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MATTHEWS, Hannah <<http://orcid.org/0000-0003-2677-2626>> and SEMPER, Heather

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‘Dropped from the system’: the experiences and challenges of long term breast cancer survivors.

Hannah MATTHEWS* BSc, MSc, PhD student ¹

Dr Heather SEMPER CPsychol Senior Lecturer in Health Psychology ²

¹Coventry University Coventry

²Staffordshire University, Stoke on Trent

*corresponding author

Address for correspondence:

Centre for Technology Enhanced Health Research

Faculty of Health and Life Sciences,

Mile Lane

Coventry University,

Priory Street,

Coventry,

CV1 2NL

E-mail: matthe94@coventry.ac.uk

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Abstract

Aims: The aim of this study was to explore breast cancer patients' experiences during survivorship. Particular attention is given to the role of specialist breast care nurses in supporting women throughout this phase.

Background: There is a relative lack of research involving long term breast cancer survivors. Yet, many survivors experience substantial psychosocial and iatrogenic harms created by diagnosis, symptoms of disease and treatment. A more comprehensive understanding may assist in supporting the needs of breast cancer survivors.

Design: An exploratory qualitative approach was used to collect data on breast cancer survivors' experiences during 2013.

Methods: Semi-structured interview data were collected from seven British women aged 38-80 years exploring the support received during survivorship. Data were analysed using Interpretive Phenomenological Analysis.

Findings: Breast cancer survivors perceived a systemic absence in support from oncology teams and rapid deterioration of support from personal support networks. Despite this, survivors were able to find benefits from the cancer experience. This allowed for adjustment and enabled patients to assume a new identity as a breast cancer survivor. We recommend specialist breast care nurses would be suitably placed to provide extended support allowing for a salient transition from treatment to survivorship.

Conclusion: This study yields insights into breast cancer survivorship and specifically the role of specialist breast care nurses. Given the growing cohort of breast cancer survivors and the increased importance on promoting and supporting optimal psychosocial adjustment, we

advise the cost-effectiveness of providing continuing nursing support and the mode of administration requires further research.

Key words: Breast cancer, psychosocial nursing, qualitative, support, phenomenology

DRAFT

Why is this research or review needed?

- There is limited research exploring long term (>5 years) breast cancer survivors, yet women with a history of breast cancer constitute the largest group of cancer survivors.
- Poor psychological functioning has been overlooked and frequently undertreated in breast cancer survivorship. However, contemporary literature acknowledges the importance of support for improved psychosocial wellbeing and quality of life after the completion of treatment.
- The use of qualitative methodology offers an in-depth exploration of breast cancer survivorship and reduces a significant gap in knowledge of the experiences of long term breast cancer survivors.

What are the key findings?

- The findings illustrate breast cancer survivors perceived a systemic absence in support from oncology teams and deterioration in social support from family and friends. We assert this decline may compound the effects of psychosocial problems experienced by survivors.
- Long-term breast cancer survivors have unmet survivorship needs and specialist breast care nurses are suitably placed to continue to provide support to allow for a salient transition from treatment to survivorship.

- Breast cancer survivors were able to find benefits from the cancer experience, allowing for adjustment and enabling the transition from a cancer patient to a breast cancer survivor.

How should the findings be used to influence policy, practise, research and education?

- Given the long-term unmet needs of breast cancer survivors and the continually increasing number of survivors, the findings of this study need to be more fully addressed both in terms of research and intervention.
- The findings of this study could be used as preliminary evidence, to highlight the need for continuation of support and phased termination of support, to replace the abrupt termination of support reported by breast cancer survivors at the end of treatment.
- Breast care nurses are a vital and somewhat limited resource. Consequently, resources should only be targeted at those who require additional support. The cost-effectiveness of providing continuing support and the mode of administration (i.e. over the phone or videoconferencing) requires further research.

INTRODUCTION

Breast cancer is the most commonly diagnosed cancer in women across the world (Rowland *et al.* 2001). Mortality rates have fallen over recent decades due to advances in diagnostics, surgical and radiotherapy techniques, molecular biology and systemic therapy (Manos *et al.* 2009), resulting in improved survival rates and a growing cohort of breast cancer survivors (Graham *et al.* 2014). Today, women with a history of breast cancer constitute the largest group of cancer survivors (Rowland *et al.* 2001). However, many breast cancer survivors experience substantial psychosocial and iatrogenic harms created by diagnosis, symptoms of disease and treatment (Fallowfield & Jenkins 2015). These harms have resulted in 38% of long term breast cancer survivors reporting moderate to high levels of anxiety and 22% experiencing high levels of depression (Mehnert & Koch 2008, Mitchell *et al.* 2013). Moreover, breast cancer survivors may also experience other adverse psychosocial consequences, including body image disturbance (Fobair & Spiegel 2009), sleep disturbance (Savard *et al.* 2009), sexual dysfunction (Broeckel *et al.* 2002), fear of recurrence (Koch *et al.* 2014) and subsequently impaired quality of life (Holzner *et al.* 2001). Although, healthcare services are organized differently in different countries similar findings have been reported internationally (Burg *et al.* 2015). Despite this, relatively little is known about survivors' experiences of long-term breast cancer survivorship, with contemporary literature identifying long-term (>5 years) needs breast cancer survivors as a key gap in cancer survivorship research (Eccles *et al.* 2013; Jacobsen *et al.* 2016). Consequently, a more comprehensive understanding could assist in supporting the unmet needs of survivors' in the United Kingdom and may be transferrable internationally.

