

**Living with and beyond breast cancer:
Exploring women's use of social media
to support psychosocial health**

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Abbreviations

DCIS	Ductal Carcinoma in situ
HCPs	Healthcare professionals
LwBC	Living with and beyond cancer
LwBBC	Living with and beyond breast cancer
NCSI	National Cancer Survivorship Initiative
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
ONS	Office of National Statistics
SDT	Self-determination theory
SNS	Social Networking Site
YBCN	Younger Breast Cancer Network

Abstract

Background

Despite the extensive use of social media, its role in supporting women living with and beyond breast cancer (LwBBC), across the survivorship trajectory, remains underexplored. Existing research has tended to focus on single or dual platform use and utilised secondary data, principally from Facebook and Twitter. In contrast, this study sought to ensure women's experiences of use took centre stage by adopting a qualitative approach to explore social media use across the survivorship trajectory.

Aims:

The aims of this thesis were to: a) explore how women LwBBC use social media; b) examine how women use social media as communicative resources in relation to LwBBC; and c) make sense of how women use social media to support their psychosocial health.

Methods

Twenty-one women (age range 27-64) participated in semi-structured interviews. Twelve participated in a photo-elicitation study using pre-existing photographs to explore social support. Nine participated in a photo-production study in which they took photographs (n=157) to represent how they communicate their experiences of LwBBC to others. A bricolaged approach to data analysis using thematic, polytextual and voice centred methodological approaches ensured women's voices were brought to the fore within the analysis process.

Findings

Social media use is integral to many, but not all, women's daily lives and considered by women an appropriate space to explore their own experiences. Women describe using multiple social media platforms, such as Facebook, YouTube, Wikipedia and WhatsApp concurrently. The use of multiple platforms simultaneously to satisfy psychosocial needs demonstrates use to be more fluid and dynamic than the current literature suggests. Through listening to women's voices, and using photographs to visualise voices, three key themes came to the fore: (i) finding relevant, timely and appropriate support; (ii) navigating disrupted identities; and (iii) (re)gaining a sense of control. Analysis shows these themes to be

entangled, interconnected, and dynamic with women's use shifting across time. Women describe social media use as both empowering but also as dislocating.

Conclusions

This is the first in depth qualitative study that takes an overview of women's engagement across social media platforms to support their experiences of LwBBC. It demonstrates significant digital labour by women through use of social media to support their physical, emotional, and (anti) social experiences of LwBBC. It indicates naturally occurring networked communities as important contributors to the ongoing psychosocial support women need at different stages of LwBBC. Social media enables women to (re) gain a sense of control and can reduce need to draw on health service provision. Knowledge of women's use can provide insight and guidance for healthcare professionals (HCPs), producers of online content, moderators of social media communities and other women LwBBC.

Chapter 1: Introducing this thesis

1.0 Introduction

The overall aim of this research was to: (i) examine how women living with and beyond breast cancer (LwBBC) use social media; (ii) explore how women use social media as communicative resources in relation to LwBBC; and (iii) make sense of how women use social media to support their psychosocial health. This introductory chapter situates this research within the fields of ‘cancer survivorship’ and ‘social media’. The reasons for carrying out this research are discussed. Finally, an overview of the structure of this thesis is provided.

1.1 The need to support women living with and beyond breast cancer

In recent years there has been a significant focus on improving survival outcomes for those diagnosed with cancer in the UK (Foster, Calman, Richardson, Pimperton & Nash, 2018). This intent has been demonstrated through the publication of the Cancer Reform Strategy (Department of Health, 2007); the establishment of the National Cancer Survivorship Initiative (2010, 2013); the Improving Outcomes Strategy for Cancer (Department of Health, 2011); and the establishment of a new Independent Cancer Taskforce in January 2015 (Cancer Research UK, 2015; NHS England, 2015), which produced a five year cancer strategy for England (2015-2020) focused on achieving world class cancer outcomes (Independent Cancer Taskforce, 2015; NHS, 2016). Against this background, it is important to provide context as to why research into the consequences of breast cancer and its treatment for women is required.

In terms of breast cancer survival outcomes in the UK, the number of women living longer post breast cancer diagnosis is increasing (Cancer Research UK, 2018). This is a result of healthcare policies focused on early detection, including the National Health Service Breast Screening Programme (NHSBSP), successful advances in drug treatment and a growing population ((Department of Health, Macmillan Cancer Support & NHS Improvement, 2013; Foster et al., 2018, NCSI, 2013). Breast cancer remains the most common cancer in the UK with 55,200 women diagnosed annually (Cancer Research UK, 2018). In 2009, it was

reported that between 550,000 – 570,000 people are living with and beyond breast cancer (Maddams et al., 2009). Estimates suggest the prevalence of breast cancer will increase threefold to affect the lives of approximately 1.5 million women by 2040, due to the improvements in treatment and an aging population (Maddams, Utley & Møller, 2012). This growth in the numbers of women surviving breast cancer is positive news. That said, mortality cannot be ignored, and breast cancer remains the second most common cause of cancer death for women in the UK with 11,433 deaths from breast cancer in 2014 (Cancer Research UK, 2018). The difference in diagnosis and mortality rates provides some sense of the growing numbers of women living with and beyond breast cancer in the UK today.

With this growing population comes a different set of healthcare issues. Macmillan Cancer Support in conjunction with the National Cancer Intelligence Network (NCIN) and Deloitte Monitor provided analysis of the ‘Routes from Diagnosis’. This analysis set out, for the first time, the experiences of women in terms of the ongoing and long-term effects of treatment for a number of cancers including breast cancer (Macmillan Cancer Support et al., 2014). This insight supports the perspective that those living with and after a diagnosis of cancer demonstrate high usage of health services (Foster & Fenlon, 2011). Women’s ongoing and unmet needs when LwBBC, including for instance, pain, fatigue, fear of recurrence, lymphedema and financial and work related issues (Aaronson et al., 2014; Burg et al., 2015; Butt et al., 2008; Cheng, Wong, & Koh, 2015; Fiszer, Dolbeault, Sultan, & Brédart, 2014; Foster, Wright, Hill, Hopkinson, & Roffe, 2008; Glare et al., 2014; Park & Hwang, 2012; Vivar & McQueen, 2005), demonstrate complex issues which require support. Some will need ongoing primary or secondary care management (Macmillan et al., 2014). The identification of these ‘Routes from Diagnosis’ comes at a time when the National Health Service (NHS) is embarked upon a cultural shift towards empowering patients to self-manage their care (Foster & Fenlon, 2011) due to resource limitations in an increasingly stretched health system (Davies & Batehup, 2011; Foster et al., 2018). Self-management refers to the full range of activities that women living with and beyond breast cancer

“may engage in to promote their health, augment their physical, social or emotional resources, and prevent adverse sequelae from their disease” (Thorne & Paterson, 2001, p. 82).

The Department of Health takes a broader and more functional approach in their definition of self-management. Self-management consists of:

“the actions individuals and carers take for themselves, their children, their families and others to stay fit and maintain good physical and mental health; meet social and psychological needs; prevent illness or accidents; care for minor ailments and long term conditions; and maintain health and wellbeing after an acute illness or discharge from hospital” (cited by The Health Foundation, 2011, p.1).

Against this background, finding alternative ways to support women, or understanding ways in which women are supporting themselves, and sharing this knowledge with others is a timely necessity. This is particularly pertinent in an era which is dominated by accelerated technological innovation. One way in which women may be managing the experiences of living with and beyond breast cancer may be through their use of social media platforms, such as Facebook, Twitter and WhatsApp. These platforms may enable communication processes that differ from those offered by other information technologies, for example online discussion boards, through offering more engaging and collaborative experiences (Merioli, Gray & Martin-Sanchez, 2013). Both the expectations of life expectancy following a breast cancer diagnosis and the environments in which women experience health and illness have changed considerably. Before the advent of the web, illness “remained largely a private experience” (Conrad, Bandini & Vasquez, 2016, p.22). With the advent of Web 2.0, information searching, and a wide range of communication approaches, have shifted illness experiences from being “private” to being “privately public” and “publicly private” (Lange, 2007; Papacharissi, 2009). Traditional and anonymous online communities are considered “privately public” spaces (Lange, 2007). These are sometimes referred to as ‘predecessor’ sites and include discussion forums, bulletin boards and chat tools. In a literature review of health outcomes and related effects of using social media in chronic disease management, Merolli et al., (2013) identified ‘online support groups’ as predecessor sites. In these, community members can keep their ‘identity’ private as they share their illness experiences with others. The social support processes which take place in online communities have been found to be empowering with potential beneficial effects for psychological wellbeing (Batenburg & Das, 2015; Rodgers & Chen, 2005; van Uder-Kraan et al. 2008; Walther & Boyde, 2002). In contrast, social media platforms, such as Facebook, are conceptualised as “publicly private” spaces. Here, private activities are presented to public audiences and real identities used (Papacharissi, 2009). While considerable literature explores the use of online (privately public) breast cancer communities (Bender, Jimenez-Marroquin, Ferris, Katz, & Jadad, 2012; Civan & Pratt, 2007; Han et al., 2012; Kim et al., 2011; Sharf, 1997; Shim,

Cappella & Han, 2011; Sillence, 2013; Vilhauer, 2009; Yoo et al., 2013), the literature exploring how women living with and beyond breast cancer engage with social media (publicly private) spaces was identified by Merolli et al., (2013) as “largely missing” (p. 962), and remains an issue five years later.

The Office of National Statistics (ONS) states that in the UK, 90% of households have internet access with 80% of adults using the internet daily (ONS, 2017). All age groups use the internet as an information source for general information, and health information (Figure 1-1). During 2016, 50% of all internet users looked for health related information online, a 33% increase since 2007.

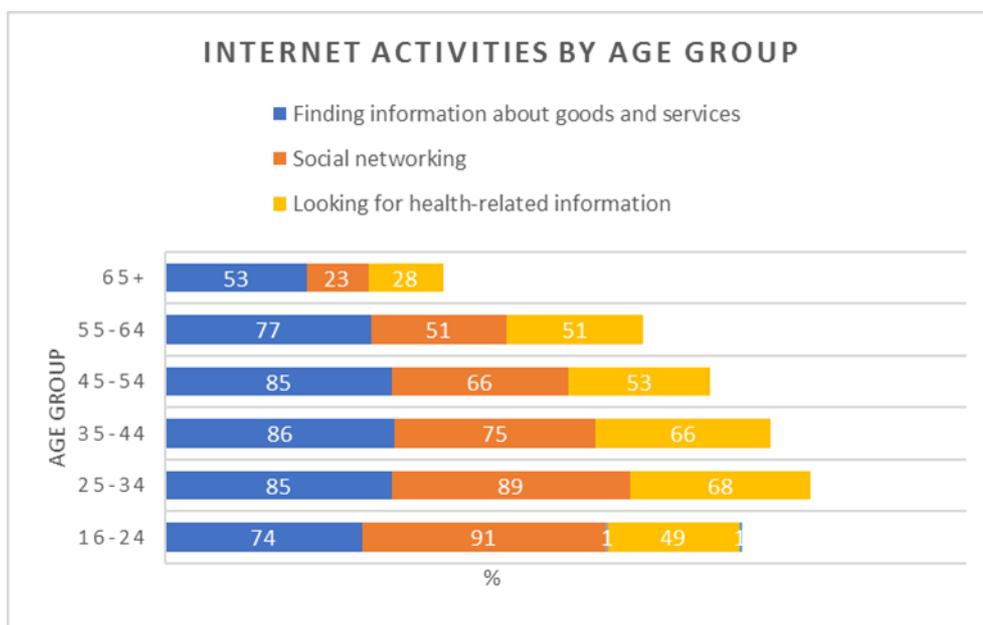


Figure 1-1 All internet activities by age group in the UK, including looking for health related information (Ofcom, 2016).

Social media is an embedded set of practices in the daily lives of women in the UK (boyd, 2015; Ofcom, 2016; Stone, 2009). Ofcom (2017) reported 78% of all women in the UK have at least one social media account or profile. Gaining understanding of how women are using these social media platforms at different stages post diagnosis can inform service developments going forwards. For example, if women use social media to satisfy informational needs, understanding gaps in information provision will provide useful insight for service providers. This may relate to actual gaps in information, anxieties expressed as a consequence of a need for information or provide insight in to alternative approaches for

information sharing and provision. In a review conducted to inform a National Institute for Health Research (NIHR) programme¹, Ziebland and Wyke (2012) argued that:

“health policymakers, clinicians, and the voluntary sector need evidence regarding the role and limitations of online patient experience in the broad canvas of people’s experiences of health and illness” (p.241).

We have seen how previous research has concentrated extensively on researching breast cancer online communities. This thesis seeks to extend knowledge by closing the gap relating to the use of social media by women LwBBC to meet their ongoing needs. Outputs will be developed post PhD to help inform health policymakers, clinicians, the voluntary sector and women LwBBC of how women experience psychosocial benefits through social media engagement.

1.2 ‘Survivorship’ and living with and beyond breast cancer

The term ‘living with and beyond breast cancer’ is used within this study, abbreviated as LwBBC. That said, on occasion the term ‘survivorship’ is also used and points to entwined discourses used to describe people who have been diagnosed with cancer.

In 2010, the UK’s National Cancer Survivorship Initiative (NCSI) acknowledged that many different definitions of cancer survivorship are used (NCSI, 2010). The term ‘cancer survivor’; originated in the US, as a motivating psychosocial term to encourage people to “learn to fight” cancer (Twombly, 2004, p.1414). Ellen Stovall, President of the National Coalition for Cancer Survivorship (NCCS) in the US stated the term was “designed to empower patients to make decisions about their care and to push for better research and treatment” (Twombly, 2004, p.1414). The NCSI (2010) defined ‘survivorship’ as encompassing:

“those who are undergoing primary treatment, those who are in remission following treatment, those who are cured and those with active or advanced disease” (Department of Health, 2010, p.21).

¹ This was in relation to the National Institute for Health Research (NIHR)–funded program (iPEX). It examined the role of online patient experiences (PEX). The iPEX program (which included qualitative interviews, an online ethnography, Internet café experiments, and a randomized controlled trial) was to help understand the role of online patient experience and provide guidelines for websites and health interventions that incorporate patients’ experiences (Ziebald & Wyke, 2012).

‘Survivorship’ has been described as “a multidimensional concept involving physical, psychological, social and spiritual aspects of life” (Foster, Wright, Hill, Hopkinson & Roffe, 2009, p.224). However, research by Khan, Harrison, Rose, Ward & Evans (2011) indicated that in the UK, “generally people with cancer do not endorse the term cancer survivor” (p.33). Using qualitative interviews, Khan et al., (2011) explored how 40 people, at least five years post diagnosis of breast, colorectal and prostate cancer, felt in relation to being a cancer ‘survivor’. The label ‘cancer survivor’ was found to not describe how people felt about their identity and was associated with an advocacy role that they did not wish to take on. When referring to people living with and beyond cancer, Khan et al., (2011) argued policy makers in the UK should avoid this term and advocated the use of descriptive terms instead such as “people who were diagnosed with cancer 5 years ago” (p.184).

While Macmillan Cancer Support fund a five-year Cancer Research ‘Survivorship’ group based at the University of Southampton, they also strive in their public, outward facing materials to identify individuals previously diagnosed with any cancer as ‘living with and beyond’. The NCSI acknowledge these various terms and that many people prefer to think of themselves, and to be understood by others, as “living with and beyond” (2010, p.9).

Consequently, the terms ‘survivorship’ and ‘living with and beyond’ are used interchangeably within this field in the UK. For instance, when the NCSI published ‘Living with & Beyond Cancer: Taking action to improve outcomes’ in March 2013 (Department of Health et al., 2013), the title included the term ‘Living with & Beyond Cancer’. The report consisted of ten sections; four providing background and six outlined actions to be taken to improve outcomes. Four of these ten section headings included the term ‘survivorship’. None used ‘living with and beyond’. Macmillan et al., (2014) in reporting the ‘Routes from Diagnosis’ continue to refer to ‘survivorship outcomes’ and ‘survival times’. Potentially, this demonstrates the constrained discourses in use in relation to this population. It also demonstrates attempts to bridge between the medicalised terminology of the health profession and public needs, given Khan et al.’s (2011) identification of the rejection of the term by those who have had cancer.

1.3 Declaring my interest

My interest in social media use by women LwBBC first stemmed from my experiences of working within a chemotherapy unit in North West England. While conducting research, I

was fortunate to sit and talk to people as they received treatment. I observed considerate medical care, concern for the individual in relation to their treatment experience and positive interactions between healthcare staff and patients. Yet demands on clinical staff limited these opportunities. Patients seemed socially isolated, in part due to the physical space between treatment chairs during treatment and in part because the experiences of those receiving treatment and those who attended to support them were very different. There seemed limited opportunity for women to share their daily experiences of living with breast cancer if they so wished. Consequently, I became interested in whether, and if so how, women were able to use social media to share these daily experiences to support their psychosocial health post diagnosis and beyond.

This led to my MSc dissertation² on the discourses used by breast cancer ‘survivors’ to position their experiences of breast cancer ‘survivorship’ through blogging (Ure, 2014). My discursive analysis highlighted two challenges women used blogging to help alleviate. Firstly, there was the expectation of being both ‘better’ i.e. well, and a ‘better person’ i.e. ‘new and improved’, as a consequence of having (had) and ‘survived’ breast cancer. A social expectation of being ‘back to normal’ was shared. Secondly, the ‘reality’ of the wider social representation of LwBBC produced and circulated by the media and charitable organisations were challenged. One way in which media representations were challenged was by problematising an image that the Susan Komen Race for the Cure charity utilised depicting a ‘breast cancer survivor’ to ‘recruit’ participants for a race. Another was the way in which women outed how they were silenced by social norms when interacting with friends and family, restricting their abilities to share their experiences and draw on social support demonstrating a spiral of silence (Noelle-Neumann, 1974). The notion of ‘being silenced’ has directly influenced my approach to this thesis. My MSc research also showed how women use blogging as a coping mechanism (Tan, 2008; Rains & Keating, 2012). Blogging represented ‘truth telling’ by enabling women to articulate their ‘realities’ of living with breast cancer. Blogging provided social support through facilitating connection with likeminded others (Hollenbaugh, 2011; Nakhaie & Arnold, 2010). While conducting this blog analysis, I became interested in the interconnectedness of platforms themselves. A plethora of platforms enables women to select numerous approaches to communicate and learn about their experiences. Focusing on one social media platform rather than exploring

² In Media Psychology.

use across multiple platforms may restrict our understanding of the benefits experienced. Exploring how women use ‘social media’ as a collection of tools, will provide new insight into how women LwBBC decide to connect with others in relation to different aspects of LwBBC.

1.4 Thesis structure

This introduction is intended to provide a brief overview of the challenges faced by women, and the broader UK health system, because of the increasing incidence of breast cancer in the UK. I have introduced the rationale for this research that will be expanded upon further in the main body of this thesis. I have introduced the challenges language brings in relation to researching ‘survivorship’ and ‘living with and beyond’ and the flexible approach to terms used within this thesis.

Chapter Two outlines in more detail the experiences of women LwBBC in the UK today. It concentrates on two aspects which underpin this study. These include a review of the new knowledge relating to the ‘Routes from Diagnosis’ (Macmillan et al., 2014) of women diagnosed with breast cancer; and an introductory exploration of the concept of psychosocial health. This chapter provides a brief introduction to the literature relating to the psychosocial needs of women LwBBC. Given my MSc findings regarding blogger’s experiences of ‘being silenced’ when seeking support from friends and family (section 1.3), using a social support lens seemed an appropriate starting point through which to explore social media and psychosocial health. Consequently, the chapter concludes with an introduction to the literature related to social support and breast cancer.

In Chapter Three, an explanation of how social media is conceptualised within this thesis is provided. Consideration is given to the role of health and digital literacies in relation to health outcomes. The literature relating to social media and social support is explored and social capital is introduced as a notion to extend thinking about social support. In the remainder of this chapter, a scoping review reports the literature relating to social media use and women’s experiences of LwBBC. It concludes by identifying the gaps in the literature which this study address.

In Chapter Four, the ontological, epistemological and methodological approaches underpinning this study are identified. A pragmatic approach has been taken to produce findings which can be successfully presented to a range of different audiences and to enable

descriptive quantitative data to be collected. I explain why using visual methods within semi-structured interviews are an appropriate technique when exploring women's experiences of breast cancer and social media use. This includes why both photo-elicitation and photo-production approaches were used to gain greater depth and breadth of data. I also outline my approach to bricolaging thematic analysis, polytextual thematic analysis and voice centred methodological approaches to analysis. Through bricolaging these approaches to analysis, women's voices were brought to the fore through text, and through being able to visualise voices through women's photographs.

In Chapter Five, the methods used for this study are outlined. This includes sampling and how data was generated with women LwBBC. I detail how data was recorded; ethical issues arising within the research process and show the methods used to bricolage thematic, polytextual and voice centred approaches to analysis. I highlight how use of the voice centred relational method provided a systematic approach which enabled women's relationships with themselves, others and their use of social media to come to the fore. The use of Nvivo and Excel as tools to support analysis is also discussed. Finally, I reflect on presenting the findings to participants.

In Chapter Six, I begin to contextualise the findings. In this chapter, I provide 'pen portraits' of the women that participated in the study. This is important for two reasons. Firstly, to ensure the analysis process including the preparation, organization, and reporting of findings can be identified as trustworthy (Elo et al., 2014). Secondly, to give identity to the women participating in this study; to ensure their voices are heard both individually and collectively. In this chapter, I provide a demographic overview of participants and a descriptive overview of both their general social media use and use specifically related to LwBBC. I conclude the chapter by presenting the final themes and subthemes identified through the analysis process. Chapters Seven, Eight and Nine each report on the three main themes identified. Each theme is reported as a set of subthemes.

