or phone number. I will check, at this stage, that each potential participant meets the inclusions criteria set for this research.

I will also ask each support group if it would be possible to display a poster (see protocol appendix F) explaining the aim of the research and how they could contact me for further information. I will also explain that participants will be purposively selected from a range of the recruiting support groups and that I may not be able to interview everyone who would like to take part in this research.

Materials

Interviews will be guided by a semi-structured interview schedule consisting of open-ended questions (see protocol appendix G). The interview questions are broad in nature, so as not to impose my understanding of the topic area on the participants' experiences (Smith, Flowers & Larkin, 20009).

At the start of each interview, basic demographic information for each participant will be collated (see protocol appendix H). Participants will be reminded that they do not have to answer any questions that they do not want to answer. With participants' consent, interviews will be digitally audio recorded and transcribed verbatim. After each interview, the audio recording will be downloaded onto a secure password protected electronic University file at the earliest opportunity as it is not possible to encrypt the portable recording device. This data can be accessed remotely if necessary. Audio recordings of the interviews will be deleted from the digital recorder immediately after each file has been uploaded to a secure, password protected file space.

To protect the confidentiality of each participant, identifiable information will be removed from each transcript prior to analysis. Each transcript will be

given a unique reference number (to enable links to be made to data). During the analysis process, paper copies of anonymised transcripts will be stored in a locked filing cabinet. Following the analysis process, all paper copies of anonymised transcripts will be shredded using a criss-cross shredder. Following the analysis of the interviews, themes identified will be stored electronically on the university secure network.

During the research process, paper copies of information (i.e. demographic information, participant consent forms) will be scanned (within two hours of receipt) and stored electronically on a secure, password protected electronic University file. All paper copies of information will then be shredded using a criss-cross shredder. Electronic copies of participants' data and information will be stored for up to ten years following completion of research, in order to ensure an audit trail is available (as stated in the Lancaster clinical psychology doctorate guidance). Audio recordings of the interviews will be deleted after the research project has been marked.

Practical issues

Each participant will be reimbursed travel costs up to the maximum value of £10. Postage, printing and photocopying costs, will be funded by Lancaster University. A Lancaster University mobile phone will be used to contact participants.

Procedure

Written consent will be sought from participants immediately prior to the interview taking place (see protocol appendix E). Interviews will take place in community centres, local to the participant, or in their own homes (to increase accessibility to the research). Rooms will be pre-booked (if necessary) and easily accessible to the participants.

I will meet the participants individually at their arranged time and location to carry out the interview. The interview will last approximately one hour. The interview process will be explained to participants at the start and referred to again during the interview, if necessary. At the end of the interview, participants will be asked to complete a Lancaster University travel claim form. This will be collected, along with their travel receipts. Travel costs up to the value of £10 will be reimbursed to the participants by post.

Participants have the opportunity to withdraw their data within two weeks of taking part. Once the interview data has been anonymised and put into themes it might not be possible for data to be withdrawn, though every attempt will be made to do so. Participants will be reminded of this at the time of the interview.

Proposed Analysis

The data will be analysed using IPA to gain detailed understanding of the ways in which the participants make sense of their experiences (Chapman & Smith, 2002). I will review one interview recording and one analysed transcript with my research supervisor and field supervisor, to strengthen the validity and coherence of the interpretation (Smith, Flowers & Larkin, 2009). I will regularly meet with my research supervisor and field supervisor to minimise potential biases and attempt to increase the validity of the analytic process.

Findings in IPA research are co-constructions of the participants' experiences and the researchers' interpretations of their experiences; I will complete a reflexive diary to reflect upon my understandings and interpretations throughout (Breakwell, Hammond, Fife-Shaw & Smith, 2006).

Dissemination of research findings

After each interview, I will ask the participants if they would like to receive a summary of the findings. Those who requested this information will be sent a summary of the research findings in the post. In this summary, I will also offer participants the opportunity to discuss the findings in further detail over the telephone. I will offer to discuss a summary of the findings at the recruiting breast cancer support groups in the North West of England and in North Wales. Findings of this research will also be disseminated to fellow colleagues at Lancaster University, and submitted for publication to a relevant journal.