Background

The primary aim of breast cancer care is to relieve the patient of distress by curing the cancer (Adler & Page 2008), once the cancer is cured the patient transitions to the survivorship phase of the breast cancer trajectory. During diagnosis and treatment specialists breast care nurses provide a range of emotional and informational support, symptom advice and act as a vital link to other staff and services (NHS Trust, 2016). However, during survivorship the support provided by specialised breast care nurses declines and stress-related symptoms increase (Benedet 2010), as patients leave the ‘safety net’ provided by contact with the oncology teams (Ganz *et al.* 2003) as a result of structural, financial and time constraints (Holzner *et al.* 2001). Survivors assume the responsibility for self-monitoring and as weekly appointments shift to periodic follow-up appointments women report feeling vulnerable and isolated (Vivar & McQueen 2005). During survivorship women are expected to return to normality and endure several challenges including: fear of recurrence, fear of developing new primary cancers, conflicting information of how to reduce cancer risk, living with uncertainty, life altering experience, body image, sexual dysfunction, reengaging in the workplace fulltime and coping with both lingering and late side effects (Ahmed *et al.* 2016; Drageset *et al.* 2016). Consequently, the needs of long term breast cancer survivors are often unmet (Vivar & McQueen 2005). More than 90% of survivors report a deficit of support from the medical profession (Royak-Schaler *et al.* 2008). Furthermore, survivors also report a decline in support from their personal support networks, compounding the effects of psychosocial problems (Adler & Page 2008). Subsequently, survivors continue to display physical and psychological concerns, signifying breast cancer survivors’ needs may be both unmet by oncology teams and personal networks (Cimprich 2005).

The past decade has seen an increase in both research and interventions to reduce psychosocial morbidity and improve coping and adjustment for breast cancer survivors (Fallowfield & Jenkins 2015). Previously poor psychological functioning was overlooked

(Fallowfield *et al.* 2001) and frequently undertreated (von Heymann-Horan *et al.* 2013). However, contemporary literature identifies that the long-term (>5 years) needs of breast cancer survivors is a key gap in cancer survivorship research (Eccles *et al.* 2013; Jacobsen *et al.*, 2016). Furthermore, there is accumulating evidence to indicate breast cancer survivors continue to have unmet needs and require continued psychosocial support (Matthews *et al.* 2016). This study will explore the experiences and challenges faced by long-term breast cancer survivors, to contribute to a substantial gap in knowledge and provide recommendations for research and practise.

THE STUDY

Aim

This study aims to explore the experiences of long term (>5 years) breast cancer survivors during survivorship. Particular attention is given to the role of specialist breast care nurses in supporting women throughout the survivorship phase.

Design

The present study adhered to the consolidated criteria for reporting qualitative research (COREQ) guidelines (Tong *et al.* 2007). This study employed a qualitative, experiential and phenomenological approach using the conventions of Interpretive Phenomenological Analysis (IPA) for data analysis (Smith *et al.* 2009). This approach considers participants as the experiential expert on the subject and allows participants maximum opportunity to discuss their own experiences (Smith & Osborn 2003). It also stresses the importance of collecting rich sets of experiential phenomenological data which are viewed through a lens of critical realism and of valuing each individual case before drawing connections across the sample (Finlay 2009). The in-depth nature of the analytic method requires very close attention to

working with the data and it is therefore well suited to rich experiential data, collected from a small number of individuals sharing a similar significant experience (Giorgi & Giorgi 2008).

Sampling and selection procedures

The purposive sample consisted of seven participants from an informal friendship group, formed in an English hospital in the Midlands during participants' primary treatment for breast cancer. Ten participants were initially contacted by post and were sent an invitation letter and information sheet containing details of the study. Seven participants replied and provided written informed consent. The sample size of seven was considered suitable due to the idiographic nature of IPA and allowed for the collection of rich experiential data (Smith *et al.* 2009). Additionally, a sample of this size allowed for homogeneity to be maintained and maximised the likelihood of meaningful cross-case comparison (Smith *et al.* 2009). Inclusion criteria consisted of female adult breast cancer survivors, who were in remission for five or more years and could speak fluent English.

Data collection

Data were collected using single occasion semi-structured interviews which are recommended as an appropriate method for IPA (Smith *et al.* 2009). The semi-structured interview guide was developed by the authors and consisted of prompts and questions regarding diagnosis and treatment, but mainly focused on the survivorship phase and sources of support breast cancer survivors received. Participants were also encouraged to freely discuss their experiences. Interviews were conducted by a trained female researcher (HM) in participants' own homes and lasted approximately 60 minutes. Interviews were audio-recorded using an Olympus VN-8500PC digital voice recorder and field notes of both descriptive and reflective information were taken throughout each interview. Data collection took place between January and June 2013.

Ethical considerations

This study was approved by a University Ethics Committee. Pseudonyms were used throughout the transcriptions to protect participants' identity. Participants provided written informed consent for the study and could withdraw or modify their contribution if they wished, although no participants asked for sections of their manuscripts to be altered or removed. Details of relevant support agencies were provided on debriefing.

Data analysis

Interviews were transcribed in full using an abbreviated form of the Jefferson system of notation (Jefferson 2004). Data were analysed by both researchers (HM & HS) using the principles and processes of Interpretative Phenomenological Analysis (Smith *et al.* 2009). Themes were derived from the data and evolved over four procedural stages: (1) reading and re-reading the data; (2) identifying and labelling emergent themes; (3) developing theme tables and (4) developing thematic maps to visually communicate each theme. Microsoft® Word was used to transcribe, analyse and display interview data.