In Chapter Ten, I discuss the main findings from this thesis and reflect on theoretical considerations and how these have supported answering the research questions. I explore issues of methodology and highlight specific issues of interest to individuals with a substantive interest in cancer care. Finally, I conclude with the limitations of this study and offer some thoughts related to future areas of research which could follow on from this study.

Chapter 2: Living with & beyond breast cancer in the UK

2.0 Introduction

This chapter introduces the concept of living with and beyond breast cancer (LwBBC). To provide context, breast cancer incidence in the UK is discussed. By providing insights into the various pathways women experience post diagnosis, this chapter begins to show the complexity of women’s experiences. This chapter also provides a brief introduction to the concept of psychosocial health and a review of factors which impact on psychosocial health. Finally, social support – a key factor which influences psychosocial health and social media use – will be introduced.

2.1 Breast cancer incidence and prevalence

The NCSI was launched with an agenda to understand the needs of people surviving cancer. It aimed to: “develop models of care that meet their needs” and “support cancer survivors to live as healthy and active a life as possible, for as long as possible” (Richards, Corner & Maher, 2011, p.1). This agenda recognises improvements in life expectancy for many cancers including breast cancer. Life expectancy for women at 1, 5 and 10 years post breast cancer diagnosis has improved significantly since the early 1970’s. Table 1 shows how survival rates have nearly doubled within the last forty years (Cancer Research UK, 2015). Improvements in survival rates are related to increases in early detection and improvements in treatments (Maddams et al., 2009; ONS, 2016).

Table 1: Breast Cancer, Age standardised One-, Five- and Ten-year Net survival (England and Wales)

Women	1-Year survival (%)	5-Year Survival (%)	10-Year Survival (%)
1971-1972	82	53	40
2010-2011	96	86	78 ³

³ Age-standardised net survival for patients diagnosed with breast cancer during 2010-2011 in England and Wales (Cancer Research UK, 2015)

Table 2 shows survival rates at one-year post diagnosis as broadly similar for those diagnosed between the ages of 15 and 69. However, 5-year survival at 87.5% is lower for women aged 15 to 44 years at diagnosis and women aged 75-99 (70.1%) than for women aged 45 to 74 years (ranging from 91.7% to 89.8.0%) (ONS, 2016). At 10 years, survival rates are 81.1% for women diagnosed between the ages of 15-44, lower than the survival rates for those diagnosed between 45-74 (range 88.3-87.1).

Table 2: Predicted estimates of one-year, five-year and ten-year net survival (%) for women (aged 15 to 99 years) that would be diagnosed with breast cancer in England in 2016, by age (ONS, 2017).

Age group	Number of patients	1-year survival (%)	5-year survival (%)	10-year survival (%)
Age-standardised	320,162	95.2	84.1	80.5
Un-standardised	320,162	95.9	85.8	82.0
15-44	36,066	98.5	87.5	81.1
45-54	76,972	98.7	91.7	87.3
55-64	81,471	98.2	91.7	88.3
65-74	70,862	97.0	89.8	87.1
75-99	54,791	89.2	70.1	66.9

However, data regarding the number of women currently LwBBC is fragmented. Cancer Research UK (2015) reported 491,300 women previously diagnosed in the UK as LwBBC at the end of 2010. Maddams et al., (2009) suggested the population was between 550,000 – 570,000. Maddams et al.’s prevalence estimates predict this figure to increase threefold by 2040, due to continued improvements in treatment, and an increasing and ageing population (2012). Maher and McConnell (2011) described the work of Maddams et al., (2009) as the first attempt to estimate the numbers of women in different stages of the ‘pathways of care’ post breast cancer diagnosis. Up until this time little data had been collected or reported about cancer ‘survivors’, evidencing an assumption held that ‘survivors’ “have no particular needs requiring specific resources” (Maher & McConnell, 2011, p.5). This remains an issue for women living with secondary breast cancer. An absence of any population data in the UK relating to women living with incurable disease has led to women advocating for improved data through their Members of Parliament (Taylor, 2017). As a result of this advocacy, Breast

Cancer Care is now pressing the Department of Health to routinely collect data for women with secondary breast cancer too (Breast Cancer Care, 2017). However, the current absence of data gives the impression that women living with incurable disease have ‘no particular needs requiring specific resources’ too.

2.2 Women’s outcomes post diagnosis

Through retrospective analysis, Macmillan et al., (2014) examined the data of 26,926 women in England diagnosed with breast cancer in 2004 and followed their routes from diagnosis through to 2011⁴. The evidence suggests that only 20% of women diagnosed with breast cancer will live ‘long term’ and in ‘good health’. ‘Long term’ was defined as “beyond seven years” and in good health as “the initial treatment for their cancer being successful and not needing hospital care for a range of other serious conditions apart from their cancer” (Macmillan Cancer Support, 2014, p.9). These definitions are important. They work to define how ‘long term survival’ was conceptualised by Macmillan Cancer Support et al., across all cancers in the UK in 2014. Foster et al., (2009) identified that a consensus on a definition of long term survival was absent. In their systematic review of the psychosocial implications of living five years or more beyond a cancer diagnosis, five years was used as the definition of long term survival (Foster et al., 2009). They argued cancer survival rates were traditionally expressed as five years post diagnosis and that most recurrence occurs within five years. They noted however that this definition was not universally taken up. While one in five (20%) of women diagnosed will “live well” and in “good health”, the remaining 80% of women LwBBC experience other serious health conditions such as heart, liver or kidney disease; develop another primary cancer; or their cancer either metastasises or comes back (Macmillan Cancer Support, 2014, p.9). Women with breast cancer who live at least five years post diagnosis increase their risk of developing a serious genitourinary condition by 40% and have a 30% increased risk of being diagnosed with another cancer (Macmillan Cancer Support et al., 2014, p.4). The Routes from Diagnosis study found that approximately 850 women (3.2%) die within a year of being diagnosed despite the cancer never spreading beyond the breast. In contrast, 0.7% live for at least seven years after diagnosis despite their cancer having spread to other parts of their body by the time it was diagnosed. 75% of these women are aged under 65 and generally in better health than average for women with breast

⁴ Through tracking their in-patient hospital activity (Macmillan Cancer Support, 2014, p.8)

cancer (Macmillan Cancer Support, 2014, p.9). These data provide a new understanding of the clinical journey and health complexities that may be in store for a woman newly diagnosed with breast cancer. It demonstrates women's experiences of LwBBC differ considerably. The provision of this new 'medicalised' understanding of the complexities of women's experiences post diagnosis indicate the 'realities' of life post diagnosis as complex, impacting women physically, psychologically, socially and spiritually (Ferrell, Grant, Otis-Green & Garcia, 1997, 1998; Feuerstein 2007; Foster et al., 2009).

2.3 Exploring psychosocial health

Despite the proliferation of the use of 'psychosocial' in journal articles, and its extensive use especially in the context of practical application in the health-care field, 'psychosocial' remains poorly defined as a concept (Dilworth, Higgins, Parker, Kelly & Turner, 2014; Egan, Tannahill, Petticrew, & Thomas, 2008; Hodges et al., 2011). The terms psychological and psychosocial are often used interchangeably. In a review of 66 studies related to psychological interventions in cancer care, Hodges et al. (2011) found that none provided any explicit definition of the term 'psychological intervention'. Prior to this Martikainen, Bartley & Lahelma (2002) argued that the roots of psychosocial health lie in the World Health Organisations' (WHO) definition of 'health' as a "state of complete physical, mental and social well-being, and not merely the absence of disease and infirmity" (p.1091). Given the WHO's definition of psychosocial health and our increasing knowledge of the complexity of the routes from diagnosis experienced by women LwBBC, psychosocial 'health' of women LwBBC is an important concept to consider. For most women, achieving a stage of 'complete physical, mental and social well-being' is open to interpretation. In seeking a clear definition of what researchers mean when they talk about psychosocial health, it becomes evident that the term is largely used in unspecified ways (Brandão, Schulz & Matos, 2017) even within narrow areas of health such as epidemiology (Martikainen et al., 2002). From a sociological perspective, a major focus of psychosocial enquiry is on everyday experience (Woodward, 2015). Exploring the psychosocial brings together "the personal and the political and the individual and the social" (Woodward, 2015, p.4). Its use signifies a focus on the 'whole person' as opposed to focusing on the stage of disease. This seems an appropriate conceptualisation for exploring social media use and whether it plays a part in satisfying aspects of the psychosocial needs of women LwBBC.

2.3.1 Identifying the psychosocial needs of women LwBBC

Women show marked variation in how they adjust to LwBBC (Brandão et al., 2017; Stanton & Bower, 2015). Studies show that a wide range of factors impact on adjustment including sociodemographic (e.g. age, education), disease related (e.g. treatment), and psychosocial factors (e.g. social support) (Avis et al., 2013; Bloom, Petersen & Kang, 2007; Brandão et al., 2017; Koch et al., 2013). In a systematic review of longitudinal studies (n=41), Brandão et al., (2017) identified six psychosocial factors that predict psychological adjustment of women when LwBBC. These were (i) psychological functioning/ state (e.g. anxiety, depression, psychological well-being); (ii) personality traits (e.g. optimism, trait anxiety), (iii) coping strategies (e.g. avoidance, positive reappraisal), (iv) social support variables (e.g. overall level of support, close relationship support), (v) cognitive and perceptual factors (e.g. self-efficacy, perceived control), and (vi) body image variables (e.g. appearance satisfaction). In addition, however, these factors warrant further analysis. For instance, definitions of psychological wellbeing comprise self-acceptance, positive relatedness, autonomy, environmental, mastery, purpose in life, and personal growth (Ryff, 1989). This definition points to the complexity inherent in exploring the multiple factors that influence psychosocial health. To find a position from which to root this inquiry into social media use, I returned to the learning from my MSc dissertation. Women had felt silenced by social norms when interacting with friends and family and blogged to gain the support they required (Ure, 2014). Utilising the psychosocial factor ‘social support’ therefore seemed an appropriate basis from which to begin an exploration of social media use.

2.3.2 Social support and breast cancer: theoretical considerations

Social support is a multi-dimensional concept (Drageset, Lindstrøm, Giske, & Underlid, 2016). It is ‘an umbrella term for various theories and concepts that link involvement with social relationships to health and well-being’ (Goldsmith and Albrecht, 2011, p. 335). Social support is theorized as having two constructs: structural support, which explores people’s relationship networks, and functional support, which includes the provision and receipt of emotional and informational support (Bloom, Stewart, Johnston, Banks & Fobair, 2001; Cohen & Wills, 1985; Helgeson, 2003; Meng, Martinez, Holmstrom, Chung & Cox, 2017; Nausheen, Gidron, Peveler & Moss-Morris, 2009).

2.3.2.1 *Structural support*

Structural support relates to networks of social relationships or ‘social ties’ and how these are organised (Thoits, 2011). Structural aspects of social support relate to relationships and include the size, range, density, homogeneity, proximity, boundedness and reachability of social ties (Nausheen et al., 2009). ‘Social ties’ are conceptualised in the literature as ‘strong’ and ‘weak’ ties (Granovetter, 1973). ‘Strong’ ties are positioned by Thoits (2011) as those ‘significant others’ to whom a women LwBBC is emotionally tied and who she considers as playing an important and influential role in her life. Typically, strong ties are represented as close family and friends who predominantly provide emotional support (Krämer, Rösner, Eimler, Winter & Neubaum, 2014). ‘Weak’ ties are conceptualised as loose connections who provide informational support and different perspectives’ (Krämer et al., 2014; Utz & Muscanell, 2015). Granovetter (1973) argues that the greater number of weak ties someone has, the greater the chances of gaining important pieces of information or opportunities that would otherwise be inaccessible. Granovetter defined the strength of tie as:

“a (probably linear) combination of the amount of time, the emotional intensity, the intimacy (mutual confiding), and the reciprocal services which characterize the tie” (p.1361).

Granovetter’s ‘strength of weak ties’ (1973) was conceptualised in relation to using wider networks to support job searching. However, it is plausible that women LwBBC may also utilise weak ties to gain information and to identify otherwise inaccessible opportunities to support their own health outcomes.

The evidence for breast cancer patients suggests that having larger social networks predicts lower overall mortality (Kroenke, Kubzansky, Schernhammer, Holmes, & Kawachi, 2006; Kroenke et al., 2016; Pinguart & Duberstein, 2010). In a prospective study of 2,835 women diagnosed with breast cancer in the US, women with small networks prior to diagnosis were twice as likely to die of breast cancer than ‘social integrated’ women (Kroenke et al., 2006). Socially isolated women were also found to have significantly lower physical well-being, higher breast cancer symptoms, and lower functional, social and emotional scores than women with larger social networks and greater social support (Kroenke et al., 2013). The Berkman Syme Social Network Index was used in the three Kroenke et al., studies (2006, 2013, 2016) to measure social networks. The index asks questions to identify four components: the presence of a spouse or intimate partner, the number of close friends and relatives, the scale of religious/social ties, and of community ties. It should be noted that the

Berkman Syme Social Network Index was being used well before the advent of social media and the social and cultural changes this use has brought to health support seeking from internet use (Hamm et al., 2013; Moorhead et al., 2013). The questions posed by this tool do not necessarily orientate women to consider their online networks when responding to questions designed to elicit the size of their social network. For instance, the questions include. “How many close friends and relatives do you have?” and in relation to community ties, “did you do weekly volunteer work in the past year? (yes, no)”. It may well be the case for instance, that women supporting other women on social media in relation to their breast cancer experiences would not represent this ‘work’ as volunteering. It is therefore unclear as to ‘who’ respondents recall when answering questions using the Berkman-Syme Social Network Index or to what extent online social networks are represented in people’s responses.

2.3.2.2 *Functional support*

Functional support relates to the extent women’s interpersonal relationships provide particular resources (Cohen & Wills, 1985). These are typically sub-divided into informational, instrumental and emotional support (Drageset et al., 2016; Helgeson, 2003; Suwankhong & Liamputtong, 2015; Thoits, 2011).

- Informational support refers to knowledge provision relevant to the situation the individual is encountering (Bloom et al., 2001).
- Instrumental support refers to concrete support such as financial assistance; help with childcare or transportation to medical appointments (Suwankhong & Liamputtong, 2015)
- Emotional support refers to having someone to listen, to sympathise, to provide reassurance, and to make one feel valued and cared for (Helgeson, 2003).

People commonly exchange emotional and informational social support using social networking sites (SNS) (Rui et al., 2013) with informational support the most prevalent. Previous research on computer mediated support groups has shown that the expression and receipt of emotional support enhances the emotional well-being of women LwBBC (Han et al., 2008; Kim et al., 2011). Figure 2-2 provides an overview of the different conceptualisations of social support that have been found in the literature as pertinent to women’s experiences of LwBBC. The figure is included to act as a framework for

understanding how social media platform use fits within the landscape of social support. It is not intended to show a vertical mapping of type, source and settings of social support

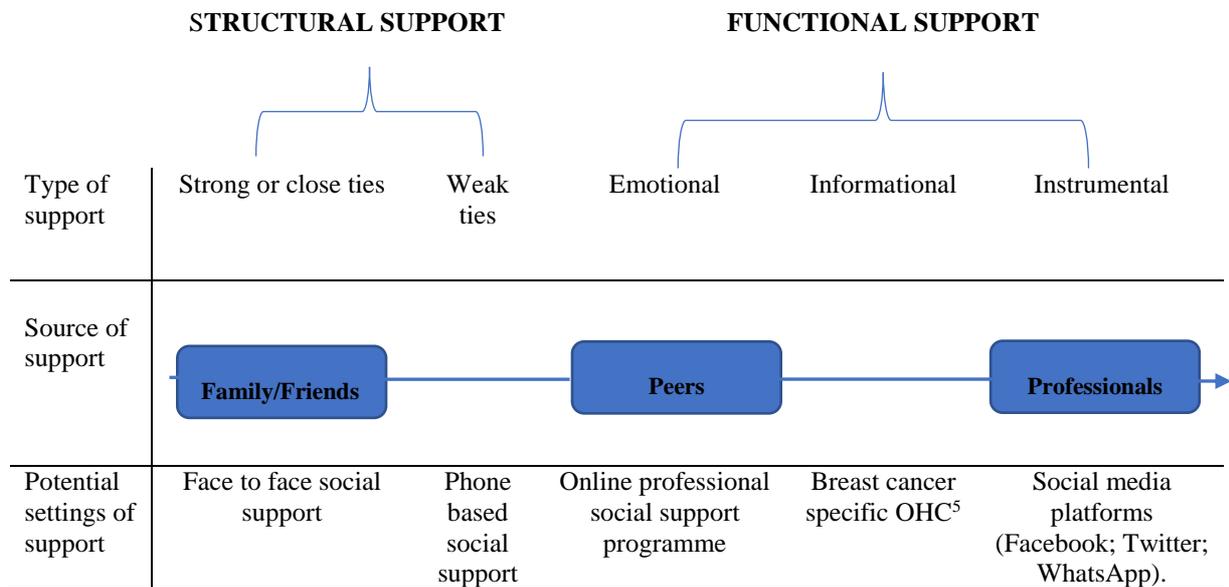


Figure 2-1 A framework for understanding how social media platform use fits within the landscape of social support⁶

Previous literature has explored functional support in online breast cancer forums and discussion boards (Han et al., 2008; Kim et al., 2011; Wang, Kraut & Levine, 2015). More recently, scholars have been trying to understand how health organisations and charities engage with their service users through Twitter from a social support perspective (Rui, Chen & Damiano, 2013; Ure, Galpin, Cooper-Ryan & Condie, 2017). In the US, Rui et al., (2013) found, using a content analysis of 1500 tweets by 58 health organisations⁷, that over 75% of tweets focused on providing informational support. Ure et al., (2017) were specifically interested in how cancer charities in the UK engaged with the experiences of women LwBBC (Appendix 1). Following content analysis of 772 tweets, it was found that 75% of tweets posted by charities over a one-month period were not directly related to women’s experiences of LwBBC. The tweets that were related to LwBBC predominately offered informational support (56%). Twenty seven percent provided women with or sought from women instrumental support and 18% related to the provision of emotional support. Both studies identified a concentration by health organisations and charities on disseminating information

⁵ Online health community

⁶ Based on Zhang, O’Carroll Bantum, Owen, Bakken and Elhadad, 2016

⁷ Health organisations were defined as agencies that are concerned with health on a national or regional level (Rui et al., 2013, p.669)

through one-way interactions, rather than using the conversational affordances of Twitter to engage in longer term relationship building strategies.

2.3.3 Social support and adjustment to breast cancer

A wide body of literature has explored how receiving social support is associated with better adjustment to breast cancer (Bloom, et al., 2001; Boinon et al., 2014; Chou, Stewart, Wild, & Bloom, 2010; Drageset, Lindstrom, Giske, & Underlid, 2012; Falagas et al., 2007; Fong, Scarapicchia, McDonough, Wrosch, & Sabiston, 2016; Kroenke et al., 2006). For example, perceptions of adequate support are associated with lower perceived stress (Israel & Schurman, 1990; Kawachi & Berkman, 2001), decreased symptoms of anxiety (Lin, Ye & Ensel, 1999; Ng et al., 2015) enhanced emotional well-being (Dukes Holland & Holahan, 2003; Yoo et al., 2014) and, overall well-being and quality of life (Kroenke et al., 2013; McDonough, Sabiston & Wrosch, 2013). On the other hand, studies have found decreasing quantity of support associated with increased depressive symptoms and stress (Fong et al., 2016; Thompson, Rodebaugh, Pérez, Schootman, & Jeffe, 2013). Fong et al., (2016) argued that finding ways to develop social support relationships in the aftermath of a breast cancer diagnosis and treatment may offer a protective mechanism for longer term emotional well-being. Figure 2-2 (p.17) demonstrates that one of the ways in which women develop social support relationships post diagnosis is through using social media. Academically, there has been considerable interest in the relationship between social support and social media but rather less about the relationship between social support, social media and the psychosocial health of women LwBBC. This will be explored in the next chapter.

2.4 Conclusion

In this chapter, the concept of living with and beyond breast cancer was discussed. Incidence data together with work carried out by Macmillan Cancer Support et al., (2014) indicate a growing population of women LwBBC with complex, ongoing health needs. Indeed, Foster et al., (2009) found 20-30% of those five years post diagnosis report ongoing problems associated with cancer and its treatment. The concept of 'returning to normal' post diagnosis may only hypothetically extend to 20% of those diagnosed. The majority of women therefore experience different 'health' pathways when LwBBC and may have ongoing psychosocial needs. Social support has been identified as a key factor in providing positive benefit to women. How social support is conceptualised in the literature and a discussion of the existing

literature relating to these benefits were explored. The next chapter considers what social media are and explores the extant literature relating to social support gained through social media use. It also summarises the limited literature relating to women's use of social media in relation to LwBBC.

Chapter 3: Social Media use by women LwBBC

3.0 Introduction

This chapter aims to provide an overview of the conceptualisation of social media used within this thesis. It then builds on social support as an important theoretical construct in relation to psychosocial health, by exploring the literature relating to social media and social support. It revisits structural support (section 2.3.2.1) and discusses the notion of strong and weak ties with respect to social media use. Finally, through a scoping review, what is already known about women's use of social media in relation to LwBBC is explored. The chapter concludes by outlining the gap in the literature this study sought to fill.