Ethical Concerns

Ethical approval for this research project will be sought through the Faculty of Health and Medicine REC (FHMREC) and Lancaster University REC (UREC).

Risk to participants or researcher:

- Before each interview, written consent will be sought from each participant (see protocol appendix E).
- Participants will be reminded that that they have the right to withdraw their data from this research up to two weeks of taking part. Once the interview data has been anonymised and put into themes it might not be possible for it to be withdrawn, though every attempt will be made to do so.
- Participation in this research is entirely voluntary and participants will not experience any repercussions for their withdrawal.
- Each participant will be given an information sheet (see protocol appendix C) outlining the details of this research and the role I will be adopting as the principal researcher. This information defines my role as a researcher, and states that I will not be acting in a therapeutic capacity. It states that I cannot

offer therapeutic advice or consultation at any point during the research process. If participants begin to seek therapeutic advice, I will remind participants of my role as a researcher.

- Participants in this research may be experiencing difficulties as a result of their current situation or experience emotional distress as a result of the interview procedure. If this situation occurred, I would sign post participants to their G.P. or provide the phone number for the Macmillan cancer support line.
- At the start of each interview I will describe what confidentiality is and its limits. If a participant discusses something that is deemed to be of risk to themselves or someone else, I will discuss this with the participant and explain that I will need to share that information with the appropriate professionals/agencies and also my research supervisor. I will keep the participant informed at every stage of the process, unless that has the potential to increase the level of risk.
- The questions asked at interview may be regarded by some as intrusive in nature as I will be asking participants about their personal experiences and feelings around a potentially sensitive topic. Participants could become upset or distressed during the interview process. I will try to make participants feel as comfortable as possible when expressing this emotion, and provide them with the adequate space and time needed during the interview process. I will also remind participants that they are able to take breaks at any time during the interview process.
- Participants will be reminded that they do not have to answer every question asked.

- I will make every attempt to make participation in this research as accessible as possible by carrying out interviews in the participants' home or local community centre.
- The University Safety and Health Association (USHA, 2005) and Lancashire Care Foundation Trust (LCFT, 2013) lone working policies will be adhered to throughout this research process.

Timescales

Date	Research Paper and project management	Literature Review	Ethics Proposal	Critical review	Appendices and Abstract
April 2014	Finalise choice of strategy.	Collect and organise references for literature review.	Identify ethics committee. Get forms and deadlines.	Start reflective diary.	
May -June 2014	Agree research timetable.	Collect and organise references for literature review.	Prepare and submit ethics proposal (25.6.2014)		Keep copy of ethics documentation and correspondence
July 2014			Make amendments and resubmit ethics documentation as requested.	Reflect on ethics process in diary	
Aug- Sept 2014	Collect data. Develop analysis strategy. Choose journal for research paper	Choose journal for literature review paper		Reflect on data collection process.	
Sept - Oct 2014	Analyse data			Reflect on thoughts during analysis and record in diary.	
Oct -Dec 2014	Review analysis of data. Write draft version of method and introduction.	Hand in draft structure of lit review by end of Oct 2014. Hand in first draft of lit review by December 2014.			
Jan-March 2015	Draft of abstract, results & discussion. Review second draft of introduction and method.	Check for new relevant references Hand in 2 nd completed draft for review by end of Feb 2014.		Organise themes in diary. Organise under headings identified.	Organise appendices. Write abstract draft for thesis.
March 2015	Submit final drafts for review			Hand in draft of CR by end of March 2015.	
April- May 2015	Complete final version. Submit thesis May 2015	Complete final version.		Complete final version of CR.	Finalise appendices, abstract, cover sheet. Submit to programme end of April for soft binding.
June 2015	Viva				

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Protocol Appendices

Protocol Appendix A: E-mail to the cancer support groups

Protocol Appendix B: Letter to prospective participants

Protocol Appendix C: Participant information sheet

Protocol Appendix D: Consent to contact form

Protocol Appendix E: Consent form

Protocol Appendix F: Poster

Protocol Appendix G: Interview schedule

Protocol Appendix H: Demographic information sheet

Protocol Appendix A

E-mail to the Cancer Support Groups

Hi,

My name is Nicola and I am training to become a clinical psychologist at Lancaster University.