Validity and reliability/Rigour

This study employs a phenomenological and interpretive research paradigm. Participants were presented with both their transcripts and thematic maps to allow for member validation. Through the process of member validation participants could verify and on occasions influence the interpretations of the researchers. This provided a sense of conviction and credibility to the findings of this analysis (Lincoln & Guba 1985). To reduce the likelihood of researcher influence on the data obtained, both researchers took a naïve approach to the study and kept a reflexive log throughout the analytic process to bracket researcher expectations, preconceptions and judgements (Yardley 2000). Both authors analysed all of the transcripts.

Initial themes were generated and cross checked across all the transcripts by the first author and then validated by the second author (Tong *et al.* 2007). This was also used to facilitate the analytic processes. Meyrick's (2006) review of rigour informed this piece of research. This review centres on transparency and continual systematic negotiation throughout the research process. This study addressed these by detailing the study aim and the focus of the analysis; selecting suitable methods of data collection and analysis; providing details regarding sampling; providing details of data collection; providing a clear association between results and conclusions; and providing other relevant literature to promote the identification and exploration of implications for practice.

FINDINGS

Participants were aged between 38-80 years old. All participants described themselves as White British, three participants were married and one participant was widowed and the remaining participants were single. All participants were between 5 and 15 years in remission for breast cancer. Three inter-related themes were selected for discussion in this paper – all are illustrated with a series of extracts from interview data. The three main themes identified and discussed are: 'dropped from the system', 'varying specialist nursing support' and 'living and thriving as a cancer survivor'.

Dropped from the system

This theme encapsulates participants' perceptions of support and highlights the need for greater support throughout survivorship. Participants described how the support they received during diagnosis ended abruptly after the completion of treatment. Consequently, participants' needs were not adequately met. This discrepancy between desired support and actual care is acknowledged in the literature (Fors *et al.* 2011; Mallinckrodt *et al.* 2012), with as many as 90% of breast cancer survivors reporting inadequate support throughout

survivorship from the medical profession (Royak-Schaler *et al.* 2008). All participants expressed feelings of isolation and neglect by healthcare professionals, family and friends at some point during the survivorship phase.

All of a sudden it seemed like your support network had gone because you're not going in for treatment anymore so you're not seeing people regularly (...) and I think I could have still rang the breast cancer nurses (..) but you feel as though you don't really want to bother them anymore (.) and you just felt as though you had been dropped from the system (Sarah).

Sarah describes experiencing a sense of vulnerability and isolation from the rapid depletion of her immediate support network. Sarah perceives the medical profession role is complete, she is now cured and in remission and therefore feels somewhat indebted to both the healthcare professionals and the system. Consequently Sarah perceives asking for any further support as a burden to the system which untimely saved her life. Oncological literature supports this conceptualisation and suggests as cancer evokes a premature confrontation with mortality, survivors often feel indebted to the medical profession (Ogden 2004).

Consequently, as a result of declining support from healthcare professionals many of the participants attempted to seek access to social support, although most participants also described a significant decline of support from personal support networks.

They just took it for granted that I was alright (.) I think because I didn't show if I was having a bad day (.) I wouldn't let them know (.) the only person that would know would be my husband (.) and he would know (Mary)

It was alright I think (.) I suppose it was a case of you've had it now mother (.) well I suppose no-one admits mothers can be ill (.) do they (Alice)

Mary conceals her emotional and psychological struggle and displays a positive and healthy persona. This suggests perceptions of how an individual entering remission should feel and behave may directly influence a woman's response to the survivorship phase. Both Mary and Alice describe consistently experiencing medical and social support during diagnosis and treatment and report struggling with the decline of support in the survivorship phase.

Consequently, this suggests the psychological consequences of cancer and the extent to which breast cancer infiltrates survivors lives may not be fully understood or acknowledged by both healthcare professionals and their social support systems. Literature advises the early withdrawal of social support from relatives is often detrimental and may result in psychological distress (Lutgendorf *et al.* 2005, Mallinckrodt *et al.* 2011). Subsequently, participants also described the support they would have liked to receive from other breast cancer survivors:

um (...) well I think to be able to talk to someone about it (.) to communicate with someone who has gone through the experience (.) I know the nursing staff are wonderful (.) but to talk to someone who has had breast cancer (.) because it's such a shock (.) it's like someone smacking you on your face (.) it's like wow this has happened, I've had cancer now what am I going to do (.) you need more support and to talk to people that have gone through it so they can help you (Mary)

Mary uses the idiom a 'smack in the face', which implies she feels surprised and somewhat insulted by the withdrawal of support during the survivorship phase. Mary assumes the unique identity of a breast cancer survivor. Often, after women have survived breast cancer they assume a new identity as survivor and this identity persists throughout their lives (Zebrack 2000). Subsequently, we must acknowledge how cancer changes the self, daily routines and the affect this may have on others. Mary expresses the desire to be able to discuss survivorship with others who have gone through the same experience and suggests a

support group may be a suitable outlet for this discussion. As Mary positions herself as a survivor she believes only other survivors fully understand her emotions and experience. Support groups have been shown to provide advice and emotional reassurance to cancer survivors through the acknowledgement others were also struggling (Lutgendorf *et al.* 2005).

Varying specialist nursing support

Whilst, some participants expressed praise and gratitude towards breast care nurses and described the support they received as invaluable, other participants felt they required more support from specialist breast care nurses.