3.1 Defining 'social media'

Social media are a group of online applications, which use Web 2.0 technologies, that enable the creation and sharing of user generated content (Hamm et al., 2013; Kaplan & Haenlein, 2010). Merolli et al., (2013) argue that the underlying principles of social media are "participation, communication, user centeredness, collaboration and openness" (p.958). Social media scholars have, to date, considered the following as social media: social networking sites (SNS) (e.g. Facebook), blogs or microblogs (e.g. WordPress, Twitter), content communities (e.g. YouTube); discussion forums (Yahoo), collaborative projects (e.g. Wikipedia), virtual and social worlds (e.g. World of Warcraft) (Hamm et al., 2013; Kaplan & Haenlein, 2010; Merolli et al., 2013; Moorhead et al., 2013; Osatuyi, 2013; Stoycheff, Lui, Wibowo & Nanni, 2017). Since Kaplan and Haenlein's initial categorisation of social media, new applications such as WhatsApp and Snapchat have become significant. A noticeable absence in the above description of social media platforms are online communities. Merolli et al., (2013) argue that 'grey areas' exist when considering whether online communities, support groups, discussion forums and message boards are social media. They argue that differences exist in terms of the architecture and degree of connectedness. The interfaces of these sites are considered more akin to Web 1.0⁸ technologies. While they enable connection

⁸ Web 1.0 technologies refers to the first stage in the World Wide Web, which was entirely made up of web pages connected by hyperlinks. Web 1.0 is generally believed to refer to the web when it was a set of static websites that were not yet providing interactive content (Technopedia, 2018).

between users and collaborative dialogue, user profiles are limited, and anonymity is often preferred (Kang, 2017; Rains, 2007; Rains, 2014; Yoo et al., 2014). Early definitions of social media emphasized the importance of a public profile (boyd, 2010). Potentially an alternative way to distinguish social media is through their user-friendly designs and interfaces; their ease of access; and their enabling of fast communication (Han, Lee & Demiris, 2017). Notably, Zhang et al., (2016) conceptualised online health communities as distinct from social media platforms (Figure 2-2, p.17). Table 3 provides an overview of the social media ‘landscape’.

Table 3: Categorisation of social media tools⁹

Tool	Description	Example platforms
Collaborative projects	Enables the joint and simultaneous creation of content by many end-users	Wikis (e.g. Wikipedia) Delicious
Blogs or microblogs	Websites that display date-stamped entries. They are usually managed by one person but provide the opportunity to interact with others through the addition of comments	WordPress Blogger LiveJournal Twitter
Content communities	Allow for the sharing of media content between users, including text, photos, videos and presentations.	Flickr YouTube Instagram
Social networking sites	Enable users to connect by creating personal information profiles that can be accessed by friends and colleagues, and by sending instant messages between one another	Facebook
Virtual worlds	Platforms that replicate 3D environments in which users can adopt a personalised avatar and interact with others as they would in real life	Second Life World of Warcraft

As Table 3 shows, social media are predominantly conceptualised as commercial enterprises that use brands (Stoycheff et al., 2017). This is the conceptualisation of social media adopted within this thesis. Platforms have different purposes and affordances¹⁰ such as identifiability and networked information access (Halpern & Gibbs, 2013). For instance, the SNS Facebook is ‘bounded’ requiring users to open an account, set privacy settings and provide basic demographic information (boyd & Ellison, 2007). In contrast, YouTube, as a content

⁹ Based on Kaplan & Haenlein, 2010; Hamm et al., 2013

¹⁰ Hutchby (2001) defined affordances of objects as “the possibilities that they offer for action” (p.447). For instance, WhatsApp may offer a family a free group chat through which they organise domestic arrangements on a day-to-day basis. Additionally, or alternatively, it may be used by a parent to gain reassurance that their newly independent child (living away from home) is alive and contactable, through being able to see when they were last online.

community does not require users to create a profile page (Kaplan & Haenlein, 2010) and is therefore more anonymous and depersonalised (Halpern & Gibbs, 2013).

General trends in social media in the US and UK are changing. Users are moving away from single platform use to having accounts or profiles on multiple platforms (Greenwood, Perrin & Duggan, 2016; Ofcom, 2016; Ofcom, 2017). A survey conducted by Pew Research Center¹¹ across a national sample of 1,520 adults (18 or older), demonstrated substantial ‘reciprocity’¹² across major social media platform use (Greenwood et al., 2016). They found 56% of online adults used more than one of the five social media platforms measured in the survey (Facebook, Instagram, Pinterest, Twitter and LinkedIn). In the UK, Facebook continues to be the most popular social media platform with 95% of all adult internet users having a Facebook account (Ofcom, 2017). However, 45% also use WhatsApp, 31% Instagram, 30% YouTube, 26% Twitter, 23% Snapchat and 12% Pinterest. Compared to 2015, social media site users are more likely to say they have a profile/account on six sites or apps: WhatsApp (45% vs. 28%), Instagram (31% vs. 22%), YouTube (30% vs. 22%), Snapchat (23% vs. 12%), Google+ (16% vs. 11%) and Pinterest (12% vs. 7%) (Ofcom, 2017, p. 54). There are however, issues with categorizing use in this way. For instance, a Facebook user is able to perform multiple activities through their Facebook account including instant messaging, photo sharing, video and blog posting. It is important, therefore to be mindful that when considering single platform use, this may fail to contextualise use appropriately (Erfani, Aberdin & Daneshgar, 2013).

Understanding why and how people are now using multiple platforms is an area of academic endeavour that is struggling to keep up with changes in the daily use of technology. The advent of the smartphone has created the ability to have access to multiple platforms and applications instantly. Meanwhile, the literature continues to be dominated by studies exploring Facebook use (Meng et al., 2017; Rains & Brunner, 2015; Stoycheff et al., 2017). In a content analysis of all articles published in six interdisciplinary journals¹³ between 2005 and 2014 (n= 633), Facebook studies accounted for 51.9% of the scholarship; Twitter 16.7% and YouTube 7.2%. Studies featuring platforms such as Instagram, Reddit, Yelp, Tumblr,

¹¹ Between March 7-April 4, 2016

¹² The percentage of users who used more than one social media platform.

¹³ Computers in Human Behavior; Cyberpsychology, Behavior, and Social Networking; Information; Communication & Society; Journal of Broadcasting & Electronic Media; Journal of Computer-Mediated Communication; and New Media & Society (Stoycheff et al., 2014, p. 970).

and Flickr accounted for <1% of all studies. Studies featuring newer brands like Snapchat were entirely absent (Stoycheff et al., 2017).

In examining women's use of social media when LwBBC, it is important to acknowledge the role of health and digital health¹⁴ literacies in this use. Social media can potentially improve health literacy by enabling users to obtain, process and understand health information which enables appropriate decision making (Kamel Boulos, 2012). Digital health literacy is defined as the "ability to seek, locate, comprehend, and assess health information from electronic sources" (Norman and Skinner, 2006) and is closely related to health literacy¹⁵. Health literacy is defined as:

"the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health" (World Health Organisation, 2018)

Increasing health literacy at an individual level is required to enable people to feel empowered to take responsibility for the effective management of their own health¹⁶ (WHO, 2018). Health literacy has been found to be strongly related to health outcomes (Simmons et al., 2017). For instance, Bostock and Steptoe (2012) reported that one third of older adults in England have difficulties reading and understanding basic health related written information. The researchers found this poorer understanding to be associated with higher mortality. In relation to cancer, health literacy is a critical factor affecting cancer communication across the cancer continuum, with challenges experienced in relation to understanding about the risks and benefits of treatment options and patient understanding of informed consent for routine procedures and clinical trials (Davis et al., 2008). Neter and Brainin (2012) report increased digital health literacy as related to better health outcomes because of health information seeking online. They found that those with high digital literacy were younger, had higher socio-economic status; greater access to computers and used the Internet more frequently compared with the low literacy group in their sample of the Israeli adult population. Digital disparities relating to age, education, ethnicity, and income have also been

¹⁴ Also referred to as eHealth literacy (van der Vaart and Drossaert, 2017)

¹⁵ Sorensen et al., (2012) identified 17 definitions of health literacy using 12 conceptual models in a systematic review of definitions and models of health literacy and public health indicating a breadth of approach used by researchers of health literacy

¹⁶ In terms of survivorship and ongoing cancer care in the UK, this fits with the current self-management approaches within the Recovery Package (Macmillan, 2018).

found to impact on online health information seeking following cancer diagnosis in the U.S. (Ginossar, 2014; 2016). Given the increasing proliferation of smartphones¹⁷, it is relevant to note that patients with low health literacy are less likely to use health apps, or perceive them as easy or useful, and are therefore less likely to benefit from their use (Mackert et al., 2016). It is potentially the case therefore that women with lower health and digital literacy are less inclined to use social media when LwBBC. This needs to be kept in mind given a number of previous studies specifically exploring health literacies of women with breast cancer identify women as having high health literacy (Brown et al., 2011; Mercieca-Bebber et al., 2017). However, it should be noted the participants surveyed in the Mercieca-Bebber et al., study (n= 101) were drawn from the Breast Cancer Network of Australia (BCNA) Review and Survey Group - a database of women willing to participate in research projects. This points to this sample being a highly motivated group with a high level of interest in health. Significantly, the authors reflect that in assessing the health literacies of women diagnosed in the previous five years with DCIS, they did not test knowledge of DCIS. They conclude that women's perceptions about their health literacy may differ from their actual knowledge of DCIS. It is not the purpose of this thesis to investigate women's level of digital or health literacies. It is however important to note that women previously participating in research recruited through web-based breast cancer groups have been found to have a high level of health literacy (Mercieca-Bebber et al., 2017).

3.1.1 Social media and social support

In Chapter Two, the evidence for social support improving health outcomes for women LwBBC was established. In this section, the literature relating to social media and social support will be explored.

In 2017, a narrative review (n=88 studies) was published reporting the results of a review of articles on social networking sites and social support from 2004 to 2015 (Meng et al., 2017). The authors' conceptualised social networking sites as:

“all web-based services that allow for creating personal profiles, making and publicly displaying personal connections within a bounded system” (p.2).

¹⁷ Seven in ten adults used a smartphone in 2016 (Ofcom, 2017)

They state the literature currently focuses on social support gained from Facebook use (53%), followed by Twitter (10.2%). Studies of social support gained from other sub-genres of social networking sites were more limited. However, using the taxonomy of social media provided by Kaplan and Haenlein (2010) and Hamm et al., (2013) represented in Table 3 (p.21), Twitter is generally considered a micro-blogging platform. Indeed, the search terms for this narrative review included LinkedIn, Pinterest and Instagram. These are social media but not generally categorised as social networking sites (Kaplan & Haenlein, 2010; Hamm et al., 2013). This indicates the complexity inherent in social media research and is indicative of social media researchers using different approaches to categorising social media platforms. For instance, Meng et al., (2017) define social networking sites using aspects of the design of each site such as: the creation of a personal profile; the making and displaying of personal connections; and, situated within a bounded system. In contrast, Kaplan and Haenlein (2010) categorise social media in relation to social presence/media richness¹⁸ and self-presentation/self-disclosure¹⁹. The narrative review failed to provide information about which other (social networking) sites, apart from Facebook and Twitter, were studied. This lack of transparency limits understanding of the authors' conceptualisation of social media and social networking sites and limits understanding of the breadth of the literature. The findings of the review however demonstrate a lack of a firm theoretical basis regarding social support gained from social media use. Across the 88 journal articles reviewed, 38 referenced a theoretical framework and 23 different theoretical frameworks identified. The authors did not provide details of papers categorised by theoretical approach, again limiting transparency. This review also demonstrated this field of inquiry as dominated by quantitative approaches with 76.1% of studies using quantitative methods. Fifty-one studies focused on measuring aspects of social media use including self-reported usage of SNS's and communication behaviours performed through SNS's for example. Only 12.5% of studies used qualitative methods.

¹⁸ Social presence relates to the intimacy (interpersonal versus mediated) and immediacy (synchronous versus asynchronous) of the medium. Media richness relates to the amount of information that the medium can transmit in a given time interval and therefore its ability to resolve ambiguity and uncertainty (Kaplan & Haenlein, 2010).

¹⁹ Self-presentation relates to how people desire control over the impressions others have of them. Self-disclosure on social media relates to people's conscious or unconscious revelation of personal information and the degree it requires (Kaplan & Haenlein, 2010).

3.1.2 Exploring social capital

As seen, in Chapter 2 (section 2.3.2.), social support is conceptualised as comprising structural support and functional support. Within this thesis, social support is explored through both a functional lens (exploring emotional, informational and instrumental support) and through a (structural) social capital lens (Putman, 2000). Social capital refers to the “resources and benefits available to people, communities and /or broader society through people’s social interactions” (Autheunis, Abeele & Kanters. 2015. p.401). Social media researchers often use Putman’s (2000) concepts of bridging and bonding capital to explore the relationship between social media use and social support. Bonding capital relates to individual’s strong ties such as close friends and family in that these provide emotional support including listening, caregiving and affection (Gottlieb & Bergen, 2010). In contrast, bridging capital relates to more distant, looser connections between people which generally do not involve the provision or exchange of emotional support (Autheunis, et al., 2015). A third type of social capital, maintained social capital, refers to people someone has known earlier in their lives, living in different communities some distance away, where face to face contact has been lost (Ellison, Steinfield & Lampe, 2007). Conceivably, maintained social capital may play an important part in women’s experiences of LwBBC.

From a social media perspective, most research attention has concentrated on examining social capital on Facebook (Brandtzaeg, 2012; Burke, Kraut & Marlow, 2011; Burke, Marlow & Lento, 2010; Ellison, Steinfield, and Lampe, 2007; Ellison, Steinfield & Lampe, 2011; Johnston, Tanner, Lalla & Kawalski, 2011; Lampe, Vitak & Ellison, 2013; Lee, Kim & Ahn, 2014; Papacharissi & Mendelson, 2011; Steinfield, Ellison & Lampe, 2008; Stutzman, Vitak, Ellison, Gray & Lampe, 2012; Vitak, 2012; Vitak, Ellison & Steinfield, 2011; Yoder & Stutzman, 2011). In summarizing the findings from these studies, Autheunis et al., (2015) found a positive relationship between intensity of Facebook use and bridging social capital. One study found time spent on Facebook positively affects bridging social capital (Burke, Kraut & Marlow, 2011), with light and non-use of Facebook associated with lower levels of bridging social capital (Lampe, et al., 2013) and SNS use compared with non-use (Brandtzaeg, 2012). The evidence regarding a relationship between the intensity of Facebook use and bonding capital is less clear. Ellison et al., (2011) found a small, positive relationship between the two, whereas Burke et al., (2011) and Vitak et al., (2011) found no relationship

between them. However, in one study heavy users and non-users of Facebook reported higher bonding capital compared to light users (Lampe et al., 2013).

Autheunis et al., (2015) synthesized findings of seventeen peer-reviewed articles of social capital and Facebook. This led to the structuring of different types of interactions users engage in on Facebook, under four headings: directed communication; consumption; broadcasting and passive consumption (see Appendix 2 for an overview). While this overview provides valuable insight into how social capital is developed on Facebook, there are a range of methodological issues which need to be considered in relation to this thesis. Firstly, there has been an overdependence on use of student populations to provide data relating to social media use and social capital. The median age of participants, across fourteen studies (Brooks, Hogan, Ellison, Lampe & Vitak, 2014; Burke et al., 2011; Burke et al., 2010; Ellison et al., 2007; 2011; Ellison et al., 2014; Johnston et al., 2013; Lampe et al., 2013; Lee et al., 2014; Steinfield et al., 2008; Stutzman et al., 2012; Vitak, 2012; Vitak et al., 2011; Yoder & Stutzman, 2011), was 28.4. Papacharissi and Mendelson (2011) state 88.4% of their student participants (n=344) were aged 18-25. They provide no further details regarding the age distribution of the remaining 11.6%, (approximately 40) participants. Brandtzaeg's three wave longitudinal analysis of social media users and non-users (n=2000) age range 15-75, included the widest range of users. The study found a significantly higher score in 3 out of 4 social capital dimensions (face-to-face interactions, number of acquaintances, and bridging capital) among SNS users in comparison to nonusers. There remains however, limited empirical evidence utilising study samples representative of the general population and this weakens this area of scholarly endeavour.

3.1.3 Theoretical underpinnings of social media research and breast cancer

In a systematic review of social media and breast cancer, Falisi et al., (2017) identify 98 relevant publications. They discuss the theoretical underpinnings in 38²⁰ intervention studies using 'social media'²¹. Less than half (n=18) referenced a theoretical framework. Across those 18 studies, 23 different theoretical models were utilised²². Of interest to this thesis is

²⁰ The authors did not capture the theoretical underpinnings for each journal article routinely on a data extraction form.

²¹ Falisi et al., (2017) conflate online support groups with 'social media'.

²² Self-efficacy theory (n=1), salient belief theory (n=1), Comprehensive Model of Information seeking (n=2), social enhancement model (n=2), social comparison model (n=2), Equity theory (n=1), Broaden and build theory (n=1), social exchange theory (n=1), social comparison theory (n=1), helper therapy principle (n=1),

one study that referenced using social capital as a theoretical basis (Radin, 2006). However, this article was published in 2006, and related to an online support group. To my knowledge, no studies have been conducted which explore social media use and social capital for women LwBBC.

Given the benefits identified in relation to breast cancer and social support (Chapter 2, section 2.3.3.) including better adjustment to breast cancer, lower perceived stress and enhanced emotional wellbeing, social support is largely characterized by a general assumption that all support is beneficial (Thoits, 2011; Wortman, 1984). Being mindful of the ongoing debate regarding the impact of social media use on subjective wellbeing (Chou & Edge, 2012; Veissière & Stendel, 2018; Verduyn, Ybarra, Résibois, Jonides & Kross, 2017), and issues relating to social media use and body image (Perloff, 2014) for instance, it is plausible that social support experienced by women LwBBC through social media channels may increase anxiety and feelings of isolation. In a systematic review of the use of online support groups for women LwBBC, McCaughan, Parahoo, Hueter, Northouse & Bradbury (2017) found that any emotional distress experienced from use of online groups was not measured. Conceivably, any findings which suggest women LwBBC experience emotional distress from social media use would problematise and add nuance to the concept of social support as beneficial.

3.2 Reviewing the literature relating to social media use by women LwBBC

3.2.1 Carrying out a scoping review of the literature

Noble & Smith (2018) highlight the challenges experienced by healthcare researchers in identifying an appropriate review design for reviewing the literature. They highlighted seven possible designs for consideration: the systematic review, rapid evidence assessment, scoping review, integrative review, realist review, narrative review and metasynthesis or review of reviews.

social cognitive processing model (n=1), disease psycho-social model (n=1), Theory of 'Type C' personality (n=1), self-perception theory (n=1), medium theory (n=1), social capital theory (n=1), problem focused and emotion focused coping (n=1), constructivist theory (n=1), social learning theory (n=1), self in relation theory (n=1), cognitive adaptation model (n=1), emotional exposure habituation model (n=1), model of hyper-personal communication (n=1).

A number of these approaches to reviewing the literature focus on addressing specific and sometimes highly focused clinical questions, including systematic reviews (Centre for Reviews and Dissemination, 2009) and integrative reviews (Christmals & Gross, 2017). These approaches were not deemed appropriate for this particular study as they are typically used to “address a highly focused clinical question” (Noble & Smith, 2018, p. 40). Rapid Evidence Reviews are also useful to inform practice but are conducted typically because of resource constraints including time. Consequently, only specific research designs (meta-analyses or controlled studies) might be included and data extraction can be more limited (CEBMA, 2018).

A metasyntesis or review of reviews that compiles evidence from multiple research syntheses in order to summarise existing evidence seemed inappropriate given the expectation that the literature in this area would be limited. Similarly, a realist review focuses on understanding the mechanisms by which an intervention does or does not work (Noble & Smith, 2018) and aims to enable decision makers to reach a deeper understanding of an intervention and how it can be made to work (Pawson, Greenhalgh, Harvey & Walshe, 2005). The use of social media as a planned healthcare intervention was not under investigation in this thesis and therefore a realist review was not appropriate.

A narrative review would have been feasible if I was seeking to describe and appraise published articles however, in a narrative review the methods of selection for articles are not typically described. As I was keen to gain a sense of the size and scope of the research related to women’s use of social media use when LwBBC, it seemed important to conduct and make transparent a wide systematic literature search. Using a ‘scoping’ methodology supported a systematic, rigorous approach to identifying and retrieving all relevant studies related to social media use and LwBBC. Scoping reviews are useful to map the literature in a broad context in an emerging area of healthcare prior to determining whether a more comprehensive review or systematic review is needed or to identify the gaps in the literature (Noble & Smith, 2018). They support the examination of “the extent, range and nature of research activity” (Arskey & O’Malley, 2005, p.21) and are useful when “an area has not been comprehensively reviewed before” (Mays, Roberts & Popay, 2001, p.194) or when researchers are not seeking to answer very specific research questions. By taking this approach, a comprehensive understanding about what is ‘known’ about how women use social media is evidenced and gaps in current knowledge related to women’s use of social

media in relation to psychosocial health identified. Scoping reviews however do have limitations, as they do not specifically include a process of quality assessment. In a scoping review of the conduct and reporting of scoping reviews (n=494) between 1999 and 2014, 86% of scoping reviews did not use a quality appraisal tool (Tricco et al., 2016). There is a risk therefore that the availability of studies rather than their quality informs any conclusions provided (Grant & Booth, 2009).

This scoping review is presented in three sections. The first section presents the aims of the review and the methods used to identify, retrieve and evaluate the relevant literature. The second section presents the findings of the review and key themes within the extant literature. Finally, I summarise the findings and conclude by establishing the gap in the literature this study fills.

3.2.2 Aims of the scoping review

The aim of this scoping review was to explore current evidence-based knowledge about women's experiences of social media use (Facebook, Twitter, YouTube etc.) when LwBBC (post diagnosis – pre-end of life).

3.2.3 Developing a keyword search strategy

To identify 'search' keywords, examples of previous search strategies used in the peer reviewed literature were drawn on including systematic reviews of: social media and cancer care (Koskan et al., 2014); online support groups for women with breast cancer (protocol) (McCaughan, Parahoo, Hueter & Northouse, 2015); uses of social media in HIV communication (Taggart, Grewe, Conserve, Gliwa, & Roman Isler, 2015) and Kaplan and Haenlein's (2010) seminal paper on social media. The key search terms were 'breast cancer', 'social media', 'mobile technologies' and 'Internet' (See Appendix 3 for an example of the terms used in the Ovid Medline database 1946-December 31st, 2017).