As part of the doctorate training programme, I am carrying out a piece of research. The title of my research project is: 'The experience of friendships following a diagnosis of breast cancer'.

The experience of friendships following a diagnosis of breast cancer is not yet fully understood. I am therefore hoping to carry out interviews that will last about an hour, to explore the area of friendships.

I would very much like to attend a group meeting to briefly talk about the research, and to give out some information packs.

Let me know what you think.

I look forward to hearing from you.

Nicola

P.S. Feel free to give me a call if you would like to talk through any of this in more detail

Nicola Fedyszyn
Trainee Clinical Psychologist

University of Lancaster
Furness College
Lancaster
LA1 4YF

T: XXX

E: 

Protocol Appendix B

Letter to Prospective Participants



*Lancaster University
Doctoral Programme in Clinical
Psychology*

Hi,

I am contacting you to see if you would like to take part in a research project about breast cancer. This research aims to explore the experience of friendships following a diagnosis of breast cancer.

I am a trainee clinical psychologist at Lancaster University and I am conducting this research as part of my training.

The aim of the research is to find out about **your experiences**. If you choose to take part, you will be invited to an interview that will last about an hour. The interview can take place at your home or at your local community centre, wherever is most convenient for you.

I have included an **Information Sheet** to give you some more detailed information about the research. If you would like to find out more about the research and discuss the possibility of taking part, please contact me by completing the form included in this letter. You can also get hold of me through my contact details at the bottom of this letter. If possible, please get in touch within 3 weeks of receiving this letter, if you think you might like to take part. If you do choose to take part, Lancaster University will reimburse your travel expenses up to a maximum of £10.

I look forward to hearing from you.

Kind regards,

Nicola Fedyszyn
Trainee Clinical Psychologist

Address: Faculty of Health and Medicine, C12 Furness College, Lancaster University, Lancaster, LA1 4YG

E-mail: [REDACTED]

Mobile number (university): XXX

Protocol Appendix C

Participant Information Sheet



*Lancaster University
Doctoral Programme in Clinical
Psychology*

The experience of friendships following a diagnosis of breast cancer.

My name is Nicola Fedyszyn and I am conducting this research as part of my clinical psychology doctorate training at Lancaster University. Before you decide if you want to take part, it is important to understand why I am doing this research and what it will involve for you. So please read this information carefully.

What is the study about?

The purpose of this study is to find out how friendships are experienced following a diagnosis of breast cancer.

Why me?

You are being asked if you would like to take part because this research requires information from women over the age of 18, who received a diagnosis of breast cancer between January 2011 and December 2013.

Do I have to take part?

No. It is completely up to you to decide whether or not you take part.

What will I be asked to do if I take part?

If you decide you would like to take part, you will be invited to an interview that will last approximately one hour. The interview will take place either at your home or at your local community centre, whichever you prefer. During the interview, I will ask questions about your experiences. You do not have to answer all the questions if you do not want to, and there are no right or wrong answers.

Will my data be confidential?

The information you provide during your interview is strictly private and confidential. The data collected for this study will be stored securely and only the researchers conducting this research will have access to this data:

- Anonymised electronic copies of interview transcripts and data will be kept by the University for 10 years after the research has finished as stated in the Lancaster clinical psychology doctorate guidance. After the 10 years, all written transcripts will be destroyed and/or deleted by the clinical psychology administration team. Audio recordings of the interviews will be deleted after the research project has been marked.
- Paper copies of documents will be transferred onto a computer. Computer files will be encrypted (that means that no-one other than the researchers will be able to access them) and the computer itself will be password protected.
- The typed version of your interview (transcript) will be made anonymous by removing any identifying information including your name.
- Direct quotations from your interview may be used in reports or publications from the study, but no one will know that you said them as all identifying information will have been removed.