I would have liked someone to have talked to me one to one and tell me what to expect (.) it's been years since I had breast cancer (.) even now you can get an itch and it hurts around my arms (.) they should have a nurse who they can send and you can have a chat with and can complain about anything (.) or check if things should be happening or not (Janet)

Janet describes the relentless and continuing physical and psychological burden of the disease. Janet feels uncertain and anxious about the future as a result of no informational or psychological support entering and throughout survivorship. Janet advises specialist breast care nurses would be suitably placed to providing continuing support and recommends patients homes as a suitable environment.

it sort of caught up with him (.) we used to sit and talk and I would say just tell me how you feel (.) so we were supporting each other (.) I was supporting him (.) but he could have done with more support maybe from a nurse (.) I mean that was the only thing that was lacking (.) I can't moan about the treatment whatsoever and I never would because they saved my life because that meant a lot and it still does (Mary)

During the survivorship phase Mary's health gradually improves and she requires less clinical and psychosocial support, therefore her husband's role as her primary carer/supporter is no longer clearly defined. As a consequence, the psychological burden her husband previously suppressed to support his wife is increasingly acknowledged, placing both emotional and psychological demands on their relationship. Subsequently, Mary manages the physical and psychosocial demands of the disease in survivorship and the needs of her husband. Mary expresses specialist breast care nurses would be suitably placed to support her husband. Literature surrounding support for relatives of cancer patients is both limited and inconclusive, with some literature suggesting nursing support is virtually non-existent for relatives (Ferrell *et al.* 1998). Yet, with consistent psychological support for relatives, relatives may be able to provide increased patient support (Jiwa *et al.* 2010). It is of note, that Mary also describes feeling indebted to the healthcare professionals that ultimately saved her life.

I went in and spoke to one of the nurses about breast reconstruction and she was brilliant (.) and then all this stuff came out about what you look like and what you feel like and you just need someone to talk to (.) they were just brilliant (.) I think the breast care nurses were invaluable (Sarah)

Sarah praises the breast care nurses, who provide her with a sense of comfort, reassurance and a lack of formality, allowing for her anxieties and concerns to be somewhat alleviated. Interestingly, research indicates appearance concerns after mastectomy are often considered secondary to primary physicians (Jiwa *et al.* 2010). However, for Sarah the divergence in the medical care provided by physicians and her psychosocial needs was minimised by the support provided by specialist breast care nurses.

They did ask me if I wanted a Macmillan nurse but I remember saying this (.) No (.) No (.)
I'm not that far gone yet I'll wait until I'm nearly there (Alice)

I think I was offered a Macmillan nurse right at the beginning (.) but I never really felt the
need (.) I dealt with it (.) in my own way (.) and I had people to talk to when I needed to
(Betty)

Two participants were offered and declined support from Macmillan nurses. A Macmillan nurse performs a similar role to specialist breast care nurses in the NHS, although Macmillan nurses typically have specialist qualifications, skills in oncological care and may support patients through palliative care (Macmillan Nurses 2013). Alice categorically rejects the support of a breast care nurse as she perceives Macmillan to be strongly and solely associated with palliative care. Both Alice and Betty hold the connotation of Macmillan being related to end of life care. Subsequently, by accepting support from the Macmillan nurses they believe they would be accepting mortality as an option, however through rejecting support they believe they are rejecting the possibility of dying from the disease and instead are active participants in their recovery. Whilst the first Macmillan posts were established to enhance the palliative care in the community, today Macmillan nurses help to support decision making, pain and symptom management and provide psychological support for complex cases of breast cancer (Addington-Hall & Altmann 2000).

Living and thriving as a cancer survivor

This theme describes the continuing demands and challenges participants endure as a breast cancer survivor. The theme also encapsulates the psychological benefits of surviving breast cancer. Participants describe how finding benefits from the disease, enabled them to overcome the role of a cancer patient and adjust to their new identity as a breast cancer survivor.

because what happens after you've had the treatment you don't trust your body anymore (.) because you were well before and then found out you had cancer (.) because if I had left it and it had spread then things could have turned out much worse (.) I didn't know it was there and it's taken me a while to trust my body again and I'm not sure if I completely trust it now (Sarah)

Sarah describes feeling unable to trust her body due to the symptomless nature of her breast cancer. Sarah's sudden confrontation with cancer acts as a catalyst for premature confrontation with mortality, provoking her vulnerability to the fear of recurrence. The fear of recurrence is a type of anxiety or worry which results in a fear that cancer could return in the same breast, opposite breast or metastasises in other parts of the body (Simard & Savard 2009). The fear of recurrence is highly prevalent among long-term breast cancer survivors, although most survivors' only experience low levels of anxiety (Koch *et al.* 2014). Nevertheless, this is known to have an impact on both psychological adjustment and wellbeing during survivorship (Curda 2011).

I've still been tired and I've got a pain in my hip and I feel as though my body has aged (.) I went out with Rita (.) an elderly lady I care for (.) the other day and we'd been sitting chatting and after we'd got up we were both stiff and things ((laughs)) (Sarah)

Furthermore, Sarah emphasises the burden breast cancer has placed on her body and perceives herself as irreversibly aged. Sarah's change in identity (as a breast cancer survivor) and self-concept (as prematurely aged) may influence numerous domains of her life including her personal, social and sexual life (Johnston 2012), in turn suggesting breast cancer has far reaching implications on survivors.

I accepted it (.) I thought if it's going to save my life and give me a quality of life fair enough I will (.) you know it's the sort of thing if it was going to help me live for longer (Mary)

Mary considers the removal of her breast as the removal of the cancer and her disease and interprets the removal of the breast as a positive lifesaving action. Often a mastectomy is considered to have a transformational effect (Denford *et al.* 2011). Mastectomy patients often describe going through a profound journey of acceptance, where the importance of the breast is minimised and emphasis is placed on a renewed sense of life importance (Denford *et al.* 2011).