3.2.4 Data sources and selection

The following electronic databases were searched: CINAHL, PubMed, Web of Science Core collection (1900 to December 31st 2017), Communication & Mass Media Complete and Medline via OVID (1946 to December 31st 2017) and PsychInfo via OVID (2002 to

December 31st 2017). Two electronic searches were completed. The first extracted all journal articles published up to and including May 17th, 2016. The second search was completed for articles published between May 2016 and December 31st, 2017.

3.2.5 Inclusion criteria

Articles were included if they were: (i) written in English, as financial constraints removed the ability to have papers translated; (ii) related to how women use social media platforms such as Facebook, Twitter, YouTube or similar; (iii) related to breast cancer post screening; (iv) related specifically to women's experiences of LwBBC; and (v) were published in peer reviewed literature.

3.2.6 Screening

Title and abstracts for papers were retrieved. These were exported into EndNote (EndNote X8, 2016) and then Microsoft Excel (Microsoft, Redmond, Washington, USA) following removal of duplicates using the EndNote software. Using Excel, each title and abstract were screened by assessing them against the inclusion criteria (section 3.2.5.). For studies where there was not sufficient information from screening the title and abstract, the full paper was obtained.

3.2.7 Results of the scoping review

The initial search identified 13775 articles (Figure 3-1) from which 3786 duplicates were removed.



Figure 3-1 PRISMA diagram demonstrating article retrieval and selection

Details of 9989 articles were transferred into Excel. After title and abstract screening, 9934 articles were excluded as they did not meet the eligibility criteria. Fifty-five articles received a full text screening and 39 were excluded. Reasons for removal are detailed in Figure 3-1. Where analysis specifically related to women’s experiences of LwBBC could not be extracted from findings, papers were excluded. For instance, studies which explored Facebook use by women with ovarian cancer (Erfani, Blout & Abedin, 2016) were excluded as was the Croson and Keim-Malpass (2016) blog analysis of young women’s grief regarding cancer experiences. Although, this paper looked to be relevant no information was provided related to the type of cancer the bloggers had. A request for further information from the corresponding author and editor of the journal received no response. A paper which explored how brands facilitate the transformation to heroic survivor (Hollenbeck & Patrick, 2016) carried out interviews with female cancer survivors and analysed five blogs of women. However, there was no information provided regarding type of cancer. Email contact was made with the lead author requesting further details of the study population; specifically, how many of the women participants had breast cancer. In response, accurate data was

unavailable²³. Therefore, due to the lack of robust data regarding participants, the paper was excluded.

Falisi et al., (2017) carried out a study entitled ‘Social media for breast cancer survivors: a literature review’, which at title review seemed relevant for this scoping review. However, it failed to meet the inclusion criteria as it does not address how women use social media platforms. Indeed, a wide definition of ‘social media’ was adopted within this literature review. The authors provided a breakdown of the ‘social media’ investigated in 85 observational and intervention articles. They found the field dominated by studies focusing on online support groups or communities (61%, n=52), message boards or web forums (24%, n= 20), Twitter (6%, n=5), Facebook (5%, n=4), Blogs (3%, n=4), YouTube (1%, n=1), online mailing lists (1%, n=1). Thirty-eight articles were specifically related to aspects of ‘social’ media use within web-based interventions but none used social media platforms within these interventions. The authors identified a lack of attention to naturally occurring groups and communities as a gap in the literature. They argued a need to understand potential differences between organically occurring groups or communities and ones intentionally created for an intervention. They identified limited attention given to the impact of social media interactions on health outcomes. Despite these useful insights, there was a lack of transparency in this article, with links to studies identified as related to Twitter and Facebook not provided. The article was therefore not included in the scoping review.

Where there was ambiguity as to whether inclusion criteria were satisfactorily met, discussions were held with supervisors. Discussions continued until consensus to include or exclude was reached.

3.2.7.1 *Relevant studies*

The sixteen studies included in this scoping review are summarised in Table 4. These are reviewed in detail in the next section. I have noted against each study **WV**; an idea I have borrowed from Wray (2011). WV is shorthand for ‘women’s voices’ and I use it to broadly categorise whether women’s voices have been actively sought (interviews, focus groups) or are more passively involved in data collection (e.g. secondary data analysis of data posted on social media platforms). It acts as a summary note and identifies whether women’s voices

²³ Lost in an office move.

were positioned centre stage within the research. As Wray (2011) noted, this is “a value judgement” (p.32) yet it provides a further lens through which to understand the research conducted to date in this field. Although typically scoping reviews do not utilise quality assessment processes (Tricco et al., 2016, 2018), I did critique articles using the Critical Appraisal Skills Programme (CASP, 2016) tools and survey appraisal tools from the Centre for Evidence Based Management (CEBMA, 2016) to inform my knowledge and understanding of the research studies undertaken. An example of a critical appraisal of a survey study is provided in Appendix 4 and a qualitative study in Appendix 5.

Table 4: Summary of included peer reviewed studies

	<i>Short Reference</i>	<i>Platform</i>	<i>Method</i>	<i>Sample size and characteristics</i>	<i>Main Findings</i>
1	Attai et al., (2015) Twitter Social Media is an effective tool for Breast Cancer patient education and support: Patient-reported outcomes by survey <i>Journal of Medical Internet Research</i>	Twitter	Quantitative Online survey posted on Twitter, the #BCSM ²⁴ blog and the #BCSM Facebook page.	206 respondents. 92.7% (191/206) were female. 91.7% were white. 61.1% were aged between 45-64. 53.9% had a graduate level education or above. 45.1% had been involved in the #BCSM chats for over 12 months. 69.4% (143/206) of respondents were breast cancer patients. Survey originated from the US. Location of respondents is not reported.	Increased knowledge was reported in 9 domains; overall knowledge (80.95); survivorship (85.7%); metastatic breast cancer (79.4%); cancer types and biology (70.9%); clinical trials and research (66.1%); treatment options (55.6%); breast imaging (56.6%); genetic testing and risk assessment (53.9%) and radiotherapy (43.4%). The study also showed 31.2% of women seeking a second opinion or bringing information to the attention of their healthcare team as a consequence of involvement. WV: Women were research participants.
2	Bender et al., (2011) Seeking support on Facebook: A content analysis of breast cancer groups <i>Journal of Medical Internet Research</i>	Facebook	Quantitative Content analysis	Searched Facebook using the term breast cancer. 620 breast cancer groups identified.	620 groups with 1,090,397 members. Data collected in 2008. Four main types of group identified: for fundraising (44.7%); for patient/caregiver support (46.7%); awareness (38.1%); and product or service promotion (9%). 47% of the support groups had been established by high school or college students. The awareness group contained by far the most members (n=957,289). WV: Women were not research participants and had no direct involvement in the research process.

²⁴ BCSM is short for breast cancer social media.

	<i>Short Reference</i>	<i>Platform</i>	<i>Method</i>	<i>Sample size and characteristics</i>	<i>Main Findings</i>
3	<p>Bender et al., (2013) What is the role of online support from the perspective of face-to-face support groups? A multi-method study of the use of breast cancer online communities <i>Patient Education and Counseling</i></p>	Facebook and online communities	Utilised a multi-method design – cross sectional survey and qualitative interviews. The survey asked questions relating to use of the Internet, social media and online communities.	Data was drawn from an attendee list (2008-09) of a support group facilitator training programme by a national US non-profit support agency. Questionnaires completed (n=73) Survey respondents recruited for interview (n= 12); face to face (1); telephone (11).	17.8% of facilitators used Facebook to communicate with other breast cancer survivors. Nearly all interview participants described Facebook as an inappropriate platform due to its “perceived popularity and lack of privacy” (p.475). Facebook was perceived to afford less control over interactions with others than online communities did. Lack of anonymity was cited as an issue relating to Facebook use. The authors acknowledged that support group facilitators are not necessarily ‘typical’ of women LwBBC. WV: Women were research participants.
4	<p>Coll-Planas and Visa (2016) The wounded blogger: analysis of narratives by women with breast cancer <i>Sociology of Health & Illness</i></p>	Blogs	Categorical analysis: identified ‘narratives’ and ‘problems of embodiment’ using ‘modern’ and ‘postmodern’ logic.	7 blogs (547 entries) written by Spanish women (aged in their 30’s and 40’s) and specifically detailing aspects of LwBBC were analysed. All visual and textual data was analysed.	Modern logic outcomes: the majority of blogs search for predictability of the body; try to hide side effects; do not address mortality; and accept medical logic. The body can appear monadic and disassociated. Postmodern logic outcomes: women adopt projects which enable productivity; the body is considered as part of a network of affect, care and solidarity; women show acceptability and visibility of the bodily changes experienced. WV: Uses women’s voices as unit of analysis. No direct involvement.

	<i>Short Reference</i>	<i>Platform</i>	<i>Method</i>	<i>Sample size and characteristics</i>	<i>Main Findings</i>
5	Crannell et al., (2016) A pattern-matched Twitter analysis of US cancer-patient sentiments <i>Journal of Surgical Research</i>	Twitter	Qualitative and quantitative content analysis	146,357 US tweets of people LwBC collected from Twitter Application Programming Interface (API) from March – December 2014 and divided into tweetsets analysed by cancer type.	Across cancer tweet sets, breast cancer was tweeted about the most frequently (n=15,421) and by the largest number of ‘patients’ (n=161). The authors found inter-diagnosis variability in what patients tweeted about. Breast cancer patients were more likely to tweet about treatment (chemotherapy, radiotherapy and hospital visits) than about diagnosis. WV: Uses voices as unit of analysis. No direct involvement. The proportion of tweets posted about breast cancer, made by women LwBBC, is unknown.
6	de Boer and Slatman (2014) Blogging and breast cancer: Narrating one’s life, body and self on the Internet <i>Womens Studies International Forum</i>	Blog	Qualitative Narrative analysis	Five blogs written by five different women were followed on a monthly basis for one year (Feb 2012-Feb 2013). All visual and textual data was analysed.	Four types of self-narration identified: The Estranged Cancer Patient; the Transient; The Heroic Survivor; and The Disfigured Woman/Girl. Self-narrative allows sense making enabling re-owning and re-appropriating themselves. Authors question extent of liberation blogging enables. WV: Uses women’s voices as unit of analysis. No direct involvement.
7	De la Torre-Diez et al., (2012) A content analysis of chronic disease social groups on Facebook and Twitter <i>Telemedicine and E-Health</i>	Facebook & Twitter	Quantitative Content analysis	Searched Facebook & Twitter using terms "colorectal cancer," "breast cancer," and "diabetes." 216 breast cancer groups identified.	More social groups about breast cancer are on Facebook (approx. 82%) than Twitter (approx. 18%). Social networks are a useful tool for supporting patients with these diseases. Facebook shows a higher usage rate than Twitter because a) it is newer and b) its uses is less generalised. WV: Women were not research participants and had no direct involvement in the research process.
8	Doh and Pompper (2015) Beyond the wounds: The	Facebook	Qualitative Hermeneutic phenomenological	Facebook posts from the Surviving Cancer: Absolute Reality (SCAR) Project page	Two themes emerged in relation to how posters addressed their own mastectomy body: 1) Inspiration and support and 2) Cancer Scar

	<i>Short Reference</i>	<i>Platform</i>	<i>Method</i>	<i>Sample size and characteristics</i>	<i>Main Findings</i>
	<p>SCAR Project as space for examining breast cancer and mastectomy experiences</p> <p><i>Social Semiotics</i></p>		theme analysis	captured between 15 January 2010 & 30 June 2013. Included posts (n = 138) analysed using van Manen's (1990) technique for examining 'lived experiences'.	<p>meanings. Two themes emerged in relation to how posters' breast cancer narratives interplayed with femininity on the SCAR Facebook page: 1) Authenticity and 2) Redefined beauty and femininity. The SCAR project page acts as a counter –public sphere.</p> <p>WV: Uses women's posts/voices as unit of analysis. No direct involvement.</p>
9	<p>Foley et al., (2014) A Qualitative Content Analysis of Breast Cancer Narratives Hosted Through the Medium of Social Media</p> <p><i>British Journal of Medicine and Medical Research</i></p>	YouTube	Qualitative Content analysis	Used search terms "breast cancer survivor" & "breast cancer stories" to extract clips from YouTube. 19 video clip posts analysed. 9 posts by 'cancer free' individuals; 5 individuals were receiving treatment; 5 women had a terminal prognosis.	<p>Overarching theme was 'the experience of fighting cancer'. Five categories were identified: 1) First finding out 2) Coping strategies: 'Doing what you have to do' 3) Living with uncertainty 4) Reaching out and giving back, and 5) Learning lessons. Health Care professionals (HCP's) identified as 'strangers' in terms of support and importance of family and friends for tangible social support stated. Need for development of relationships between women and HCP's throughout the 'cancer journey' highlighted.</p> <p>WV: Uses women's posts/voices as unit of analysis. No direct involvement</p>
10	<p>Freedman et al., (2016) Learning from Social Media: Utilizing Advanced Data Extraction Techniques to Understand Barriers to Breast Cancer Treatment</p> <p><i>Breast Cancer Research and Treatment</i></p>	Message boards, social networks, blogs, topical sites	Qualitative content analysis	1,024,041 unique posts related to treatment were analysed (1/02/14 – 31/01/15) relating to breast cancer treatment. Post were drawn from message boards (31%), blogs (27%), topical sites e.g. Susan Komen (16%), content sharing sites e.g. YouTube (14%) and social	In 1,024,041 posts - 54% of posts asked questions; 33% shared content; 57% were skewed negatively; 31% neutral and 12% positive. In a subset, sentiment analysis was applied to 627,381 posts in which the phase of treatment was evident (prediagnosis, diagnosis, etc.). 172,274 posts described a specific treatment (surgery, radiation, etc.). Posts discussed chemotherapy (35%), surgery (33%), radiation (15%), 'drugs' (10%),

	<i>Short Reference</i>	<i>Platform</i>	<i>Method</i>	<i>Sample size and characteristics</i>	<i>Main Findings</i>
				networks e.g Facebook/Twitter (12%).	and hormonal therapy (7%). 50% of all treatment posts were skewed negatively. WV: Uses women’s posts/voices as unit of analysis. No direct involvement. The proportion of tweets posted about breast cancer, made by women LwBBC, is unknown. .
11	Harris, Cleary and Stanton (2015) Project Connect Online: User and visitor experiences of an Internet-based intervention for women with breast cancer <i>Psycho-oncology</i>	Personal websites with blog functionality	Randomised Control Trial. In the intervention arm, women created personal websites with a blog function. The intervention participants were assessed at one and six months using questionnaires in relation to website use and outcome measures. Content analysis of blogs and use of Linguistic Inquiry & Word Count (LWIC) to measure use of positive emotion (PE), negative emotion (NE) and cognitive processing (CP)	88 breast cancer patients were randomly assigned to an intervention (n=46) or waiting list control (42). In the intervention arm, 74% were married; 63% college graduates; 87% non-Hispanic white; and 85% had been diagnosed two or more years previously. 46% worked. Age range: 28-76 years. Average age = 55. 10 women were in treatment; 9 had secondary breast cancer.	On average, 3.00 blog entries were made per person within the first month (SD = 3.99; range = 0-17 posts). At six months, women had posted on average 5.28 entries (SD=6.57; range = 0-28 posts). Therefore, use of the websites tapered off after the first month. Most women used the blogs to share their story of their diagnosis and treatment, their emotional experiences, spirituality, positive interactions with medical providers, support received from others, benefits experienced as a result of the cancer experiences and their involvement in the project. The authors state specific aspects of blogging predicted improvements in psychosocial functioning. Use of LWIC showed PE word use was significantly associated with positive affect. More use of negative word use decreased depressive symptoms. WV Women were research participants.

	<i>Short Reference</i>	<i>Platform</i>	<i>Method</i>	<i>Sample size and characteristics</i>	<i>Main Findings</i>
			words		
12	Himmelboim et al. (2014) Cancer Talk on Twitter: Community Structure and Information Sources in Breast and Prostate Cancer Social Networks <i>Journal of Health Communication</i>	Twitter	Quantitative Network analysis	Twitter talk related to breast cancer (& prostate cancer) captured for one composite week (April/May 2011). Each day represented 1 data set. Each data set contained the most recent 1000 users who had posted a tweet including the keyword 'breast cancer'. 'Hubs' were identified – the most highly followed users (media, academic org; health org; grassroots (individuals/blogs); or celebrity. Visiting and core communities also identified.	Visiting communities were not common in breast cancer networks. Visiting communities do not appear to be related to breast cancer or even health but occur as a result of celebrities posting a message about the topic. Interestingly, visiting communities played a larger role in the prostate cancer networks. In terms of information sources, the Twitter hubs in these core communities did not include institutional sources, but primarily individuals or small websites specific to each cancer. In contrast visiting communities often followed institutional hubs associated with traditional 'media' health e.g. American Cancer Society. WV: Women were not research participants and had no direct involvement in the research process. The proportion of tweets posted about breast cancer, made by women LwBBC, is unknown. .
13	Kim et al. (2016) Predicting retweeting behaviour on breast cancer social networks: Network and Content characteristics <i>Journal of Health Communication</i>	Twitter	Quantitative Social Network analysis and computer aided content analysis	Twitter talk related to breast cancer captured for one composite week (Aug/Sept 2011). Each day represented 1 data set. Each data set contained the most recent 1000 users who had posted a tweet including the keyword 'breast cancer'.	Tweets posted by authors who are popular, are connected with others, and have higher levels of personal influence are more likely to be retweeted. When the tweet contains more positive emotion and fewer tentative words, tweets are retweeted more often, Twitter can be an effective tool for the dissemination of health information. Future study needs to redefine the notion of opinion leaders by exploring the role interactive interactions between opinion leaders and followers has on shaping health related attitudes and

	<i>Short Reference</i>	<i>Platform</i>	<i>Method</i>	<i>Sample size and characteristics</i>	<i>Main Findings</i>
					behaviours of others on social media. WV: Women were not research participants and had no direct involvement in the research process. .The proportion of tweets posted about breast cancer, made by women LwBBC,is unknown. .
14	Tan et al. (2014) Patient information on breast reconstruction in the era of the world wide web: A snapshot analysis of information available on youtube.com <i>Breast</i>	YouTube	Qualitative and Quantitative Qualitative categorical analysis	The term ‘breast reconstruction’ was input into YouTube on 1 st Sept 2011. The first 100 videos were analysed qualitatively in relation to oncology information; patient factors and reconstruction factors. A quantitative analysis of the characteristics of the videos uploaded was also conducted.	83% and 13% of videos were uploaded from the US & UK respectively. Of 100 videos, 9 were created by ‘amateurs’; 91 were professionally made. Of these 41% were taken from TV shows or medical news programmes. 40.7% were grouped as ‘marketing’ productions which included patients’ testimonials; individuals; surgeons and surgical institutions. Charities uploaded 2.2% of the overall content relating to breast reconstruction. WV: Women were not research participants and had no direct involvement in the research process
15	Tapi Nzali et al., (2017) What Patients Can Tell Us: Topic Analysis for Social Media on Breast Cancer. <i>JMIR Medical Informatics</i>	Facebook	Quantitative Topic analysis using Latent Dirichlet Allocation	Extracted messages from 4 public Facebook groups and a French Public Health forum (October 2010-October 2014 to identify extent to which topics discussed ‘naturally’ related to functional and symptomatic dimensions used in clinical trials (EORTC), the Quality of Life Questionnaire Core 30 (QLQ-C30) and breast cancer module (QLQ-BR23). No of users: Facebook (n=1394); forum (n=675)/ No of discussion	In relation to topics discussed in the Facebook groups - for the 53 questionnaire items - 36 relationships were validated,17 were invalidated (68%). This compared with 74% alignment of topics discussed through the public health forum. The topics identified as most frequently occurring on Facebook were diagnosis, chemotherapy, breast cancer as a daily battle, hair loss, secondary effects of treatment, body care and body image during cancer, family background and cancer, worklife during cancer and financial effects, breast reconstruction and support from patients family and friends. Information about topics that did not relate to

	<i>Short Reference</i>	<i>Platform</i>	<i>Method</i>	<i>Sample size and characteristics</i>	<i>Main Findings</i>
				threads: Facebook (n=11,013); forum (n=1050)/No. of messages: Facebook (n=70,092); forum (n=16,868). No moderation on any sites.	questionnaire items and were therefore invalidated were not discussed (32%). WV: Women were not research participants and had no direct involvement in the research process. Proportion of content posted by women unknown.
16	Tsuya et al. (2014) Do cancer patients tweet? Examining the Twitter use of cancer patients in Japan <i>Journal of Medical Internet Research</i>	Twitter	Quantitative content analysis	Search conducted on 18 th August 2013 of every publicly available Twitter user profile in Japan. Search terms were for a range of cancers including breast cancer. The latest tweets (max 200) from each account were collected. Text mining was used to extract nouns. Co-occurrence analysis of keywords was conducted. Breast cancer was referenced more than any other cancer (n=313).	The keywords identified for breast cancer relating to 'diagnosis' was 'self-diagnosis'; to 'symptoms' were 'metastasis' and 'lymphedema'; to 'treatments' were 'chemotherapy' and 'hormonal treatments'; and in a category termed 'others' was 'palliative care' and 'the pink ribbon'. The study demonstrated that information related to cancer (and breast cancer) such as diagnosis, symptoms and treatment is shared by cancer patients on Twitter. WV: Women were not research participants and had no direct involvement in the research process

3.2.7.2 *Synthesis of findings from the scoping review*

Despite the emergence of YouTube in 2005, Facebook in 2006 and Twitter in 2008, the first paper specifically focused on social media use and breast cancer did not emerge until 2011 (Bender, Jimenez-Marroquin & Jadad). It seems the field remains slow to develop given the limited number of publications. Thirteen of the sixteen studies (81%) related to women's use of social media platforms used secondary data. The sixteen studies demonstrate global interest across developed nations in social media use and breast cancer with studies originating in Canada (2), The Netherlands (1), UK (1), Spain (2), USA (7), Japan (1), Ireland and Canada (1), France (1) (see Table 5)

Table 5: Peer reviewed publications by year, country of origin and platform.