- What is said in the interviews will be kept private and confidential unless what is said makes me think that you, or someone else is at significant risk of harm. If this happens, I will have to break confidentiality and share the information with the appropriate professionals/agencies. I will also have to discuss this with my supervisor. Where possible, I will tell you if I have to do this.

If you decide you no longer want to be involved in this research, you can choose to withdraw your interview data within two weeks of taking part. Your data will then be destroyed and not used in this research. After two weeks, it might not be possible for your data to be withdrawn, though every attempt will be made to do so.

What will happen to the results?

The results will be summarised and reported in a thesis and may be submitted for publication in a professional journal, or presented at conferences. I will also send you a written summary of the results if you want, and give you the option to further discuss the findings of this research.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress following the interview procedure please let me know. Or if you would prefer, contact my research supervisor using the contact details in this information sheet.

Are there any benefits to taking part?

Although you may find participating in this research project interesting, there are no direct benefits to yourself in taking part. I will not be able to offer advice on any current difficulties you may be facing, as I am not acting in a therapeutic role during this research. However, the University will refund any travel expenses you incur whilst taking part in the research, up to a maximum of £10.

Who has reviewed the project?

This study has been reviewed by the Faculty of Health and Medicine Research Ethics Committee, and approved by the University Research Ethics Committee at Lancaster University.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please do not hesitate to contact me using the following contact details:

- Nicola Fedyszyn, Trainee Clinical Psychologist
Faculty of Health and Medicine, C12 Furness College, Lancaster University, Lancaster, LA1 4YG
E-mail: [REDACTED]
Course mobile number: XXX
- Research Supervisor: [REDACTED]

Complaints

If you wish to make a complaint or raise concerns about any part of this study and do not want to speak to myself, you can contact: Professor Bruce Hollingsworth, Head of the Division of Health Research, on 01524 594154, E-mail: b.hollingsworth@lancaster.ac.uk Or Professor Paul Bates, associate Dean for research, faculty of health and medicine at Lancaster University, on 01524 593718, E-mail: p.bates@lancaster.ac.uk

Thank you for taking the time to read this information sheet.

Protocol Appendix D

Consent to Contact Form



*Lancaster University
Doctoral Programme in Clinical
Psychology*

By completing this form, you have decided you are happy to be contacted as a potential participant for the following research project:

The experience of friendships following a diagnosis of breast cancer.

Your name: _____

Telephone Number (home): _____

Telephone Number (mobile): _____

Address: _____

The name of the support group you attend: _____

The approximate date you were diagnosed with breast cancer: _____

I give my permission for Nicola Fedyszyn (researcher) to contact me using the details above

Signature: _____

Date: _____

Please return this form to: Nicola Fedyszyn, trainee clinical psychologist, Faculty of Health and Medicine, C12 Furness College, Lancaster University, Lancaster, LA1 4YG.

Thank you for your support

Protocol Appendix E

Consent Form



Lancaster University
 Doctoral Programme in Clinical
 Psychology

The experience of friendships following a diagnosis of breast cancer.

I am asking if you would like to take part in a research project that aims to explore your experiences within friendships following a diagnosis of breast cancer. Before you consent to participating in the study, please read the participant information sheet and mark each box below with your initials if you agree with the following statements. Please let me know if you have any questions or queries before signing the consent form.

Please initial box after each statement

1. I confirm that I have read the information sheet and fully understand what is expected of me within this study.
2. I confirm that I have had the chance to ask any questions and to have them answered.
3. I understand that my interview will be digitally recorded and then made into an anonymised written transcript by the principal researcher (Nicola Fedyszyn).
4. I understand that anonymised written transcripts of the interview will be kept by Lancaster University for 10 years after the study has finished as stated in the Lancaster clinical psychology doctorate guidance, and that audio recordings will be deleted after the research project has been marked.
5. I understand that taking part in this research is voluntary and that I can withdraw at any time without giving any reason.
6. I understand that once my interview data has been anonymised and put into themes it might not be possible for it to be withdrawn, though every attempt will be made to do so.
7. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published.
8. I consent to information and quotations from my interview being used in reports, conferences and training events.
9. I understand that any information I give will remain strictly private and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal researcher (Nicola Fedyszyn) may need to share that information with the appropriate professionals/agencies and with her research supervisor.
10. I consent to take part in the above study.