Once treatment ended I thought to myself thank goodness I didn't have to go anymore (.) it took over my life (.) it was such a relief (.) you soon pick up your life and carry on (.) it hasn't held me back in my life (.) I've moved on from breast cancer (.) but you do think about it (.) I don't know what else to say (.) you just carry on (.) I blocked it out (Doris)

Doris describes the sense of relief she feels entering remission and the survivorship phase.

Often, cancer forces individuals to evaluate priorities in their lives (Kauffman 1995).

Through this evaluation the concept of what is important becomes clear and Doris realises maintaining her health and daily routines is of vital importance. Therefore, Doris allows breast cancer to act as a propellant in her life, allowing Doris to overcome the role of a patient and successfully enter into survivorship, by refusing to let her experience affect her (Kauffman 1995).

It's made me a more positive person (.) I never take life for granted anymore (.) your life is just put on hold (.) so I never take anything for granted anymore (.) I live life day to day and each day to me is a bonus (.) and that's the way I look at life now (Mary)

During treatment Mary lived existentially and became isolated. However, during survivorship Mary's self and social identity altered, as she perceived life as transient and insecure allowing Mary to gain a renewed appreciation for life. Approximately 75% of breast cancer survivors report positive changes concerning their outlook on life (Sears *et al.* 2003, Bower *et al.*

2005). This is consistent with the perspective of existential theorists, who advocate life threatening experiences may inspire positive change as an individual face the possibility of a shorter, yet more profound life span (Frankl 1963; Yalom 1980).

I was meant to go back on the second week of June (.) but I said I'm going (.) I'm going to Eastern Europe for two weeks and I thought (.) I might not get on holiday again so I'm going (Alice)

Alice strives for a sense of normality during survivorship. This is evident by the importance Alice places on going away with relatives. The repetition of her intent to go away, demonstrates her sense of conviction in her actions. Alice understands the seriousness of the disease she survived and was forced to acknowledge the transient nature of life. Often, if the notion of mortality is acknowledged survivors place a higher value on life in the present (Bowman *et al.* 2004; Documet *et al.* 2012). Alice acknowledges mortality and subsequently grasps her time and memories.

Discussion

It is evident that breast cancer survivors continue to experience the psychosocial consequences of the disease up to fifteen years after the initial diagnosis of breast cancer. It is of note that although five participants had been in remission for nine or more years, many became visibly upset during the interviews. We suggest survivors may have unresolved fears or underlying issues surrounding their experience. We also advise the psychological and emotional burden of the disease remains long after the physical effects of breast cancer have subsided. *Dropped from the system* explored the withdrawal and decline of support from oncology teams and personal support networks. Existing literature also suggests diminishing and inadequate support is provided by oncology teams during survivorship (Vivar & McQueen 2005, Meneses *et al.* 2007) and that this problem occurs internationally (e.g.

Sammarco, 2001; Cappiello, Cunningham, Knobf, & Erdos, 2007) and acknowledges the reduction of support often contributes to reduced wellbeing and quality of life (Ogden 2004). Participants also described a decline in trust towards bodily functioning, which placed a significant emotional and psychological burden on survivors, threatening their ability to cope. Interestingly, a running notion throughout two themes (*dropped from the system* and *varying specialist nursing support*) was the idea of participants feeling indebted to the healthcare professionals and the healthcare system. Some participants perceived themselves as a burden to the healthcare system, a system which ultimately saved their lives. As a consequence participants were often reluctant to ask for advice and support during survivorship.

Varying specialist nursing support highlighted the role of specialist nurses supporting patients' physical and psychosocial needs and the gratitude and respect breast cancer survivors held for these professionals. Nearly all participants suggested occasional and routine home or telephone support from specialist breast care nurses may provide a source of comfort throughout survivorship. Evidence suggests both home and telephone appointments may increase satisfaction and reduce pre-appointment anxiety, as a result of forgoing clinical examinations in clinical environments (Beaver *et al.* 2010). and that this is something that is important regardless of the country where the breast cancer survivor lives (e.g. Wang, et al, 2014). Therefore, it is recommended that specialist breast care nurses would be suitably placed to provide increased and extended support, allowing for a salient transition from treatment to survivorship. However, there is a pressing need for future studies to address cost issues of extending psychosocial support for breast cancer patients, to determine if the initial cost becomes cost-effective overtime.

Living and thriving as a cancer survivor explored the continuing demands and challenges participants endure as a breast cancer survivor, including the fear of recurrence and how participants strive for normality. Our findings are consistent with previous literature, which

suggested fear of cancer recurrence whereis a significant challenge for many breast cancer survivors (Pinto & Azambuja 2011, Saquib 2011). Protection Motivation Theory asserts breast cancer survivors should be educated regarding their vulnerability and susceptibility of recurrence and provided with suitable coping mechanisms to mediate their fears (Rogers 1983). Again, specialist breast care nurses would be suitably placed to provide educational and informational support surrounding this challenge. Participants were also able to find benefits from the breast cancer experience. Benefit finding allowed participants to adjust and ultimately overcome the role of a cancer patient and transition into a survivor. These findings are consistent with existing literature which suggests patients with breast cancer are able to gain psychological benefits from cancer diagnosis and treatment, including a greater purpose of life, a clearer outlook on life and closer relationships (Wang *et al.* 2014). Therefore, to improve the longer-term adaptation and adjustment of patients benefit finding could be used as a targeted intervention.