Year	No-of papers	Authors	Country of origin	Platform
2011	1	Bender, Jimenez-Marroquin & Jadad	Canada	Facebook
2012	1	De la Torre-Díez, Díaz-Pernas & Antón-Rodríguez	Spain	Facebook and Twitter
2013	2	Himmelboim & Han	US	Twitter
		Bender, Katz, Ferris & Jadad	Canada	Online communities and Facebook
2014	4	de Boer & Slatman	Netherlands	Blogs
		Foley, O'Mahony, Lehane, Cil & Corrigan	Ireland/ Canada	YouTube
		Tan, Kok, Ganesh & Thomas	UK	YouTube
		Tsuya, Sugawara, Tanaka & Narimatsu	Japan	Twitter
2015	3	Doh & Pompper	US	Facebook
		Attai, Cowher, Al-Hamadani, Schoger, Staley & Landercasper	US	Twitter
		Harris, Cleary & Stanton	US	Blog functionality on personal websites
2016	4	Kim, Hou, Han & Himmelboim	US	Twitter
		Freedman, Viswanath, Vaz-Luis, & Keating.	US	Multiple
		Crannell, Clark, Jones, James & Moore	US	Twitter
		Coll-Planas & Visa	Spain	Blogs
2017	1	Tapi Nzali, Bringay, Lavergne, Mollevi & Opitz.	France	Facebook & a Public Health forum

In terms of methods used, research to date has included quantitative approaches including: surveys (Attai et al., 2015); content analysis (Bender et al., 2011; De la Torre-Díez et al., 2012; Tsuya et al., 2014); network analysis (Himmelboim & Han, 2013; Kim et al., 2016); and topic analysis using latent dirichlet allocation (Tapi Nzali et al., 2017). Four studies used mixed methods (Bender et al., 2013, Crannell et al., 2016; Harris et al., 2015; Tan et al., 2014). Qualitative approaches used include narrative analysis (de Boer & Slatman, 2014); content analysis (Foley et al., 2014; Freedman et al., 2016);, categorical analysis (Coll-Planas & Visa, 2016) and phenomenological thematic analysis (Doh & Pompper, 2015). To date most attention has been paid to how women LwBBC use Twitter (n=5 studies), Facebook (n=4), blogs (n =3); YouTube (n=2); Facebook and Twitter (n=1) and multiple social media (n=1).

3.2.7.3 *Key themes*

As part of the analysis, papers were themed in relation to area of focus and categorised into four key areas: (i) group, communities and interaction; (ii) information seeking and learning (iii) exploring women's experiences and (iv) measuring psychosocial outcomes of women's experiences.

Groups, communities and interaction

The early work in this field used content analysis to explore breast cancer group networks on Facebook and Twitter. Bender et al., (2011) identified 620 breast cancer Facebook groups (1,090,397 users). Four main activities across groups were identified: Fundraising (n=277; 44.7%); Awareness (n=236; 38%); Promote-a-site (n=61; 9.84%) and Support (n=46; 7.42%). 'Awareness' groups had the largest membership (n =957,289) and 'support groups' the fewest (n=16,940), suggesting that at the time of data collection (2008) Facebook was not used extensively by women LwBBC seeking support. In 2011, De la Torre-Díez et al., (2012) collected data on the purpose and use of breast cancer Facebook and Twitter groups. Notably, fewer breast cancer groups were identified across the two platforms (n = 216) than identified by Bender et al., (2011) (n = 620) (7, 765,483 users). Five types of groups were identified: 'fund collecting'; 'awareness'; 'support'; 'prevention' and 'disease fighting'. However, use is reported using eight subgroups (prevent, get, fight, research, information, made aware,

support and other) without linking the groups and subgroup hierarchies together, hindering understanding of group structures. The 'prevention' sub-group received most attention from users (33.95%). This early group analysis demonstrates a focus on fundraising, awareness and prevention rather than social media use as a supportive mechanism for women LwBBC. Within these studies the different types of users (women LwBBC; family members; the general public; charitable organisations etc.) accessing and contributing to discussions relating to breast cancer are not extrapolated. Consequently, while the studies provide some insight into use of social media in relation to LwBBC, no specific claims can be made about how women LwBBC align themselves with Facebook or Twitter groups or their use of them.

Two social network analysis studies (Himmelboim & Han, 2014; Kim et al., 2016) used the same dataset to analyse Twitter interactions across the breast cancer community. Using the keyword 'breast cancer', they examined where breast cancer related communities derive their information from and the patterns associated with breast cancer 'talk'. Himmelboim & Han (2014) provide insight into the flow of information related to breast cancer on Twitter derived from messages posted during one composite week. They identified five main groups or 'hubs' who posted about breast cancer: the media, academic organisations, health organisations, the grassroots (individuals/blogs) and celebrities. Core community hubs were users who tweet about breast cancer persistently. These users were all specific to breast cancer and primarily grassroots (women LwBBC); forming dense clusters, indicating more information flow between users. Of significance, is the finding that the core community gains information primarily from information sources specific to breast cancer, that is from other individuals LwBBC and small websites specifically addressing breast cancer, rather than institutional sources, such as the American Cancer Society.

Using the same data set, Kim et al., (2016) explored the nature of user interaction further by analysing retweeting behaviour within breast cancer communities. The researchers, specifically interested in effective ways to disseminate health information to women LwBBC, found that tweets posted by those who had the highest number of followers; closer relationships and similarities with others, and with higher levels of personal influence over the interaction are more likely to be retweeted by others; as were non-tentative positive emotion tweets. The authors considered tweeters as a homogenous group thereby limiting

understanding of the interaction between the hubs described by Himelboim & Han (2014) and more specifically the retweeting behaviours of women LwBBC.

The numbers of users of Facebook and Twitter groups points to a significant amount of interest in breast cancer. The early work in this field shows there has been a focus on group purpose (e.g. fundraising, awareness and prevention), and community structures (core and visiting). While these studies begin to extrapolate the group structures and interactional processes occurring within these structures, their use of secondary data does not give voice to women LwBBC or insight into women's perspectives of their use of social media.

Information sharing and learning

This theme pulls together studies which demonstrate explorations of Twitter (Attai et al., 2015; Crannell et al., 2016; Tsuya et al., 2014), and multiple platforms (Freedman et al., 2016) to understand organic sentiment posted on social media in relation to women's experiences of breast cancer.

Three papers (Attai et al., 2015; Crannell et al., 2016; Tsuya et al., 2014) used Twitter to understand actual use and the knowledge benefits gained by using social media for women LwBBC. The studies found that women LwBBC share issues relating to their experiences of diagnosis, treatment and LwBBC openly on Twitter (Crannell et al., 2016; Tsuya et al., 2014) and in doing so increase their breast cancer knowledge across a wide number of areas (Attai et al., 2015). Tsuya et al., (2014) identified through content analysis, women using Twitter to share medical information and to talk about aspects of LwBBC including self-diagnosis, lymphedema, metastasis, chemotherapy, hormonal treatment, palliative care and the Pink Ribbon²⁵. Crannell et al., (2016), supported this. In a content analysis of US cancer tweets, Crannell et al. identified breast cancer patients tweeted about treatment aspects of their experience – chemotherapy, radiotherapy and hospital visits – more often than their diagnosis. The exploration of 627,381 unique posts by Freedman et al., (2016) to identify barriers to breast cancer treatment used a range of online communities, including contemporary social media platforms (blogs – 27%; content communities e.g. YouTube – 14%; social networks e.g. Facebook and Twitter – 12%). They identified a range of barriers to

²⁵ The Pink Ribbon is an international symbol of breast cancer awareness.

treatment expressed in 387,238 posts. Emotional barriers (anxiety, fears, denial, depression) accounted for 23% of posts; personal beliefs (misinformation, health care preferences, spiritual/religious/cultural) for 21% of posts; 18% to physical concerns (limitations, body changes, side effects), 15% to resource barriers (costs, logistics, insurance), 9% to health care perceptions (trust, communication, negative experiences, accessibility of services), 7% to issues with treatment processes/duration (complexity, regimen), and 7% to relationships (including children, friends, intimacy). Using a subset of posts (n=172,274) which specifically talked about treatment, 35% discussed chemotherapy, 33% surgery, 15% radiation, 10% drugs, and 7% hormonal therapy.

In contrast to identifying what women posted about in relation to LwBBC, Attai et al., (2015) used an online survey to explore with 206 respondents, how participation in the #bcsm Twitter chat was supportive. They identified increases in overall knowledge of breast cancer and knowledge across multiple aspects of care. Additionally, following participation in #bcsm, 71.9% of respondents reported either seeking a second opinion regarding aspects of LwBBC or taking additional information to their treatment team. Such results indicate the role of social media in giving women greater confidence to advocate for themselves. Participation was also found to decrease levels of anxiety in those initially reporting 'high' or 'extreme' anxiety ($P < .001$).

These studies show Twitter as a public space is utilised to talk about experiential aspects of breast cancer. Crannell et al., (2016) and Tsuya et al., (2014) provide insight into the main issues women comment on while Attai et al., (2015) demonstrates evidence of benefit from Twitter use related to patient education, self-efficacy and anxiety. This analysis of primary self-reported survey responses gives voice to women's experiences and offers insights into the benefits of social media use by a limited demographic group (91.7% = white; 61.1% aged 45-64; 53.9% = graduate level education).

Exploring experiences

Five papers address aspects of women's lived experiences of breast cancer. Two focus specifically on outcomes related to mastectomy (Doh & Pompper, 2015; Tan et al., 2014). Three explore and understand women's experiences of LwBBC across a longer temporal period (Coll-Planas & Visa, 2016; de Boer & Slatman 2014; Foley et al., 2014).

Two different approaches to understanding aspects of women's experiences of LwBBC were explored through the analysis of videos posted on YouTube (Foley et al., 2014; Tan et al., 2014). One (Tan et al., 2014) evaluated, using qualitative and quantitative categorical analysis, the quality of information posted on YouTube related to breast reconstruction to determine whether YouTube is an appropriate source of information for patients. The other (Foley et al., 2014), analysed, using qualitative content analysis, women's narratives of their experiences of LwBBC. At the time of analysis, Tan et al., (2014) found 91% of breast reconstruction videos were professionally made by television shows (e.g. Embarrassing Bodies), news clips (e.g. BBC news), or media companies. The median number of viewers per video was 758. Interestingly, just 9% were 'amateur videos' describing personal experiences from cancer excision to reconstruction. However, the most viewed video (n= 485,306) was an 'amateur' video filmed post bilateral prophylactic skin sparing mastectomies suggesting considerable interest in the 'real' experiences of mastectomy. There is however no data available related to 'viewers', so no conclusions can be drawn regarding the motivations for viewing content or the extent to which women LwBBC seek out uploaded video content regarding other women's experiences. There is both an absence of women's views on amateur versus professional reconstruction videos and on women's perspectives regarding what they would find beneficial in relation to (YouTube) video based information on breast reconstruction. This knowledge would be helpful to breast reconstruction clinicians and other health care professionals.

In contrast, Foley et al., (2014) identified the advantages of using YouTube narratives to understand more fully women's experiences, from which new knowledge could inform health care professionals' practices. Foley et al., (2014) explored nineteen women's narratives posted on YouTube related to LwBBC. Women's reasons for posting on YouTube included: providing support and advice to other women LwBBC; raising awareness of different aspects of LwBBC; and telling their stories of cancer. Qualitative content analysis identified one overarching theme – 'the experience of fighting cancer', with five sub-themes related to: finding out; coping; living with uncertainty; reaching out and giving back; and learning. In contrast, therefore, to the physical and practical topics identified as pertinent to women LwBBC through Twitter analysis (Tsuya et al., 2014), YouTube narrative analysis provides insight into the psychosocial challenges women experience when LwBBC.

The physical and psychological challenges resulting from the experience of mastectomy were also identified when Facebook comments (n=138) posted on the SCAR (Surviving Cancer: Absolute Reality) project page were analysed (Doh & Pompper, 2015). Use of this project page provided women with inspiration and support and demonstrated women's alternate cancer 'scar' meanings. Women identified greater support and encouragement available through this channel than "might be received through official medical caregivers" (p.604). This finding is in line with the significance of peer and social support to women LwBBC, identified by Foley et al., (2014) and the absence of the role of the health care professional in women's narrated experiences. The authenticity of experiences was a further benefit identified by women of the SCAR project. They positioned posts on this Facebook page as "true to reality" (p. 605). Additionally, Doh & Pompper (2015) identified content shared as enabling women post mastectomy to redefine their definitions of femininity and beauty.

Women's drive to make sense of an altered self when LwBBC was also identified by Coll-Planas and Visa (2016) and de Boer and Slatman (2014) through blog analysis. De Boer and Slatman analysed five blogs, followed monthly for a year in 2013. Four types of self-narration were identified which point to a range of psychosocial challenges experienced by women LwBBC at different temporal periods post diagnosis: The Estranged Cancer Patient (predominantly evident at the time of treatment); the Transient; the Heroic Survivor and the Disfigured Woman/Girl (post-surgery/treatment). Notably, de Boer and Slatman (2014) posit that these narrations should be considered as inter-related and all types of self-narration could occur at any stage of LwBBC. Faced with significant physical and psychosocial disruption, blogging is seen to enable sense making. This corresponds with the findings of Foley et al., (2014) and Doh and Pompper (2015) regarding women's use of social media demonstrating a re-owning of the changed self and the re-appropriation of their changed bodies and sense of self.

This re-appropriation is also identifiable through the work of Coll-Planas and Visa (2016). They analysed how seven Spanish women LwBBC represented their 'wounded body' using Frank's (1995) modern and postmodern logic²⁶ as a framework. Coll-Planas and Visa

²⁶ Frank (1995) distinguished between modern and postmodern ways of experiencing illness. These take different views to the problems of embodiment (control, body-relatedness, other-relatedness and desire) as well as different narrative types (restitution, chaos and quest) (Coll-Planas & Visa, 2016). .

summarised the modern logic approach as experiencing illness as ‘colonised’ by medical knowledge. In contrast, the postmodern logic framework follows “the quest narrative, in which illness is seen as a challenge which opens up the way to new experiences from which one can learn and share with others” (Coll-Planas and Visa, 2016, p.886). Their findings suggest that within blogs women shift narratives and positions and argue that Frank’s distinction between modern and postmodern logic does not ‘fit’ women’s experiences. The authors state that women take on the ‘language of survival’ (Bauman 1992) and focus on self-control and individual responsibility regarding life style including physical activity, eating habits, and managing emotions. This they argue is because the current discourse around cancer focuses on personal responsibility. Cancer is seen in terms of “a failure of the self to take care of itself” (Bell, 2010, p.350). They argue that women do adopt aspects of ‘the modern logic’ which is represented in their blogs through ‘searching for the predictability of the body and its restitution’, trying to hide the side effects of treatment, and ignoring discussions of mortality. Women convey a sense of accepting medical logic and being passive recipients of care, “obeying the dictates of the doctors” (p.896). Yet at the same time, blogs show women accept and make visible the physical impact of treatment, get involved in collective projects and consider themselves as part of a close network or ‘cyber-family’.

The evidence from this small number of studies shows that women are using various social media platforms (Facebook, YouTube, Blogs) to negotiate and share aspects of their lived experiences. The benefits identified demonstrate social media as an enabler, empowering women to: share and read authentic experiences; draw inspiration and support from other women LwBBC; raise awareness of different aspects of LwBBC; and renegotiate aspects of self through ‘making sense’ of experiences. These benefits are understood from analysing and interpreting posts made by women LwBBC on social media platforms using secondary analysis.

Considering social media use in relation to clinical outcomes.

Two papers have sought to look at social media use and its relationship with clinical outcomes. Tapi Nzali et al., (2017) explored the extent to which naturally occurring talk on Facebook corresponded with questionnaire items in the Quality of Life (QoL) self-administered cancer care questionnaires, developed by the European Organization for Research and Treatment of Cancer (EORTC). The authors state The EORTC Quality of Life

Questionnaire Core 30 (QLQ-C30) and QLQ_BR23, the EORTC breast cancer module²⁷ are most often used. The authors captured messages posted to a French public health website - cancerdusein.org (n=16,000) and on four different Facebook public groups (n=70,092) between October 2010 and October 2014. This suggests Facebook groups as a particularly active environment in comparison to the online forum under consideration. Interestingly, the authors identified greater alignment between the topics discussed on cancerdusein.org (74%) with the dimensions investigated in the questionnaires, than on the Facebook groups (68%). None of the settings used moderators, suggesting that discussion in the different settings occurred naturally. The data acquired from Facebook matched all of the topics investigated by the breast cancer module (QLQ-BR23). In relation to the Quality of Life Questionnaire Core 30 (QLQ-C30), the authors found matches for all of the topics except global health status and QoL; cognitive functioning, and role functioning. They suggest that measuring QoL of women LwBBC through analysis of ‘candid’ social media posts using machine learning models may be an alternative to using self-administered questionnaires. This suggests that QoL measurements are extrapolated for benefit at a structural level rather than used to understand women’s needs at an individual level. No consideration of the topics that equated to 32% of the variance between questionnaire items and Facebook discussion was raised. This data may point to potential gaps in QoL measures that should be explored further.

3.2.8 Conclusion of the scoping review

In examining the current evidence, it is apparent that understanding of women’s social media use in relation to their experiences of LwBBC is both limited and fragmented.

Crannell et al., (2016), Freedman et al., (2016), and Tsuya et al., (2014) identified key areas of interest for women LwBBC via tweets and posts on Facebook relating to symptoms, aspects of treatment and ongoing effects. Only one study by Tan et al., (2014) has examined the quality of information available online in relation to one aspect of treatment (reconstruction) on one social media platform (YouTube). How women are sharing information and narratives across social media platforms related to these aspects of breast

²⁷ Tapi Nzali states this is usually administered with the EORTC QLQ-C30 and is designed to measure QoL for breast cancer patients at various stages and with different treatment modalities (p. 5)

cancer and ongoing unmet needs requires further investigation. Given the extent of content creation on the internet related to breast cancer, it is surprising that more research has not been published regarding use specifically by women LwBBC.

Studies to date have relied largely on secondary data analysis to identify content of women's social media posts, often to inform health professionals' practice. While qualitative approaches enable an exploration of the richness of conversations and provide some insight into the sharing of experiences online, little is known about how naturally occurring content supports other women LwBBC or the benefits experienced by women who generate content. Falisi et al., (2017) stress a need for more research on established social media platforms with existing social networks. Additionally, in using secondary data analysis, researchers are limited to exploring publicly available data. Understanding use of closed or secret groups remains hidden from view. Furthermore, little remains known about how use changes for women across the cancer continuum, reflected in an absence of longitudinal studies and studies which give voice directly to women's experiences.

Our knowledge of the use of social media by women LwBBC is currently understood through limited exploration of Facebook, Twitter, YouTube and blogging. Meng et al. (2016) called for additional research to explore use of diverse social media sites. In conclusion, studies to date have not explored why this social media use is important to women LwBBC; how it complements or replaces more traditional support group structures, or provides a more holistic understanding of how naturally occurring and community created content based social media communities benefit women. Primary data collection and analysis is now needed to build on these early foundations to understand the benefits and challenges of social media use by women LwBBC.

Chapter 4: Ontological, epistemological and methodological considerations

4.0 Introduction

This study seeks to explore women's experiences of the role of social media in their lives as they are diagnosed, treated and LwBBC. In simplistic terms, it asks 'how do women use social media within their daily lives and what does this use 'do' for them and what do they 'do' with that use?' This question stems from the knowledge that women are using social media in relation to their experiences of LwBBC (See Chapter Three, section 3.2.7), yet research studies about use are largely based on secondary data pulled from social media platforms. A deeper and more complex understanding can be generated directly from women themselves. This study therefore centres on the lives of women and "digs down into the knowledge landscape to uncover new voices and perspectives" (Hesse-Biber, 2010, p.170). In this chapter, I outline the ontological and epistemological considerations underpinning this study and examine how visual methods, thematic analysis, and a voice centred approach to analysis, provide deeper/further insight into the complexities of social media use when LwBBC.

4.1 Study background

The approach taken to researching social media use when LwBBC was underpinned by two objectives. Firstly, to produce findings that 'speak' to many different stakeholder groups, to educate and inform disparate audiences who play a role in the ongoing care and support of women LwBBC. These include clinicians, healthcare professionals, charitable bodies, academics, women LwBBC and funding agencies. This objective was informed by my experiences of working within a chemotherapy unit, my previous research (Ure, 2014; Ure, Coen & Condie, 2015; Ure et al., 2017) and my experiences of attending conferences to disseminate findings of this previous work. In setting this objective, I acknowledge the prevalence of essentialist, quantified, realist approaches taken to understanding social support gained from social media use (see Chapter Three, section 3.1.1) and the psychosocial health of women with breast cancer (see Chapter Two, section 2.3.1). I acknowledge the call for researchers to "extend influence and impact beyond the academic community, including

engaging with policy, practice and public audiences” (Foster, Calman, Richardson, Pimperton & Nash, In press) and at the same time the need for “good quality evidence regarding the impact of cancer and its treatment on people’s lives [...] to inform decision making around the design and planning of effective services to bring about desired improvements in care and outcomes” (Foster et al., In press). This study takes a qualitative, interpretivist direction because of the limitations essentialist, objective approaches have in developing knowledge of how women interpret the impact of cancer on their lives.