Name of Participant: _____ Signature: _____ Date: _____

Name of Researcher: _____ Signature: _____ Date: _____

Protocol Appendix F

Poster



Lancaster University
Doctoral Programme in Clinical Psychology



Lancaster University
Doctoral Programme in Clinical Psychology

Friendships following a diagnosis of Breast Cancer

**Would you like to take part in a
research project?**

My name is Nicola and I am carrying out a piece of research as part of my doctorate training in clinical psychology.

I am looking for volunteers to take part in interviews exploring your experiences of friendships following a diagnosis of breast cancer.

For more information please contact Nicola Fedyszyn at the Lancaster University

E-mail: [REDACTED]

Tel: XXXxxx



Protocol Appendix G

Interview Schedule



Lancaster University
Doctoral Programme in Clinical Psychology

Introduction

Thank you for taking the time out to participate in this research. As you know, this research is about *your* experiences. There are no right or wrong answers to any of the questions that I am going to ask. You do not have to answer all the questions asked.

Remind participant about:

- Confidentiality
- Right to withdraw at any time
- Last approximately an hour
- Break- any time participant wants

Interview questions and prompts:

- Can you tell me about your diagnosis?
 - How did you find out you had breast cancer?
 - What treatment/treatments did you have?
 - Where are you up to with your treatment now
- How did you experience your diagnosis?
 - What has your journey through treatment been like?
- How has your diagnoses affected you?
- How did your friends react when you told them about your diagnosis?
 - What did you notice?
- What do you think you needed from your friends at the time of diagnosis?
 - What would you have liked to happen?
 - What would you have liked to have been different?
- What do you need/would like from your friendships now?
- What changes, if any, have you noticed in your friendships?
 - Improved your relationship/become more difficult?
 - What do you make of those changes?
 - How did you respond?
- How do you see your friendships in the future?

- What have you learnt if anything, about your friendships since receiving a diagnosis of breast cancer?
 - What have you noticed now that you did not notice before?

Check participants contact details

Remind them about the right to withdraw

Provide participant with another information sheet- to ensure that they have my contact details, and are aware of how to get in touch with me.

Ask if they would like a 'summary of the findings' to be sent out at the end of the research. Make a note of their response.

Thank you for your participation in this research.

Complete travel claim forms

Protocol Appendix H
Demographic Information Sheet



Lancaster University
Doctoral Programme in Clinical Psychology

Name:

Age:

Sex:

Ethnicity:

Approximately when were you diagnosed with breast cancer?:

Which support group do you attend?:

Appendix B

University Ethics Confirmation Letter



Applicant: Nicola Fedyszen
Supervisor:
Department: DHR

08 September 2014

Dear Nicola and

Re: The experience of friendships following diagnosis of breast cancer

Thank you for submitting your research ethics application for the above project for review by the Faculty of Health and Medicine Research Ethics Committee (FHMREC). The application was recommended for approval by FHMREC, and on behalf of the Chair of the University Research Ethics Committee (UREC), I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact the Research Ethics Officer, Debbie Knight (01542 592605 ethics@lancaster.ac.uk) if you have any queries or require further information.

Yours sincerely,

A handwritten signature in cursive script, appearing to read "S. Taylor".