Limitations

This study yielded valuable insights into the phenomena of breast cancer survivorship, although limitations are present. Firstly, no black or minority ethnic (BME) patients were included in the study. The majority of participants were middle class white women. Therefore, we cannot suggest the findings from the present study are directly transferable to BME patients. In addition, the health care services in the UK may not be comparable to all other countries as it is free at point of contact (Calnan & Sandford, 2004). Nonetheless, international research has also shown that breast cancer survivors experience breast cancer survivorship in a similar manner (e.g. Knobf, 2015; McGinty, Goldenberg & Jacobsen, 2012). Secondly, participants were recruited from an informal friendship group and as friendships often occur between people with similarities, the participants included in this study may be more similar in their views and outlook than an unacquainted group of breast

cancer survivors. It is also likely that the participants included in this study supported each other and that their experiences of breast cancer were cushioned by their friendships.

Therefore, we suggest women who do not have a strong support network may experience a more negative survivorship phase than the participants included in this study.

CONCLUSIONS

In summary, the findings illustrate breast cancer survivors experience a range of psychosocial concerns throughout survivorship. Despite this, breast cancer survivors perceive a systemic absence in support from oncology teams and rapid deterioration in support from personal support networks. The findings of this study are consistent with previous literature which acknowledges long-term breast cancer survivors have unmet needs. Breast cancer survivors were also able to find benefits from the cancer experience, allowing for adjustment and enabling a successful transition from a cancer patient to a breast cancer survivor. The challenges breast cancer survivors experience are both diverse and complex and each individual requires different levels of support, at varying times throughout the breast cancer trajectory. Consequently, we assert specialist breast care nurses are suitably placed to provide continuing support into and throughout survivorship. Although, we acknowledge breast care nurses are a vital and somewhat limited resource. Therefore, we suggest the continuation of support into and throughout survivorship may not be appropriate or necessary for every breast cancer survivor. Consequently, resources must be targeted at only those who require additional support. Furthermore, we recommend future investigators consider the cost-effectiveness of providing continuing support by breast care nurses, particularly considering different modes of administration (i.e. over the phone or videoconferencing) to provide efficient and cost effective support. Currently, the evidence is not sufficiently conclusive to inform change to the provision of breast cancer care in health services. Future research

should explore the effects of terminating support for breast cancer survivors and should be prospective and longitudinal.

DRAFT

References

- Addington-Hall, J. & Altmann D. (2000) Which terminally ill cancer patients in the United Kingdom receive care from community specialist palliative care nurses?. *Journal of Advanced Nursing* 32(4), doi:799-806. 10.1046/j.1365-2648.2000.t01-1-01543.x
- Adler N.E. & Page A.E. K. (2008) *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*. National Academies Press, Washington, US.
- Ahmed K., Marchand E., Williams V., Coscarelli A. & Ganz P.A. (2016) Development and pilot testing of a psychosocial intervention program for young breast cancer survivors. *Patient Education and Counseling* 99(3), 414-20. doi: 10.1016/j.pec.2015.09.014.
- Beaver K., Williamson S. & Chalmers K. (2010) Telephone follow-up after treatment for breast cancer: views and experiences of patients and specialist breast care nurses. *Journal of Clinical Nursing*, 19(19-20), 2916-2924.
- Benedet R.D. (2010) *The Role of the Specialist Breast Nurse*. Springer, Stanford, CA.
- Bower J., Meyerowitz B., Desmond K. & Bernards C. (2005) Perceptions of positive meaning and vulnerability following breast cancer: predictors and outcomes among long-term breast cancer survivors. *Journal of Behavioural Medicine* 29(3), 236-245.
- Bowman K.F., Smerglia V.L. & Deimling G.T. (2004) A stress model of cancer survivorship in older long-term survivors. *Journal of Mental Health* 10, 163–182.
- Broeckel J.A., Thors C.L., Jacobsen P.B., Small M. & Cox C.E.(2002) Sexual functioning in long-term breast cancer survivors treated with adjuvant chemotherapy. *Breast Cancer Research and Treatment* 75, 241–48.

Burg M.A., Adorno G., Lopez E.D., Loerzel V., Stein K., Wallace C. & Sharma D.K. (2015) Current unmet needs of cancer survivors: analysis of open-ended responses to the American Cancer Society Study of Cancer Survivors II. *Cancer* 121(4):623-30. doi: 10.1002/cncr.28951.

Cappiello, M., Cunningham, R.S., Knobf, M.T., & Erdos, M (2007). Breast cancer survivors: Information and support after treatment. *Clinical Nursing Research*. 16 (4), 278-293

Calnan, M.W., & Sanford, E. Public trust in health care: the system or the doctor? *Quality and Safety in Health Care* 13, 92-97

Cimprich B., Janz N.K., Northouse L., Wren P.A. Given B. & Given C.W. (2005) Taking Charge: A Self-management Program for Women Following Breast Cancer Treatment. *Psycho-Oncology* 14(9), 704-717.

Collins N.L. & Feeney B.C. (2004) *An attachment theory perspective on closeness and intimacy*. Lawrence Erlbaum, London, UK.

Curda A. (2011) The Damocles Syndrome: Where we are today. *Journal of Cancer Education* 26(2), 397-398.

Denford S., Harcourt D.D., Rubin L.L. & Pusic A.A. (2011) Understanding normality: A qualitative analysis of breast cancer patient's concepts of normality after mastectomy and reconstructive surgery. *Psycho-Oncology* 20(5), 553-558.

Documet P.I., Trauth J.M., Key M., Flatt, J. & Jernigan J. (2012) Breast cancer survivors' perception of survivorship. *Oncology Nursing Forum* 39(3), 309-315.