The second objective is to provide a space from which women’s own experiences of using social media to support their experiences of breast cancer can be voiced. ‘Voice’ is not used to indicate a ‘true’ or ‘authentic’ voice to which a researcher can gain full access. Rather, voice is:

“a signal that there are issues around our ability to hear what is being said about private, domestic and personal lives and then to speak it again (represent it) retaining its meaning and context in a public forum” (Edwards & Ribbens, 1998, p.17).

In this study, women’s voices will be shared using written and visual representations provided by women LwBBC. This approach is influenced by my previous research where women LwBBC used blogging to express how their experiences are ‘silenced’ by social scripts of ‘how to do cancer’ and mainstream media representations of breast cancer survivorship (Ure, et al., 2015). Further work carried out by Ure et al., (2017) arguably supports the notion of women’s experiences being silenced. When exploring how UK charities engage with women LwBBC on Twitter, we found that charities prioritise engagement with wider audiences with limited one to one engagement and dialogical support with women LwBBC (Appendix 1). My scoping review (Chapter Three) also identified the limited ‘space’ previously given to women voices regarding use of social media and its role in their lives post diagnosis. Additionally, there seems to be a disconnect between the extensive use of the internet and social media by women LwBBC (Attai et al., 2014; Bender et al., 2011; de la Torre-Diez et al.,2012; Katz et al.,2015; Quinn et al., 2014) and the limited use of social media for breast cancer clinical care (Simmons, Rajmohan, Poonja & Adilman, 2014). By examining use from the perspective of women LwBBC, a qualitative approach is more appropriate to facilitate ‘giving voice’. A qualitative approach is interested in how women make sense of the world post diagnosis, how they experience events, such as

treatment and life post treatment; how they manage everyday life; how they feel and how they communicate with others (Reavey, 2011; Willig & Stainton Rogers, 2008; Willig, 2013).

A qualitative approach enables women's experiences of using social media when LwBBC to be understood as always situated, in that they are historically and culturally located (Morgan, 2014). The women participating in this study for instance, experience breast cancer in an individualistic, technologically advanced Western culture, with free access to healthcare. In terms of exploring psychosocial health, it is important to understand lived experience from the point of view of those who live it (Schwandt, 2000) by asking women 'what', 'why' and 'how' social media use is experienced when LwBBC (Rasmussen et al., 2010). This positioning of experience as situated and constituted through lived experiences aligns with interpretivist approaches to inquiry.

Interpretivism is rooted in the phenomenological understanding that lives are carried out intersubjectively; are experienced sensually and known "linguistically from moment to moment and day to day" (Angen, 2000, p.385). Interpretivism is concerned with understanding or developing theory, or induction, in contrast to positivism, which is concerned with objectivity, empiricism and the testing of theory, or deduction (Guba & Lincoln, 1994). However, I have been pragmatic when seeking to answer the aims of this study. For instance, the first aim – to examine how women LwBBC use social media provides the opportunity to understand for the first time the breadth of social media women use. Qualitative inquiry can offer new insight by enabling an understanding of the complexity of use including type, intensity, extent and fluctuation of use. This can be further understood using quantitative descriptive analysis as a complementary component to contextualise use by identifying which platforms women use. I drew on Biesta's (2010) advice that researchers:

'Should choose the combination or mixture of methods and procedures that works best for answering your research questions'
(p.96).

Capturing quantitative descriptive data could enable more productive, targeted discussion with participants by developing a shared understanding of preferred social media. This approach fits with using exploratory methods. By exploratory methods, Onwuegbuzie & Leech (2005) conceptualised descriptive statistics as exploratory quantitative data whilst

exploratory qualitative data analysis includes thematic analysis. Both methods are utilised in this study. Mason (2006) argues these approaches to data collection can “open our perspective to the multi-dimensionality of lived experience” (p.11). The capturing of descriptive statistics related to platform use facilitates the interpretivist stance taken to exploring psychosocial health and social media use, by providing added insight into the complexities of social media when LwBBC. This is particularly useful given the aim to explore whether women’s experiences of use change at different temporal periods since diagnosis. The approach taken to this study is therefore a pragmatic interpretivist one.

4.2 Ontological and epistemological position

4.2.1 Introduction

From an ontological and epistemological perspective, the challenge of offering insight to different stakeholder groups and ‘giving voice’ to women LwBBC requires consideration as they produce dilemmas in relation to their compatibility. To achieve these aims, I am aware of the potential conflict with how I remain ‘true’ to the women in my study and to be faithful to women’s voices about their social media use when health is provided in a political and economic context (Jones-Devitt & Smith, 2007). For instance, key journals in the fields of medicine and healthcare including the BMJ and the Journal of the American Medical Association (JAMA) consider qualitative studies to be of low priority, lack practical value or are not of interest to readers (Greenhalgh et al., 2016). Qualitative research produces useable, important, necessary knowledge to advance care for women LwBBC (Greenhalgh et al., 2016). To ignore the complexities of experience, to reduce women and their experiences to statistics and numbers alone, is unhelpful. A decision to ensure women’s voices are included in debates about psychosocial care has influenced my approach to analysis and writing up my findings. These are communicated using a discursive socio-cognitive visual approach to both ‘give voice’ to women LwBBC and to ‘speak to’ different audiences simultaneously. Given my interest in sharing findings with healthcare professionals, I made decisions to write up my findings using language that would be meaningful to them. However, I also sought to acknowledge the expertise of women LwBBC as ‘experts in their own lives’ (Clark-Ibanez, 2004) and produce findings that could be comprehended by lay audiences too. This decision

making is indicative of power relations in play in research environments, given my perceived need to deliver research in particular ways (Ribbens & Edwards, 1998).

4.2.2 The three fundamental philosophical questions

Guba & Lincoln (1994) argue that inquiry is rooted in three fundamental questions. In relation to this thesis, these questions are:

- The ontological question: What is the form and nature of ‘reality’ and what is there that can be known about women’s use of social media when LwBBC?
- The epistemological question: “What is the relationship between the knower or would be knower and what can be known” (p.108)
- The methodological question: “How can the inquirer (would be knower) go about finding out whatever he or she believes can be known?” (p. 108)

4.2.3 Discussing realist and relativist ‘realities’ of social media use by women LwBBC

In understanding the ontology or ‘reality’ of women’s experiences of social media use when LwBBC, it is acknowledged that having cancer and using social media are ‘real’. Cancer denotes physical and physiological change to the body. Furthermore, a diagnosis of breast cancer is delivered as factual evidence and rooted in a biomedical and positivist paradigm, often communicated as ‘you have cancer’. Given the definition of cancer survivorship (Chapter One, section 1.1, p.24) living with and beyond cancer is an activity people ‘do’ in a ‘real’ sense. This thesis was interested in how these ‘realities’ are experienced and how they change over time. It captured women’s experiences who had been diagnosed in the preceding twelve months; diagnosed within one – five years; and diagnosed over five years previously. To support this exploration, I have approached aspects of data collection and analysis using a realist perspective. For instance, I have accepted women’s descriptions of the social media platforms they use as ‘truth’ in that these are largely knowable and ‘as they appear to be’ (Madill, Jordan & Shirley, 2000).

However, when considering the reality of LwBBC a more nuanced perspective is necessary. Women’s realities of what they make of having breast cancer “and the social constructs they utilise to make sense of it and to impose order on it” (Guba & Lincoln, 1994, p.265) are experienced through interaction with others. Women’s experiences of changes to their

physical world impact on psychosocial health because they are experienced as “fears, hopes beliefs, values, prejudices, dreams, ambitions, frustrations and possibilities brought to the physical realities” (Guba & Lincoln, 1994, p.266) women inhabit. Women’s experiences of breast cancer, and their use of social media in relation to breast cancer, is therefore important in terms of the meanings they attach to that use. For instance, the women in this study are located within a Western culture and western notions of womanhood, femininity and health. The meanings they attach to these are their constructed realities (Guba & Lincoln, 1994). Within this thesis, women’s experiences are therefore considered as being on a ‘realist’ and ‘relativist’ continuum. Their experiences of having and ‘doing’ breast cancer is real, but women are also active participants in generating their realities. In relation to social media use in relation to the experiences of LwBBC, there is not as single truth or reality but only interpretations of reality (Hammersley, 2002). Therefore, this study is underpinned by an interpretivist epistemology

4.2.4 Interpretivism and ‘the everyday’ as an epistemological lens

Epistemology “is a way of understanding and exploring how we know what we know” (Crotty, 1998, p.3). Unifying all interpretivist approaches is a “phenomenological base, which stipulates that person and world are inextricably related through lived experiences of the world” (Sandberg, 2005, p.43). A subjectivist epistemology understands women’s experiences of breast cancer as mediated through the specific culture, historical time, and language, in which they are situated (Sandberg, 2005). This is particularly relevant in exploring social media use by women LwBBC, given its arrival as a relatively recent healthcare phenomenon with Facebook, Twitter and You Tube for example, still less than fifteen years old.

Indeed, Brabham (2015) argues that social media researchers should be giving more attention to studying ordinary, everyday topics. Whilst LwBBC cannot be categorised in any straightforward way as ‘ordinary’, the definition of cancer survivorship (section 1.1.) suggests LwBBC can be theorized as an ‘everyday’ activity. Brabham (2015) comments, “the vast majority of what happens on social media is unremarkable” (p.1) but the attention of social media scholars has become caught up in big data sets or “the edge cases” (p.1). Somewhat ironically, Brabham referencing the Arab Spring, reminds us that “very few social media users use social media tools to coordinate revolutions” (2015, p.1) and calls upon

researchers to understand the significance of everyday use; to explore the nuance of mediated human experiences. He advocates “actually talking to social media users” (p.2) to ensure new forms of sociality are not overlooked or understated.

As discussed in Chapter Two (section 2.3), a major focus of psychosocial inquiry is on everyday experience (Woodward, 2015). The notion of psychosocial health as bringing together “the personal and the political and the individual and the social” (Woodward, 2015, p.4), suggests meanings women attach to social media use in relation to their health experiences may be complex and entangled. One way of establishing “how we know what we know” about women’s everyday use of social media is to situate their experiences in ‘dailiness’ (Apthekar, 1989). ‘Dailiness’ is concerned with familiarity and the “taken-for-granted character of daily living” (Moore, 2007). Utilised in feminist inquiry, ‘dailiness’ focuses upon the meanings women attribute to aspects of their daily lives and has been applied to critically explore aspects of domesticity. Its focus is on women’s ordinary lives and:

“the struggle to preserve quality of life for your family in the face of exploitation and oppression, to hold on to and nurture a positive sense of self in a culture that demeans and devalues you” (Sprague & Kobrynowicz, 2006, p.33).

Here there is potential for the wider debates about women’s ‘oppression’ and the ‘devaluation’ of women’s lives. However, what is most pertinent to this study is how this definition of ‘dailiness’ corresponds with aspects of women’s lived experiences of breast cancer (struggle; quality of life; quality of life for family; nurturing a positive sense of self; being part of wider social culture; being devalued or demeaned). ‘Dailiness’ in this thesis therefore explores social media use as embedded - a taken for granted aspect – of life today and suggests a way of knowing from the meanings women give to their (digital) labours (“Theory, Feminism, and Feminist Theory”, n.d.).

While ‘being on’ social media is now a ubiquitous aspect of everyday life, so too is mobile phone and camera phone use (Bender et al. 2013; Cruz & Thornham, 2013; Erfani et al., 2016; Hjorth, 2007; Malik, Dhir & Nieminen, 2016) and life without them may seem inconceivable (Baym, 2015). Attending to the ‘dailiness’ of social media use therefore necessitates an analytical approach which “explores the patterns women create and the meanings women invent each day and over time” (Apthekar, 1989, p.43). (Apthekar (1989)

argues that the point is not to describe every aspect of daily life or to prioritise some activities as more important than others but to take a “bottom-up” approach, enabling a search for the meanings women articulate in relation to the daily activities of their lives. She argues that by discovering and connecting these meanings, a “map” or a different way of seeing women’s realities from women’s point of view can be developed. Interpretivist knowledge creation therefore involves a joint process or co-construction between the researcher and the researched together (Yost & Chmielewski, 2013). This co-construction positions the researcher and participants as embedded together in subjective knowledge practices and argues that we cannot separate ourselves from what we know (Cohen & Crabtree, 2006). It is the co-construction of knowledge through cultural artefacts and practices that are used to negotiate ‘truth’ (Cohen & Crabtree, 2006) in relation to social media use and its role in supporting psychosocial health. The next section explores how visual methods within interviews are used as a way of co-constructing knowledge.

4.3 Visual methods as methodology

Guba and Lincoln (1994) (section 4.2.2) asked “how can the inquirer go about finding out whatever he or she believes can be known?” From an epistemological perspective, in seeking to give voice to women LwBBC, I had a commitment to select methods that enabled participants to interpret and give meaning to their individual and unique experiences (Hansen-Ketchum & Myrick, 2008; Harrison, 2002). Furthermore, in seeking to develop knowledge about social media use, the importance of Western visual culture and its embeddedness in everyday life (Landry, 2006; Mirzoeff, 2009) needed to be acknowledged. As Reavey and Prosser (2012) state “visuals are pervasive in public, work, and private space, and we have no choice but to look” (p.2). Vision is a dominant, yet taken for granted, way of knowing in Western society (Harrison, 2002). Visual methods were therefore selected as an appropriate methodology to gain access into the meaning women give to their social media use and used as an attempt to ensure conversation was rooted in real life examples of women’s day to day use of social media. Visual methods seemed an obvious way to explore what can be known about women’s social media use when used as facilitators of conversations and to initiate and direct conversations. This was achieved through using two different methods using photographs – photo-elicitation and photo-production. Photo-

elicitation techniques use pre-existing photographs or images within the research interview while photo-production techniques ask participants to create photographs as part of the research process (Willig, 2013). In the photo-production study, I asked women to take their own photographs to, in effect, provide a visualised voice. In the remainder of this section, I will outline the use of visual methods in psychology and health research and the benefits of using visual methods to address the aims of this study. This section concludes with a brief introduction to photo-elicitation and photo-production.

A range of visual methods including the use of photographs, video and film, timelines, painting, drawing, art and collage are increasingly being used to explore the psychosocial aspects of health and well-being (Frith & Harcourt, 2007). Indeed, Silver (2013) argues that visuals are a “form of language” (p.163) which provide the researcher with important information about participants, “the culture they inhabit and/or the researchers’ own subjectivity” (p.163). Pink (2007) and Radley (2009) contest that limitations exist in looking at people’s experiences using language alone. They argue that a multi-modal approach utilising ‘extra-discursive modalities’ is beneficial to making sense of health experiences. Frith and Harcourt (2007) positioned visual methods as useful approaches to access information which might be difficult to access using other methods, while Gillies et al., (2005) suggests visual methods alter the voice of the research and have the capacity to disrupt ‘well-rehearsed’ accounts. These enable both the researcher, and the subsequent audiences for the research findings, to “broaden their experience, comprehension and representation of the topic” (Silver, 2013, p.157) under investigation. Previous research has shown women have ‘well-rehearsed’ cancer narratives (Kendall et al., 2015), however it is unlikely that women will have ‘well-rehearsed’ accounts of their social media use in relation to LwBBC given it is not a topic women are frequently asked about (see Chapter 3; section 3.2.7). Through using visual prompts during the interview, more complex and layered accounts (Collier, 1957, cited in Reavey, 2011) are anticipated as women vocalise and share meaning about the way they use different social media. Harrison (2002) argues this occurs because of reflexivity on the part of the participant in studying the images under consideration and their ‘verbalisation’ which produces the data for onward analysis and interpretation. Visual tools can change the dynamic within the interview setting with participants feeling less pressured when discussing sensitive topics (Prosser, 2011). This is because the ‘artefact’ removes the ‘spotlight’ as people need not speak directly about a topic they may feel vulnerable about but

instead “work through a material go-between” enabling the expression of more difficult “memories and powerful emotions” (p.484). It is an approach which also works to recognise participants as experts in their own lives (Clark-Ibanez, 2004).

Visual approaches are not considered as realist methods employed to seek out “objective knowledge about the world” but are relativist in that they seek to gain insight into how women view their “particular world at a particular moment in time” (Silver, 2013, p. 163). Guillemin (2004) advocates the use of visual methods to understand experiences of health and illness arguing that text-based data such as field notes and transcripts restrict the multiple ways illness is understood, enacted and experienced. Given the routes from diagnosis already discussed (Chapter Two, section 2.2), we know that women’s physical experiences of illness and health are varied. At the same time their ongoing psychosocial needs (see section 2.3.1) are experienced in the wider context of societal, political and environmental influences. Utilising visual methods within semi-structured interviews may help women to express these experiences more freely. de Boer and Slatman (2014) for instance, identified how women produced additional insight into their experiences of breast cancer through blogging. They found one woman posting ‘empty’ blog posts – posts with no text or visual content. They interpreted empty posts as “silent screams of frustration” (p.20) reflecting “a ‘chaos story’ through a wordless story. The non-visual, visual was seen to vocalise experience by visualising a voice which lay beyond what the blogger was able to achieve through written narration. The ‘empty’ visual conveyed a sense of the experience as unspeakable. In this instance, the authors were only able to make interpretations based on the secondary data they were analysing. Had they been able to speak to the blogger, a richer, deeper interpretation of the ‘empty blog post’ may have been identified.

The growth of platforms such as Instagram and Snapchat are reflections of the changing influence of visual culture. The internet has been moving from a medium centered almost completely on text, to one increasingly image led (Mirzoeff, 2009). It is estimated that 1.8 billion images are uploaded daily to Twitter, Instagram and Facebook (Baker, 2016). In 2017, more than 4 million hours of content was uploaded to YouTube every day, and users watched 5.97 billion hours of YouTube videos each day (Schultz, 2017). This focus on visual culture is so prominent within the strategies of social media organisations that in 2016, Facebook launched a system which can ‘read’ photos and automatically tag every photo, so that

visually impaired people can ‘see’ what appears in them (Baker, 2016). Reavey (2011) argues that images posted on social media sites serve to tell us how we should look and how we should feel; they convey what is ‘acceptable’ and what is ‘normal’. In an era when women can continually view and edit images of themselves and of others, it is important that as researchers we acknowledge that we do not communicate by text alone (Silver, 2013). Given the psychosocial challenges women experience from challenges to their appearance such as breast loss, hair loss and weight gain (Freedman, 1994; Helms, O’Hea & Corso, 2008; Hunt & McHale, 2005; Mao et al., 2013; Sun, Ang, Ang & Lopez, 2017; Trusson & Pilnick 2017), it is important to understand how women navigate dominant cultural discourses related to body image. Using visual methods creates opportunities to explore, alongside the use of language, how women’s experiences are “culturally and socially contexted and bounded” and “mediated by subjectivity” (Harrison, 2002, p.857).

For instance, when women upload visual content into online spaces, they are making visible their social and pictorial worlds. Ruby (2005) points to the uploading of images as social processes in which the uploaded visual acts as an object “produced with the intention of communicating something to someone” (p.165). That said, women’s experiences of LwBBC have not been widely explored with women, using visual methodologies, except for Frith and Harcourt’s (2007) study of women’s experiences of chemotherapy. In this study, women participated in semi-structured interviews– in advance of receiving chemotherapy and after completion of treatment. They took photographs using a 27-exposure, single-use, disposable camera during treatment and discussed these photographs in the second interview. This limited exploration using visual methods is perhaps surprising given the body of literature which has explored women’s sense of disrupted appearance (Doh & Pompper, 2015; Frith, 2011; Mathieson & Stam, 1995; Piot-Ziegler, Sassi, Raffoul & Delaloye, 2010; Trusson, 2013) when LwBBC.

4.3.1 Using photo-elicitation

Harper (2002) suggests that photo elicitation should be regarded as “a form of post-modern dialogue based on the authority” (p.15) of the participant rather than the researcher. Pre-existing photographs are used as a tool to support and expand on questions and enable participants to use photographs in a way which enables them to determine how to provide access to and communicate unique dimensions of their lives (Clarke-Ibanez, 2004). These

photographs can be chosen in advance by the researcher or the participant depending upon the objectives of the study (Harper, 2002). Images do not have to be generated by participants to be able to be read as texts instead they ask participants to respond, to 'make sense', of the meanings they articulate through reading them (Harrison, 2002). The material aspect of having a photograph to pick up, consider and then respond to, provides pauses in the interview 'conversation', and feels natural for both participant and researcher. In keeping with Clarke- Ibanez's experiences, this method enabled a sense of supported reflexivity to develop within the interview setting.

4.3.2 Using photo-production

As well as using pre-existing images to open up conversation with the interview setting (photo-elicitation), I envisaged that photographs taken by women about their experiences of LwBBC and their social media use, would offer a rich source of data about the meaning and social impact of social media use (Cross et al., 2006) and how it relates to breast cancer. Photo-production is underpinned by a relativist ontology as photographs taken by women LwBBC are considered as extensions of the self, are of significance to each person; and variation in the type and quality of photographs produced is acceptable (Hansen-Ketchum & Myrick, 2008). Photo-production studies have been used previously to explore health experiences. While the literature is not vast, the most often cited papers include Radley and Taylor's (2003a, b) exploration of the experiences of being in hospital; Ziller and Smith's (2007) study of being in a wheelchair; and Frith and Harcourt's (2007) study of the effect of chemotherapy on patients' perspectives of their appearance. Photo production is a means to add depth and contextualise social media use within the everyday lives of women LwBBC. A significant benefit of utilising photo-production methods is the requirement for participants to be active in the research process with participants taking photographs which help them to express something of their experiences around the phenomenon under investigation. I was interested in enabling women to use photo-production to explore how they communicate their experiences of LwBBC to others and gain social support. Del Busso (2011) identified, from her experience of using life history interviews with women, that the request to produce photographs demanded participants to think carefully about what they want to photograph and why. This collaborative approach is seen to offer opportunities for participant empowerment (Del Busso, 2011; Harrison, 2002) by giving women greater agency and

control over the research process. This approach however does create work for women, requiring them to be engaged in the process of taking photographs over a particular timescale. By offering women the opportunity to participate in either the photo-production or photo-elicitation study, women were able to decide which study best met their own needs or was of most interest.