Sarah Taylor
Secretary, University Research Ethics Committee

Cc Fiona Aiken, University Secretary, (Chair, UREC); Professor Roger Pickup (Chair, FHMREC)

Research Support Office
Research and Enterprise Services

Lancaster University
University House
United Kingdom

*Please note the new address of the RSO is Research Support Office, B58 Bowland Main, Lancaster University, LA1 4YT

Fax (01524) 593229
<http://www.lancs.ac.uk>

Appendix C

University Ethics Amendment Letter

Health and
MedicineLANCASTER
UNIVERSITY

Our ref: FHMREC13084

14 July 2014

Nicola Fedyszyn
Division of Health Research
Faculty of Health and Medicine
Lancaster University

Dear Nicola,

Re: FHM Research Ethics Committee application for project titled: *'The experience of friendships following a diagnosis of breast cancer'*.

Thank you for sending in the paperwork for your application. We appreciated reading about the project. We have a few minor concerns, and ask that you address the following in revising your application materials:

- **Application section 12**
 - Note here the minimum number of participants.
- **Application section 11**
 - Amend the start date of your project to take into account timescales for ethical approval.
- **Application section 19**
 - Clarify here that you will be carrying out the transcription.
- **Application section 20**
 - In relation to this project, the 'service users' are professionals not patients. Please comment on the possibility of their involvement in the development of the project.
- **Application section 21**
 - Clarify what information you are storing and how you will ensure it is kept secure.
- **Application section 22**
 - Please note here that your reason for earliest possible upload or your audio recordings is that it is not possible to encrypt your portable devices. If it is possible to encrypt them, please state this here.
 - We suggest that you wait until your project has been submitted before destroying the original recordings, and amend this section accordingly.
 - Please indicate in this section who will be responsible for the storage and deletion of data once you have completed your course.



- **Application section 24**
 - Please state here the circumstances in which you may have to break confidentiality (that is the 'limits to confidentiality', when you view that a participant has indicated they may cause harm to themselves or others). We suggest that you also discuss this ethical area further with your supervisor.
- **Protocol**
 - **Recruitment strategy:** clarify how you will manage the recruitment process to ensure you avoid over-recruitment.
 - **Procedure:** Consent is usually taken immediately prior to the interview commencing. Please clarify that this is what you intend to do.
- **Appendix A**
 - **First sentence, third paragraph:** amend such that it is clear that it is friendships following a diagnosis of breast cancer is not yet fully understood.
 - **Fourth paragraph:** amend such that it reads less tentatively.
- **Participant Information Sheet**
 - **Will my data be confidential?** Include here information regarding the circumstances in which you would have to break confidentiality (harm to self or others), noting what you will do.
 - Amend Bruce Hollingsworth's email address.
 - **Complaints section:** Please add Prof Paul Bates, Associate Dean for Research, Faculty of Health and Medicine (Division of Biomedical and Life Sciences), Lancaster University, Lancaster LA1 4YD (email p.bates@lancaster.ac.uk Tel: (01524) 593718) as an additional contact for complaints.
- **Consent form**
 - Item 4 – amend this in line with changes elsewhere in the application.

In addition to the above a number of minor changes and typos are noted on your application form, attached with this letter. Please address these, as well as the matters above.

Ensure consistency between the application form, the Research Protocol and the supporting materials in line with the changes requested above.

Please use Lancaster University letter-headed paper for all participant materials

We ask that you attend to these in writing by (re)submitting to the FHMREC via Diane Hopkins (d.hopkins@lancaster.ac.uk) the application document and materials with any changes highlighted. If your responses to the above are satisfactory then approval will be recommended on Chair's action. If you have questions, please feel free to contact me.

Yours sincerely,

Health and
Medicine

LANCASTER
UNIVERSITY



Paul A. Bates

Prof Paul Bates
Chair of the Faculty of Health and Medicine Research Ethics Committee
Lancaster University

Appendix D

Research Self-Assessment Form

STUDENT FORM RESEARCH ETHICS AT LANCASTER STUDENT FORM

Stage 1 Self-Assessment Form (Part A) - for Research Students

(To be completed by the student together with the supervisor in all cases; send signed original to Research Support)

Student name and email: Nicola Fedyszyn n.fedyszyn@lancaster.ac.uk

Supervisor name: Dr. Jane Simpson Department: Health Research

Title of project: The experience of friendships following a diagnosis of breast cancer.