Drageset S., Lindstrøm T.C. & Underlid K. (2016) 'I just have to move on': Women's coping experiences and reflections following their first year after primary breast cancer surgery.

European Journal of Oncology Nursing 21, 205-11. doi: 10.1016/j.ejon.2015.10.005.

Eccles S.A., Aboagye E.O., Ali S. anderson A.S., Armes J., Berditchevski F. & ... Thompson A.M. (2013) Critical research gaps and translational priorities for the successful prevention and treatment of breast cancer. *Breast Cancer Research* 15(5):R92. doi: 10.1186/bcr3493.

Fallowfield L., & Jenkins V. (2015) Psychosocial/Survivorship Issues in Breast Cancer: Are We Doing Better? *JNCI Journal of the National Cancer Institute* 27(1), 107. doi:

10.1093/jnci/dju335

Ferrell B., Grant M., Funk B., Otis-Green S. & Garcia N. (1998) Quality of life in breast cancer survivors: implications for developing support services. *Oncology Nursing Forum* 25(5), 887-895.

Finlay L. (2009) Debating phenomenological research methods. *Phenomenology & Practice* 1, 6–25.

Fobair P. & Spiegel D. (2009) Concerns about sexuality after breast cancer. *Cancer* 15(1),19–26.

Fors E., Bertheussen G., Thune I., Juvet L., Elvsaas I., Oldervoll L. & ... Leivseth G. (2011) Psychosocial interventions as part of breast cancer rehabilitation programs? *Psycho-Oncology* 20(9), 909-918. doi: 10.1002/pon.1844.

Frankl V.E. (1963) *Man's Search for Meaning: An Introduction to Logotherapy*. Washington Square Press, Oxford, UK.

Ganz P.A., Guadagnoli E., Landrum M.B., Lash T.L., Rakowski W. & Silliman R.A.(2003) Breast cancer in older women: quality of life and psychosocial adjustment in the 15 months after diagnosis. *Journal of Clinical Oncology* 21(21), 4027–4033. doi:

10.1200/JCO.2003.08.097

Giorgi A. & Giorgi B. (2008) Phenomenology. In *Qualitative Psychology: A practical guide to research methods* (Smith J.A. ed.), London, Sage.

Graham L.J., Shupe M.P. & ... Schneble E.J. (2014) Current Approaches and Challenges in Monitoring Treatment Responses in Breast Cancer. *Journal of Cancer* 5(1), 58-68. doi:

10.7150/jca.7047.

Holzner B., Kemmler G., Kopp M., Moschen R., Schweigkofler H., Dürner M., Margreiter R., Fleischhacker W.W. & Sperner-Unterwiesing B. (2001) Quality of life in breast cancer patients-not enough attention for long-term survivors?. *Psychosomatics* 42, 117–23.

Jacobsen P.B., Rowland J.H., Paskett E.D., Van Leeuwen F., Moskowitz C., Katta S., Wollins D. & Robison L.L. (2016) Identification of Key Gaps in Cancer Survivorship Research: Findings From the American Society of Clinical Oncology Survey. *Oncology Practice* 12(3):190-3. doi: 10.1200/JOP.2015.009258.

Jefferson G. (2004) *Glossary of transcript symbols with an introduction*. John Benjamins, Philadelphia, PA.

Jiwa M., Halkett G., Deas K., Ward P., O'Connor M., O'Driscoll, C. & ... Weir, J. (2010) How do specialist breast nurses help breast cancer patients at follow-up?. *Collegian Royal College of Nursing, Australia* 17(3), 143-149. doi: 10.1016/j.colegn.2010.04.003.

Johnston D. (2012) Mindfulness: A proposed couple-based intervention for the altered self-identity of breast cancer survivors. *Mindfulness* 3(4), 282-290. doi: 10.1007/s12671-012-0093-6.

Kauffman J. (1995). *Awareness of mortality: Death, value and meaning*. Baywood, Amityville, NY.

Koch L., Bertram H., Eberle A., Holleczeck B., Schmid-Höpfner S., Waldmann A., Zeissig S., Brenner H. & Arndt V. (2014) Fear of recurrence in long-term breast cancer survivors-still an issue. Results on prevalence, determinants and the association with quality of life and depression from the Cancer Survivorship-a multi-regional population-based study. *Psycho-Oncology* 23(5), 547-554. doi: 10.1002/pon.3452

Lincoln Y. S. & Guba E. G. (1985). *Naturalistic Inquiry*. Sage, Newbury Park, CA.

Lutendorf S.K., Sood A.K. anderson B., McGinn S., Maiseri H., Duo M. & ...Lubaroff D.M. (2005) Social support, psychological distress and natural killer cell activity in ovarian cancer. *Journal of Clinical Oncology* 23(7), 105–7113. doi: 10.1200/JCO.2005.10.015

Macmillan Nurses Information and Support (2014). Retrieved from <http://www.macmillan.org.uk/information-and-support/coping/getting-support/macmillan-nurses>

Mallinckrodt B., Armer J.M. & Heppner P.P.(2012) A threshold model of social support, adjustment and distress after breast cancer treatment. *Journal of Counseling Psychology* 59(1), 150-60. doi: 10.1037/a0026549.

Manos D., Sebastián J., Mateos N. & Bueno M. (2009) Results of a multi-componential psychosocial intervention programme for women with early-stage breast cancer in Spain: quality of life and mental adjustment. *European Journal of Cancer Care* 18(3), 295-305.

Matthews H., Grunfeld E.A. & Turner A. (2016) The efficacy of interventions to improve psychosocial outcomes following surgical treatment for breast cancer: a systematic review and meta-analysis. *Psychooncology*. doi: 10.1002/pon.4199.