Photo-production has the advantage of deepening understanding of participants' worlds through 'glimpses' (Silver, 2013) into these worlds that participants' photographs provide. Harrison (2002) argues that this use of 'everyday snapshot photography' (p.859) has the potential to offer data about personal lives and experiences; forms of subjective understanding and identity construction and an insight into daily activities, all of which are applicable to understanding the role of social media use for women LwBBC. The photographs taken therefore become integral to the analytical process in a collaborative way in discussion with the participant themselves. Participants' accounts about their experiences are deepened by the continuing reflexive process they are engaged in throughout the interview, as they comment on all aspects of the production of the image under examination as well as the meanings they offer for producing the image. Harper (2002) offers a vibrant endorsement of using photographs to stimulate discussion as a "staggering simple method of data collection" (p.23) when he states that his enthusiasm:

"comes from the collaboration it inspires. When two or more people discuss the meaning of photographs they try to figure out something together. This is, I believe, an ideal model for research" (p. 23).

4.4 Conclusion

In this chapter, I have introduced the ontological, epistemological, and methodological underpinnings to this thesis. I have outlined a concern to offer a 'realist' perspective of being diagnosed with breast cancer and specific social media platform use when LwBBC. I have sought to position this 'realist' perspective as being on a continuum with 'relativist' perspectives and as complimentary in that it extends and deepens understanding of women's experiences of use. Exploring everyday use provides a useful epistemological lens to discover 'what can be known' and this is supported through exploration using a visual lens. I have outlined the significance of the 'visual' on a day to day basis and why photo-elicitation and

photo-production are effective methods for data collection. In the next chapter, I outline the methods used in this study.

Chapter 5: Methods

5.0 Introduction

This chapter sets out the methods used within this thesis to help answer the research aims of this exploratory study. These were:

- To examine how women LwBBC use social media
- To explore how women LwBBC use social media as communicative resources in relation to their experiences
- To make sense of how women LWBBC use social media to support their psychosocial health

Within this chapter, I explain my approaches to recruitment, data collection and ethical considerations in relation to interviews and the use of visual methods. I detail my approaches to data analysis and how these evolved to ensure ‘voice’ was brought forward. The chapter concludes with the approaches taken to gain participant feedback on the findings.

5.1 Method

5.1.1 Design

To address the aims of this study a qualitative approach was utilised combining visual methods with verbal data elicited through semi-structured interviews (see section 4.3: Visual methods as methodology). Women could determine whether they wished to participate in an interview using photo-elicitation techniques (see section 4.3.1) or an interview utilising photo-production (see section 4.3.2). Both approaches offer opportunities to understand women’s experiences of LwBBC in different ways and were designed to complement one another in extending insight. The University of Salford Ethical Approval Panel granted ethical approval (HSCR 15-71) in August 2015 (Appendix 4) and minor amendments in April 2016.

5.1.2 Recruitment Strategy

Sampling was purposeful, in that a set of criteria was established for participation. Women had to have had a diagnosis of breast cancer and be over eighteen. Due to financial

restrictions²⁸, women needed to be able to speak English. To ensure variability in experiences of using social media women needed to be drawn from both ‘online’ and ‘offline’ sources²⁹. Three temporal periods for recruitment, which broadly corresponded with the timeframes Macmillan et al. (2014) describe in their ‘survivorship pathways’ (less than 12 months; 1-5 years and 5 years plus) were used.

The study was publicised at The University of Salford using a poster (Appendix 7) and through the Word of Mouth Mammography eNetwork (WOMMeN) closed Facebook group³⁰. Details of the study were posted regularly using my own Twitter account (see Appendix 8 for example tweets) and a pinned tweet was attached to my profile so that anyone visiting my Twitter account would immediately see details of the study. The tweet included a hyperlink³¹ through to a webpage on The University of Salford’s Public Health blog. This webpage provided an overview of the project and a hyperlink through to the participant information sheet (PIS) (Appendix 9 and 10) for both studies. Contact was also initiated with UK based closed breast cancer Facebook groups and an overview of the study provided (Appendix 11). Moderators determined whether they felt their ‘members’ would be interested in the study and posted details of the study if they felt this to be the case³². In total, nine groups were contacted (Appendix 12). Six posted details of the study online that included a link to the Public Health blog page.

Cancer support centres and groups in the Greater Manchester area (Appendix 13) were identified from an online PDF document entitled ‘Cancer Support Groups: Salford and Greater Manchester’ (2014) which detailed thirteen support centres operating out of hospitals in the North-West area. Each centre was sent a recruitment letter and advert for pinning up in the centre (Appendix 14). As a result of this contact, study details were posted on Macmillan Connections – a social network designed to link people who have had cancer together

²⁸ No funding was available to support interpreters being present in interviews.

²⁹ Examples of online sources are Facebook groups or through Twitter hashtags. Examples of offline sources are cancer support centres etc.

³⁰ I was a member of this closed group of almost 100 academics, healthcare professionals and women LwBBC who were working together to design a breast screening hub to connect practitioners and service users (see Galpin et al., 2017).

³¹ (<http://hub.salford.ac.uk/salfordpublichealth/131-2/>)

³² One Facebook group requested a copy of the full ethics application before posting details in their closed Facebook group.

through shared interests. Breast Cancer Care also posted details of the study in the ‘research opportunities’ section of their website and in their ‘Voices’ magazine.

Women were asked to make contact via email or phone if they were interested in participating. At this stage, I asked which study they would prefer to participate in and forwarded copies of the relevant participant information sheets and consent forms (Appendix 9, 10 and 15, 16). Dates to meet were arranged when women confirmed interest in participating. Care was taken to ensure these arrangements took account of women’s needs, in respect to hospital appointments, chemotherapy treatments, distance from Salford, work, caring commitments, and capacity to drive, for instance.

5.1.3 The sample

Forty-four women made contact in relation to participating in the study. Twenty-one women participated. Reasons for non-participation are detailed in Figure 5-1.

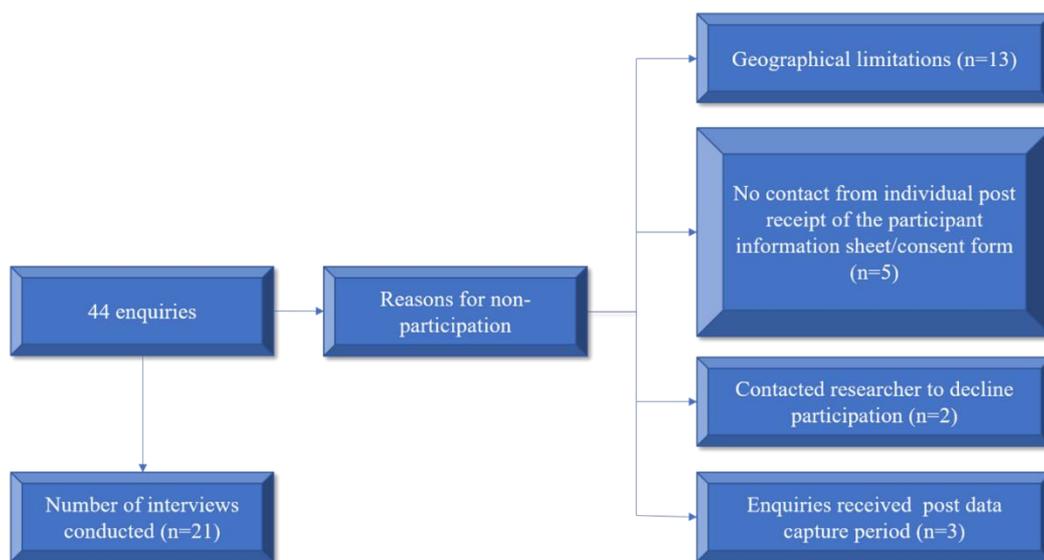


Figure 5-1 Recruitment: number of enquiries, interviews and reasons for non-participation

Participants came via online routes and offline routes as set out in Table 6 below. The majority (n=12) were recruited via four different Facebook groups (The Younger Breast Cancer Network UK (YBCN) (n=8); Flat Friends (n=1); UK breast cancer support group for survivors and sufferers (n=1) and the Word of Mouth Mammography e-Network (WOMMeN) (n=2). Three responded to my pinned tweet, retweeted using the hashtag

#bccww (breast cancer care worldwide). One responded to a Breast Cancer Care advert posted in April 2016's Breast Cancer Care's Voices magazine and another to the study details posted on Breast Cancer Care's website. The poster at The University of Salford attracted one participant and a poster in a Macmillan Support Centre another. Two responded after being informed of the study by a colleague.

Table 6: Recruitment routes of participants

Routes	Number of interested participants	Number of participants who participated in the study
Charities - Online	1	1
Charities - Offline	5	2
Facebook groups	27	12
Posters	1	1
Twitter	5	2
Word of Mouth	2	2
Unknown	3	0
Total	44	21

5.1.4 Data saturation

One of the hallmarks of qualitative research is the question 'how many interviews are enough?' with saturation being deemed the "gold standard by which purposive sample sizes are determined" (Guest, Bunce & Johnson, 2006, p.60). However, data saturation is hard to define (Fusch & Ness, 2015). Fusch and Ness (2015) argued that given the range of qualitative methods available, "what is data saturation for one is not nearly enough for another" (p.1408), in other words the 'one-size-fits-all' method fails to take account of the myriad of research designs and the differences in their methodological underpinnings. To advance methodological discussion, Hennink, Kaiser and Marconi (2016) assessed two different approaches to data saturation - code and meaning saturation. Using 23 in-depth interviews, they identified that thematic code saturation i.e. researchers had 'heard it all' was reached at nine interviews. However, meaning saturation whereby researchers 'understood it all' was reached between 16-24 interviews.

Taking every day experiences of LwBBC and social media use as an epistemological lens means that in an ever-changing technological landscape there is the probability of

experiential variation (Thorne, 2016) over time. As stated, my intent at the outset of this study was to explore social media use at different temporal periods post diagnosis. In doing so, I am not seeking to make ‘truth claims’ about women’s use at 12 months’ post diagnosis and at seven years’ post diagnosis for example, as this conflicts with the philosophical paradigms underpinning this study. Rather I subscribe to the position Thorne (2016) advocates – which is to convey through my findings what I have been able to discern based on the “exposures I have achieved, or not achieved” (p.107) through my research process.

An alternative approach to considering data saturation is to consider its “richness and thickness” (Fusch & Ness, 2015, p.1409) rather than in relation simply to the size of the sample (Burmeister & Atkin, 2012). Hennink, Kaiser & Marconi (2016) argue that data quality influences saturation. They contend that “thick” data provides deeper, richer insights than “thin” data and therefore impacts on the number of interviews required. Through using one to one semi-structured interviews and visual methods techniques, ‘rich’ data defined as “many layered, intricate, detailed, nuanced and more” (Fusch & Ness, 2015, p. 1409) was forthcoming and abundant. I took a reflective, balanced approach to determining participant numbers within each temporal period. This took into account Sandelowski’s (1995) concern that too few may result in lack of breadth and depth while too many may result in unwieldy volumes of data.

5.2 Data collection

The approach taken in the interviews sought to create space in which women could voice their personal experiences (Ribbens & Edwards, 1998). Interviews were conversational in nature (Kvale & Brinkmann, 2009), using a series of exploratory open-ended questions. The questions provided a blueprint which guided the interview but were sufficiently flexible to enable women to tell their own story in their own words and to introduce issues which they felt pertinent to their experiences, which may have remained out of the discussion should a more formal interview approach have been adopted. This approach enabled “the wording and formatting of questions used flexibly to suit the particular context of the woman” (Parton, Ussher & Perz, 2015, p.492). Photographs were introduced into the interview setting to elicit or trigger conversation (see sections 4.3.1 and 4.3.2).

For the photo-elicitation study, I decided to use semi-structured interviews in preference to focus groups to retain commitment to a relativist ontology. Given focus group methodology is distinguished from other methods through the interactions which take place within them there was the potential that all women’s voices would not be equally heard (Smithson, 2000). Furthermore, collective interpretation of photographs would limit the ability for unique experiences to be expressed (Hansen-Ketchum & Myrick, 2008). There were also ethical considerations to consider. For instance, women more recently diagnosed may experience anxiety if participating with women LwBBC who experience ongoing physical, emotional or social challenges. Twelve photo-elicitation and nine photo-production (n=21) interviews were completed (Figure 5-2).

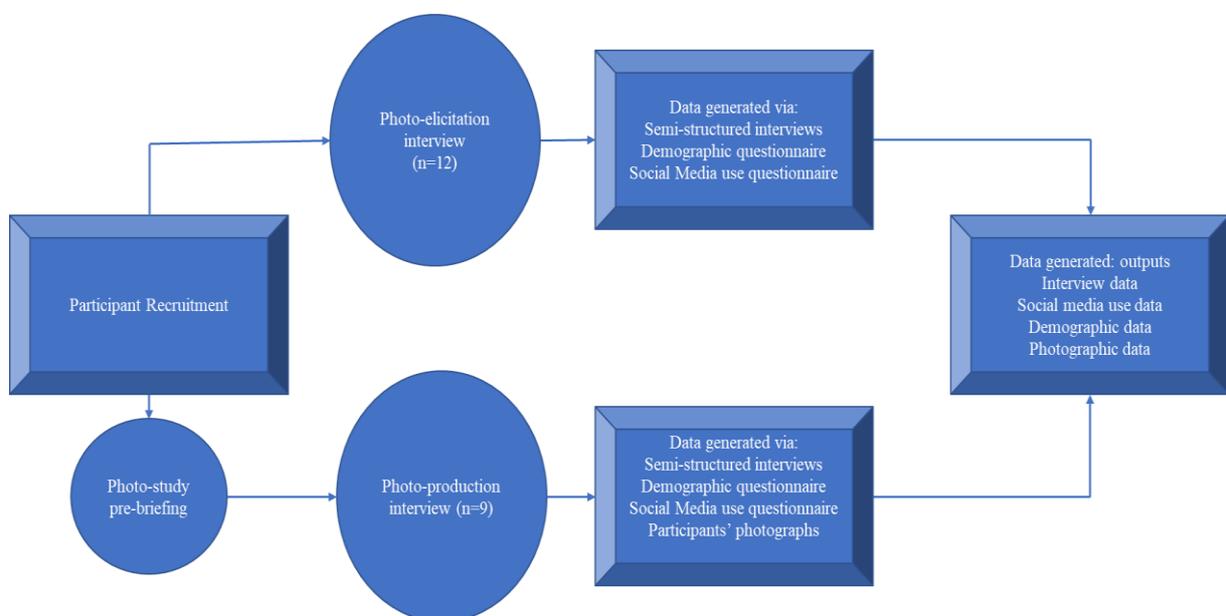


Figure 5-2 Interview processes and data generated

Of the twenty-one interviews conducted, seventeen were conducted on the University campus during week days; two on campus on a weekend; and two in a private room in local community building settings.

At the outset of interviews, women completed a consent form (Appendix 15 and 16) if they had not already done so. This included permissions to audio tape and video record interviews. I answered any questions relating to anonymity and confidentiality. Participants were then asked to complete a short paper-based questionnaire (Appendix 17). This was used to identify

how women had heard about the study (Q1); to gain demographic information relating to age at diagnosis; marital status and ethnicity (Q's 2-4); and diagnosis and treatment (Q's 5-8).

5.2.1 Photo-elicitation interviews

All interviews (n=12) began with the same set of questions. Taking this approach enabled a level of consistency in relation to the process through which participants brought forward and discussed their experiences of breast cancer and their social media use. The opening question asked at each interview was, "Can you tell me a little bit about yourself". This question was purposefully broad to enable women to begin by talking about aspects of themselves which they wished to talk about. A supplementary question was asked about their experiences of breast cancer if they did not address aspects of this within their first response.

The second question asked participants to identify which social media platforms they use. To orientate women to talking about their social media use an A4 visual prompt of 36 platforms was used to guide the conversation (Appendix 18). Once the social media platforms used were identified, women were asked to select 'platform cards'. The 'platform cards' were business card sized cards – one for each of the 36 social media platforms. These were then placed onto an A1 Venn diagram (Appendix 19) to identify whether they were used 'solely in relation to experiences of breast cancer'; 'not at all related to their experiences of breast cancer' or 'were used in their everyday experiences which included their experiences of breast cancer'. During this discussion, probing questions were asked to understand everyday use of platforms to enable women to describe how they engage with social media. Women were then provided with a set of pre-existing creative commons' images³³ considered to reflect sources of social support for women LwBBC, in line with the possible providers of social support identified by Wortman (1984). These included health care professionals, work colleagues, friends and neighbours, family including children and parents; partners, peers and service providers e.g. charities. I explained to participants that these images were simply to prompt thoughts about how they shared their experiences of LwBBC with others. They could choose which order to talk through the images and did not have to talk about them all (see example images: Figure 5-3). Follow up questions asked about how they shared experiences related to breast cancer with 'others' through social media.

³³ These have no copyright restrictions.



Figure 5-3 Photo-elicitation images relating to social support

Following each interview, I wrote up my reflections as field notes. I also added to the field notes two photographs. One of the photo-elicitation images women chose to talk to in the photo-elicitation interviews that were left in situ on the desk when the interview finished. In addition, I photographed the Venn diagram (Appendix 19). These photographs acted as aide memoirs during the analysis process.

5.2.2 Photo-production interviews

As demonstrated in Figure 5-2 (p.72), participants attended a pre-briefing prior to being interviewed. Participants were provided with a hand-held camera and a SD memory card. The camera was provided fully charged although a charger was supplied too.

During the briefing session a date to meet for interviews was agreed, issues of consent were discussed, and a consent form signed. I informed participants that issues related to the copyright of photographs would be discussed when we next met. Two participants were unable to meet at the University of Salford due to work and childcare commitments. In these instances, a camera, SD card, Participant Information Sheet, consent form and briefing note were posted out recorded delivery to the individual.

In most cases, part of the discussion at the briefing session included questions as to what participants should photograph. My responses were intended to be as non-directive as possible. I wanted women to portray their own experiences of how they communicate their

experiences of LwBBC however they saw fit whether that was “literally as physical bodies in places doing things, or more metaphorically and abstractly” (Cross, Kabel & Lysack, 2006, p.185). Previous photographic studies of patient experiences of hospital stays have required no images of people (staff or patients) due to hospital restrictions (Radley & Taylor, 2003b). While some women were in treatment at the time of their participation, there was no restriction discussed on who or what women could photograph. These decisions were left to women’s own discretion.

Prior to commencing each interview, I opened the images provided on my laptop and checked the first photograph shown was the first photograph taken in the week. The first half of the interview followed the procedure used in the photo-elicitation interviews (using the same methods set out in section 5.2.1). After women had finished discussing which platforms they used in relation to breast cancer, attention turned to the photographs.

For each photograph, I asked ‘what does this photograph represent for you’ or ‘tell me about this photograph’. Probing questions were asked to illicit further information pertinent to each photograph either to contextualise the photographs further (‘can you tell me where this photograph was taken’) or to understand elements of the photograph that may not be evident for the observer (‘can you tell me what I am looking at’). Further probing questions were asked to understand the significance of the image taken (‘what does this image represent’ or ‘how does this image relate to your experiences of breast cancer?’) After each photograph was discussed, I asked if there was anything more they wished to add.

Each interview was recorded using a video camera and audio recorder. After interviews were completed, I downloaded the video and audio files onto my laptop and backed up on to an external hard drive.

5.3 Ethical considerations

5.3.1 Anonymity of participants

One of the main tenets of ethical research is the provision of confidentiality and anonymity (AoIR, 2002, 2012; Beninger et al., 2014; British Psychological Society, 2007, 2013, 2014). However, as Silverman (2013) argued, and Ure (2015) identified when exploring blogger’s experiences of breast cancer ‘survivorship’, participants may not wish to be anonymised.

Pickering and Kara (2017) draw on Moore's (2012) work to argue that anonymising participants can operate as a form of silencing resulting in the foregrounding of the researcher's voice at the expense and loss of participant's voices.

Acknowledging the contextual nature of research is key (Hammersley, 2015). Anonymity can be challenging on the internet given the blurred boundaries between being private and being public online (Lomborg, 2012) therefore it was likely that women had addressed issues of identity and anonymity in relation to social media use previously. Women may have invested considerably in developing online identities specifically related to their experiences of breast cancer. Therefore, to assume a requirement for anonymity would negate women's abilities to ensure their voice is both identifiable and heard through their involvement in research.

In this study, at the outset of each interview - while consent forms were being completed - I checked with each participant whether they wished their data to be anonymised or whether they wanted their involvement and any quotes to be credited to them. Women most often wished to be credited for their involvement and waived their anonymity. In the photo-elicitation study, nine out of 12 (75%) women waived their rights to anonymity; one asked for their first name only to be used and two chose their own pseudonym for ongoing use. In the photo-production study, seven out of nine women (78%) waived their anonymity in relation to using any quotes and the use of their photographs. One individual wished a pseudonym to be used in relation to ongoing use of the photographs provided and did not mind whether her real name or a pseudonym was used for quotes from her interview. Finally, one individual chose a pseudonym to be used in relation to any quoted text or use of photographs. All references to these participants on spreadsheets, transcripts and questionnaires are identifiable by use of their pseudonym. Conversely, the names of those participants who asked to waive their right to anonymity have remained in transcripts, analysis and the write up of the findings from these studies. The names and contact details of participants were stored on a password protected computer, only accessible by the researcher. It is perhaps surprising that so many participants chose to waive anonymity, although the reasons for this were not explored. Rather than make any assumptions as to why this may be the case, it does indicate that given choice some women may not wish to have their voices anonymised but wish to ensure their experiences are heard.