Proposed funding source (if applicable): Not applicable

1. Please confirm that you have read the code of practice, 'Research Ethics at Lancaster: a code of practice' and are willing to abide by it in relation to the current proposal? **Yes**
If no, please provide explanation on separate page
2. Does your research project involve non-human vertebrates, cephalopods or decapod crustaceans? **No** *If yes, have you contacted the Ethical Review Process Committee (ERP) via the University Secretary (Fiona Aiken)? ?*
- 3a. Does your research project involve human participants i.e. including all types of interviews, questionnaires, focus groups, records relating to humans etc? **Yes**
If yes, you must complete Part B unless your project is being reviewed by an ethics committee
- 3b. If the research involves human participants please confirm that portable devices (laptop, USB drive etc) will be encrypted where they are used for identifiable data **Yes**
- 3c. If the research involves human participants, are any of the following relevant:
 - No** The involvement of vulnerable participants or groups, such as children, people with a learning disability or cognitive impairment, or persons in a dependent relationship
 - No** The sensitivity of the research topic e.g. the participants' sexual, political or legal behaviour, or their experience of violence, abuse or exploitation
 - No** The gender, ethnicity, language or cultural status of the participants
 - No** Deception, trickery or other procedures that may contravene participants' full and informed consent, without timely and appropriate debriefing, or activities that cause stress, humiliation, anxiety or the infliction of more than minimal pain
 - No** Access to records of personal or other confidential information, including genetic or other biological information, concerning identifiable individuals, without their knowledge or consent
 - No** The use of intrusive interventions, including the administration of drugs, or other treatments, excessive physical exertion, or techniques such as hypnotherapy, without the participants' knowledge or consent

Yes Any other potential areas of ethical concern? (Please give brief description)

Interviews will be asking participants to talk about their experiences of friendships following a diagnosis of breast cancer and may be upsetting.

STUDENT FORM STUDENT FORM STUDENT FORM

4. Are any of the following potential areas of ethical concern relevant to your research?
 - No** Could the funding source be considered controversial?
 - Yes** Does the research involve lone working or travel to areas where researchers may be at risk (eg countries that the FCO advises against travelling to)? If yes give details.
 - No** Does the research involve the use of human cells or tissues other than those established in laboratory cultures?
 - No** Does the research involve non-human vertebrates?
If yes, has the University Secretary signified her approval? ?
 - Yes** Any other potential areas of ethical concern? (Please give brief description)

Interviews will be carried out in either local community centres or participants homes. University and NHS local lone working policies will be adhered to.

5. Please select **ONE** appropriate option for this project, take any action indicated below and in all cases **submit the fully signed original self-assessment to RSO.**
 - (a) Low risk, no potential concerns identified**
The research does **NOT** involve human participants, response to all parts of Q.4 is 'NO'. No further action required once this signed form has been submitted to RSO
 - (b) Project will be reviewed by NHS ethics committee**
Part B/Stage 2 not usually required, liaise with RSO for further information. If Lancaster will be named as sponsor, contact RSO for details of the procedure
 - (c) Project will be reviewed by other external ethics committee**
Please contact RSO for details of the information to submit with this form
 - (d) Project routed to UREC via internal ethics committee**
SHM and Psychology only. Please follow specific guidance for your School or Department and submit this signed original self-assessment to RSO
 - (e) Potential ethical concerns, review by UREC required**
Potential ethical concerns requiring review by UREC, please contact RSO to register your intention to submit a Stage 2 form and to discuss timescales
 - (f) Potential ethical concerns but considered low risk, (a)-(e) above not ticked**
Research involves human participants and/or response to one or more parts of Q.4 is 'YES' but ethical risk is considered low. Provide further information by completing PART B and submitting with this signed original PART A to RSO

Student signature: _____ Date: 20/06/2014

Supervisor signature: *Jane Simpson* Date: 20/06/2014

Head of Department (or delegated representative) Name: *Susan Arwick*

Signature: *S. Arwick* Date: 25/06/2014