McGinty, H.L., Goldenberg, J.L., & Jacobsen, P.B. (2012). Relationship of threat appraisal with coping appraisal to fear of cancer recurrence in breast cancer survivors. *Psycho-Oncology* 21 (2), 203-210.

Mehnert A. & Koch U. (2008) Psychological comorbidity and health-related quality of life and its association with awareness, utilization and need for psychosocial support in a cancer register-based sample of long-term breast cancer survivors. *Journal of Psychosomatic Research* 64(4), 383-91. doi: 10.1016/j.jpsychores.2007.12.005.

Meneses K., McNees P., Loerzel V.W., Su X., Zhang Y. & Hassey L.A. (2007) Transition from treatment to survivorship: Effects of a psychoeducational intervention on quality of life in breast cancer survivors. *Oncology Nursing Forum* 34(5), 1007-1016.

Meyrick J. (2006) What is good qualitative research? A first step towards a comprehensive approach to judging rigour/quality. *Journal of Health Psychology* 11(5), 799–808. doi: 10.1177/1359105306066643

NHS Trust (2016) *The role of the breast clinical nurse specialist*. Imperial College Healthcare, UK.

Available: www.nhs.uk/ipgmedia/Local/Imperial%20College%20Healthcare%20NHS%20Trust/assets/Theroleofthebreastclinicalnursespecialist-keyworker.pdf

Ogden J. (2004) *Understanding Breast Cancer*. John Wiley and Sons Ltd, Chichester, UK.

Pinto A. & de Azambuja E. (2011) Improving quality of life after breast cancer: Dealing with symptoms. *Maturitas* 70(4), 343-348. doi: 10.1016/j.maturitas.2011.09.008.

Rogers R.W. (1983) *Cognitive and physiological processes in fear appeals and attitude change: A revised theory of protection motivation*. Guilford Press, New York, US.

Rowland J.H., Aziz N., Tesauro G. & Feuer E.J.(2001) The changing face of cancer survivorship. *Seminars in Oncology Nursing* 17(4), 236–240. doi:10.1053/sonu.2001.27912

Royak-Schaler R., Passmore S., Gadalla S., Hoy M., Zhan M., Tkaczuk K., & ... Hutchison A. P. (2008) Exploring patient-physician communication in breast cancer care for African American women following primary treatment. *Oncology Nursing Forum* 35(5), 836-843. doi: 10.1188/08.ONF.836-843.

Sammarco, A. (2001). Perceived social support, uncertainty and quality of life of young breast cancer survivors. *Cancer Nursing*. 24 (3), 212-219.

Saqib N., Pierce J.P., Saqib J., Flatt S.W., Natarajan L., Bardwell W.A., & ... Parker, B.A. (2011) Poor physical health predicts time to additional breast cancer events and mortality in breast cancer survivors. *Psycho-Oncology*, 20(3), 252-259. doi: 10.1002/pon.1742.

Savard J., Simard S., Blanchet J., Ivers H. & Morin C.M. (2001) Prevalence, clinical characteristics and risk factors for insomnia in the context of breast cancer. *Sleep* 24, 583–90.

Sears S.R., Stanton A.L. & Danoff-Burg S. (2003) The yellow brick road and the emerald city: Benefit finding, positive reappraisal coping and posttraumatic growth in women with early-stage breast cancer. *Health Psychology* 22,487–497. doi.org/10.1037/0278-6133.22.5.487

Smith J. & Osborn M. (2008) Interpretative phenomenological analysis. In *Qualitative Psychology: A Practical Guide to Research Methods*, 2nd edn. (Smith J.A. ed.), Sage, London, pp. 53–80.

Smith P., Flowers P. & Larkin M. (2009) *Interpretative phenomenological analysis: Theory, method and research*. Sage Publications, London, UK.

Tong A., Sainsbury P. & Craig J. (2007) Consolidated criteria for reporting qualitative research (COREQ): A 32 item checklist for interviews and focus groups. *International Journal for Quality in Health Care* 19, 349-357. doi.org/10.1093/intqhc/mzm042

Vivar C. & McQueen A. (2005) Informational and emotional needs of long-term survivors of breast cancer. *Journal of Advanced Nursing* 51(5), 520-528. doi: 10.1111/j.1365-2648.2005.03524.

von Heymann-Horan A.B., Dalton S.O., Dziekanska A., Christensen J. andersen I. &... Mertz B.G. (2013) Unmet needs of women with breast cancer during and after primary treatment: A prospective study in Denmark. *Acta Oncologica* 52, 382–90. doi: 10.3109/0284186X.2012.746468.

Wang, F., Liu, L., Wang, F., Ma, Z., Gao, D., Zhang, Q., & Yu, Z. (2014). The status and correlates of depression and anxiety among breast cancer survivors in eastern China: a population based cross sectional case-control study. *BMC Public Health* 14; 326

Wang Y., Zhu X., Yang Y., Yi J., Tang L., He J., Chen G., Li L. & Yang Y.(2015) What factors are predictive of benefit finding in women treated for non-metastatic breast cancer? A prospective study. *Psycho-oncology* 24(5), 533-9. doi: 10.1002/pon.3685.

Yalom I.D. (1980) *Existential Psychotherapy*. Basic Books, New York, US.

Yardley L. (2000) Dilemmas in qualitative health research. *Psychology and Health* 15, 215-228. doi: 10.1080/08870440008400302.

Zebrack B.J.(2000) Cancer survivor identity and quality of life. *Cancer Practise* 8, 238–242.

doi: 10.1046/j.1523-5394.2000.85004.

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