5.3.2 Ethical considerations regarding visual data

The U.K. Data Protection Act 1998 states that photographs of individuals are personal data (Reavey & Prosser, 2012). At the briefing meeting, I highlighted a need to talk about consent for onward use of photographs post interview and that discussions about copyright would form part of our next meeting. Through raising the issue of onward use at this stage, I felt it enabled women to make decisions about what they wanted to put into the public domain and what they wanted to use to discuss issues relating to their experiences. Photographs are also significant in giving increased access to spaces and places that would generally be hidden from researchers using non-visual methods (Frith & Harcourt, 2007). I was conscious of my role in asking individuals to share ‘glimpses’ (Silver, 2013) of their personal experiences and was mindful to enable women to determine what they wished to share.

Following discussion of the photographs in interviews, permission was sought from participants to use the photographs during the transcription process, analysis, the write up of my study and for onward dissemination. During each interview, any sensitivities to onward use of photographs were noted. Each photograph was reviewed to ensure permission for use was given. Where participants asked for a photograph not to be included in onward dissemination, I asked the participant to indicate this on the copyright release form (Appendix 20). Six participants signed the copyright release form³⁴ without any restrictions placed on ongoing use. Three asked for specific photographs not to be used³⁵.

When analysing the data, ethical questions began to arise over whether all photographs given consent for onward use, could be used. For instance, some photographs included family and friends. This was unsurprising, given the significance of social support in psychosocial health (see section 2.3.2). This question arose in relation to the inclusion of children in photographs. Only two women included images of their children and did so to convey the impact LwBBC has on the family unit. There is an assumption that people captured in images have actively consented to being represented within a portfolio of photographs for a research study. However, I did not ask the photo-production participants if they had informed others as to

³⁴ Permissions for image use are detailed in Appendix 19

³⁵ In two instances, this was because the participant realised during the session that they had inadvertently identified others in an online closed Facebook group without their consent. One participant had taken a number of photographs that demonstrated her vulnerability while going through chemotherapy. She asked that a number of photographs which were identifiable as her not be used in onward dissemination.

how the images would be used. That said, women took photographs to represent important aspects of their experiences of LwBBC. Therefore, to decide not to include images because of these ethical concerns, without further discussion with participants, could be construed as silencing topics women wanted acknowledging.

5.4 Data Analysis

Visual and verbal data was analysed by bricolaging³⁶ thematic (Braun & Clarke, 2006), polytextual thematic (Gleeson, 2011) and the voice centered relational methods (VCRM) (Brown & Gilligan, 1992). Thematic approaches to analysis can be used to “endeavour to understand participants’ experiences within the context of society” (Chen, 2014, p.121). The primary focus of qualitative research is the understanding of linguistic meaning within textual material (Madill, Jordan & Shirley, 2000). Thematic analysis is “a method for identifying, analysing and reporting patterns (themes) within data” (Braun & Clarke, 2006, p.79) and can be used across different methods (Boyatzis, 1998), including visual methods (Willig, 2013).

Within this study, meaning was also available for interpretation from the photographs provided by participants. The literature relating to ‘how to’ thematically analyse photographs was identified by Gleeson (2011) as limited. To fill this methodological gap, she developed ‘a recipe’ - a set of prescribed steps to support the researcher in conducting a polytextual thematic analysis, which was influenced by the work of Braun and Clarke (2006). This is reproduced in Appendix 22. Polytextual thematic analysis “assumes the visual, verbal and the written must be read in conjunction with one another” (Reavey, 2011, p.xxxix). Despite Gleeson’s endeavours to support other researchers in the analysis of visual materials, examples of studies using polytextual thematic analysis remain scarce. I adapted my approach to polytextual thematic analysis from the steps outlined in Gleeson’s recipe by considering the photographs separate to and in conjunction with women’s spoken text. The overall process I took to analysis is shown in Figure 5-4 and broadly follows the six stages of thematic analysis developed by Braun and Clarke (2006).

³⁶ Bricolaging means ‘weaving together’ (Yardley, 2008)

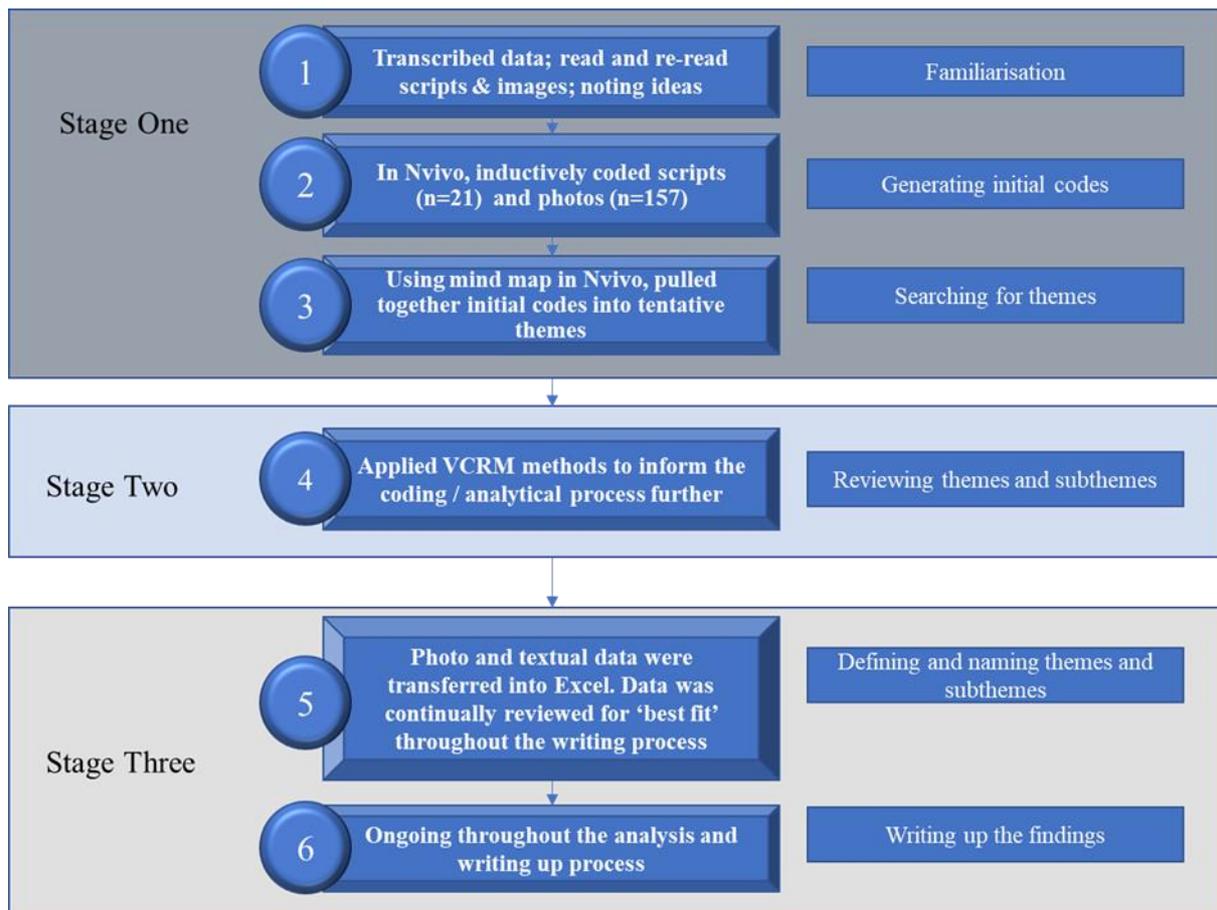


Figure 5-4 Data analysis process flowchart

5.4.1 Stage One: Familiarisation, generating initial codes and searching for themes

5.4.1.1 Familiarisation through transcribing interviews

Familiarisation began with the transcription of interviews. While interviews were at times long, they were expressions of women's personal experiences of breast cancer in the context of their lives. I took the position that to determine what should and should not be included in the transcription process in terms of the overall interaction between the two of us would be demonstrative of an unequal balance in the relationship between researcher and participant. It was therefore key to transcribe all interviews in their entirety from the moment the audio tape was turned on to when it was turned off. Given my interest in 'voice', I transcribed interviews including pauses, errs and umms. Silverman (2017) argues that because meaning is an interactional accomplishment, transcripts need to retain the basic features of interactions between interviewer and interviewee including response tokens, such as 'mm' and pauses. By transcribing all aspects of our conversations, the pauses and silences that were captured on

the page, enabled me to begin to hear when women experienced dissonance in how women spoke about their experiences (Woodcock, 2010).

Given the length of the interviews, a confidential external transcription service was used to transcribe seven photo-production interviews (ethical approval HSCR 15-71: April 4, 2016). In these seven interviews, participants had waived their rights to anonymity. The eighth interview had already been transcribed and the ninth interview was to be transcribed by myself as the participant had asked for anonymity. Tilley and Powick (2002) studied researchers' use of transcriptions produced by transcribers and raised issues related to the absence of any direction given by researchers to transcribers; researchers' use of the transcript without returning to the original data; and the omission or alteration of words by transcribers (Davidson, 2009). With these criticisms in mind, I checked transcripts on their return by listening to and watching the video of the interview. Using 'track changes' (Appendix 23) on Word (2016), where issues with transcription occurred these were amended accordingly. There were issues in relation to the use of technical terms that were unknown to the transcriber, for instance 'core biopsy' was transcribed as 'pore biopsy'. On occasion, comments made by the participant had been misheard, for instance the transcript read '*and it's all fun*' when the participant had said '*and it's awful*'. Through moving between the external transcription and the video playback and amending as necessary, I was able to ensure the transcript was trustworthy (Tilley & Powick, 2002). This process also enabled re-engagement and familiarisation with the way women spoke about their experiences, supporting the first stage of thematic analysis.

5.4.1.2 *Generating initial codes and searching for themes*

Initially, I began coding transcripts on paper. However, with lengthy interviews it soon became apparent that use of computer assisted qualitative data analysis software (CAQDAS) may be beneficial. I uploaded all interview transcripts and photographs into Nvivo 11 to support inductive coding. Photographs were included in the transcript, at the point at which they began to be talked about, to keep discourse and visual input in relation to one another. I also uploaded each photograph as a separate internal source file enabling coding specifically related to the image (Figure 5-5).

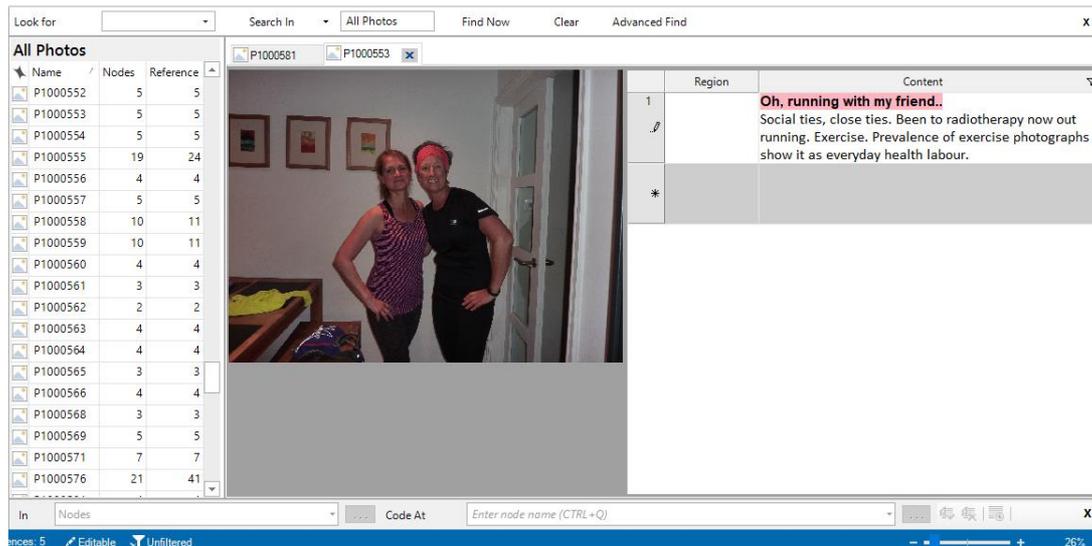


Figure 5-5 Early coding of photographs in Nvivo

The coding process involved reading and re-reading the transcript, highlighting text and assigning the text to a relevant node, to enable later retrieval. Bernard and Ryan (2010) indicate that coders tend to be either ‘splitters’ – those who look for fine grained themes – and ‘lumpers’ – those who look for overarching themes (cited in Bazeley & Jackson, 2013). Given the exploratory nature of the study, I looked for fine-grained themes. Figure 5-6 below, depicts the early stages of thematic analysis using NVivo’s mind map function. It shows a myriad of adult, child and grandchild nodes generated from the analysis at the end of stage one.

It became evident very quickly, that capturing data into node ‘silos’ (Bazeley & Jackson, 2013) decontextualized the data (Condie, 2013). I struggled to analyse ‘what was going on here’ (Suter, 2012). While Nvivo allowed me to pull together all aspects of scripts and images under one node for further analysis and write up, I found this process failed to meet my own aims for this study. This approach gave me limited sense of women’s voices. I felt distanced from women’s experiences; had no coherent overview of social media use across the different groups of women; and produced ‘analysis’ which was descriptive rather than interpretative. I was concerned that my pulling together of themes using the data coded into large ‘silos’ shifted the balance from hearing and understanding women’s experiences of social media use to hearing and understanding my broad interpretations of women’s experiences of social media use.

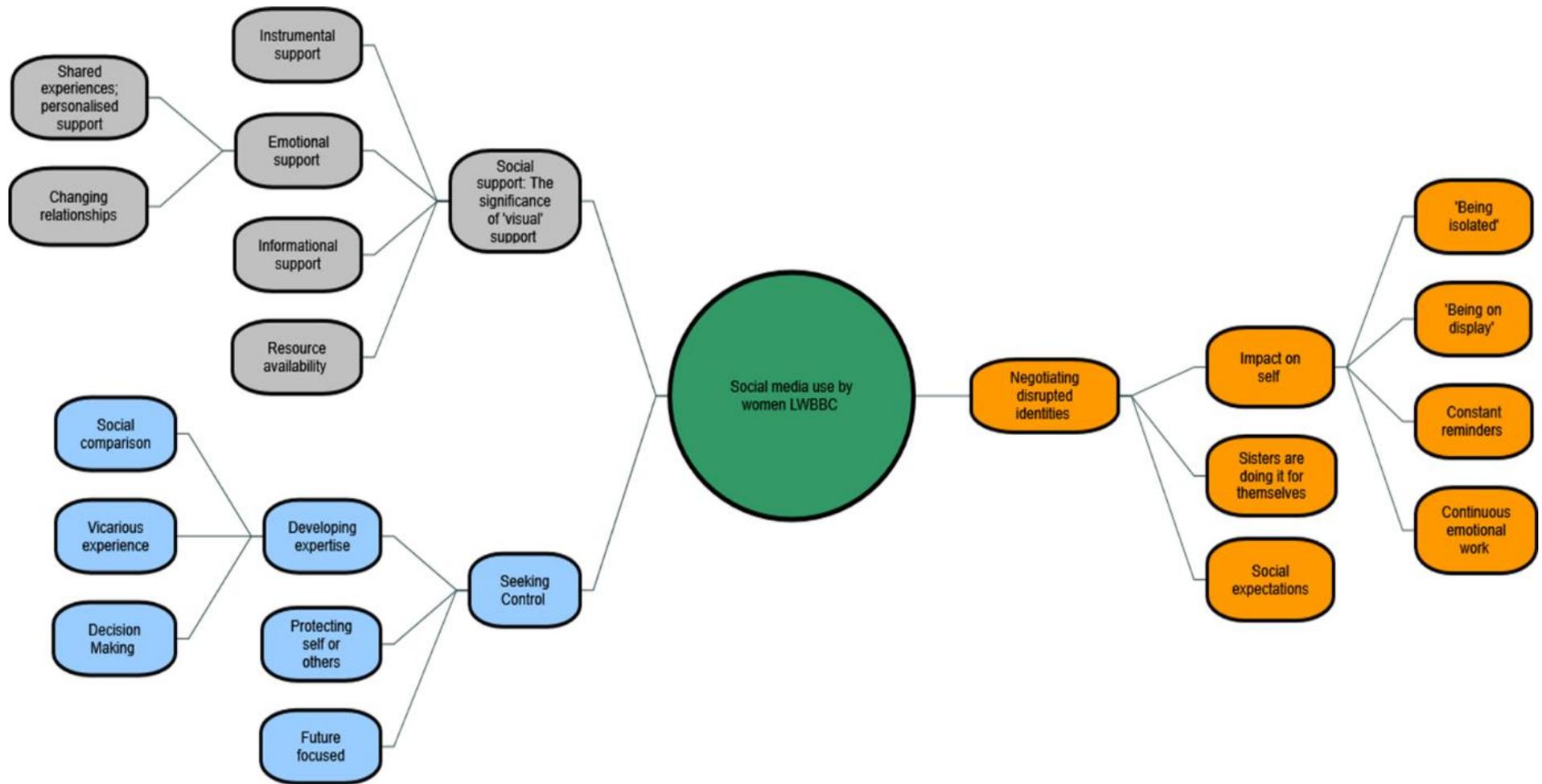


Figure 5-6 An iteration of thematic development at the end of stage one

5.4.2 Stage Two: Reviewing themes and subthemes by listening for voice

I decided to adapt the approach I was using to thematic and polytextual thematic analysis to ensure, methodologically, I was listening to women's voices and able to convey their voice. To achieve this, I adapted Brown and Gilligan's (1992, 1993) Listening Guide (LG) and applied this approach to the thematic framework under development. The Listening Guide is a practical step by step "qualitative, relational, voice centered methodology used for listening to narratives of a relational nature" (Woodcock, 2010, p.145). This method brings the researcher more into relation with each person by being attentive to 'voice', of how women speak of themselves in relation to others and their relationships with the broader social and cultural contexts in which they live (Brown & Gilligan, 1992; Doucet & Mauthner, 2008; Gilligan, Spencer, Weinberg & Bertsch, 2003; Raider-Roth, 2005; Woodcock, 2010). The Listening Guide involves multiple readings described as 'four listenings or readings' (Brown & Gilligan, 1992; Doucet & Mauthner, 2008; Mauthner & Doucet, 1998; Raider-Roth, 2005; Woodcock, 2010) which involve active documentation of the process of analysis. This seemed to offer a more step by step approach to exploring how women spoke about their experiences. The addition of this relational approach enabled me to hear women's stories in a different way, through hearing intricacies that I had previously not heard, and through hearing and seeing how women used different voices in their conversations with me. Attention is paid to shifts in the sounds of the voice as women tell their stories and the use of first, second or third person narration (Brown & Gilligan, 1992). Through this approach I was more able to locate the speaker in the story she told.

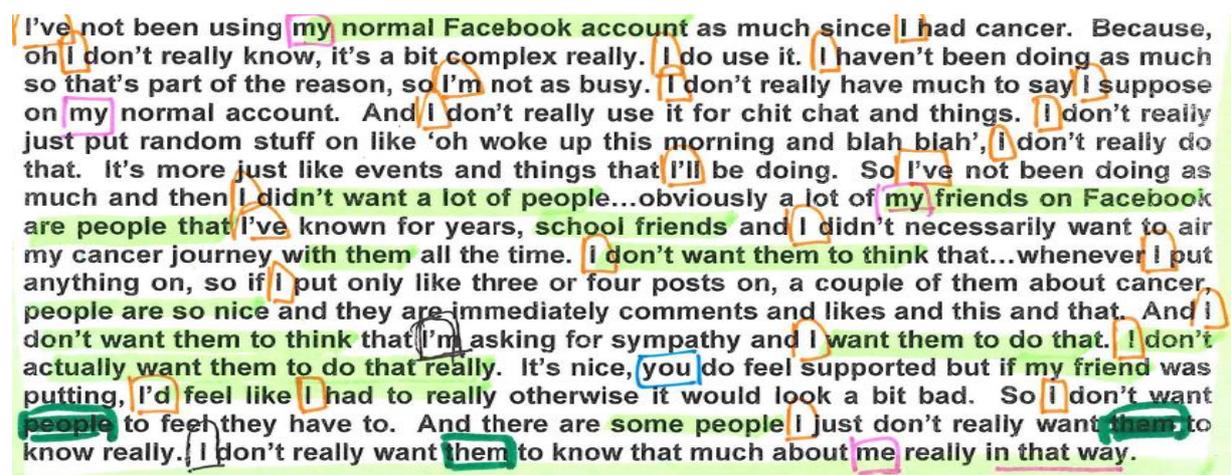
With the initial Nvivo coding in mind, I returned to one of the participant's transcripts and completed the four stages of listening for voice outlined in the VCRM method. I first re-listened to the audiotape to gain an overview of the experiences shared. I listened for emotional resonance, repeated words, phrases, images, and comments that jumped out, contradictions, omissions and revisions. I noted silences – manifested as pauses, the lowering of voices or allowing voices to trail off.

I then carried out the second listening of the transcript. This reading of the text focuses on how each woman's experiences, feels and speaks about herself by tracing the 'I', 'we' and 'you' in the transcript using coloured pens. The shifts between 'I', 'we' and 'you' signals changes in how the individual experiences and perceives herself. Through this approach, it is

possible to see how the individual speaks for herself, “before we speak for her” (Brown & Gilligan, 1992, p.27-28). An important aspect of the second listening is to extract a series of ‘I’ statements from the transcript and create a voice poem or ‘I’ poem. These draw out the internal conversations as individuals move between ‘I’s’ and ‘we’s’ and ‘you’s’. These are interpreted as internal dialogues and or dissonance within the individual. An example iPoem is provided in Appendix 25.

In the third reading, I traced how women spoke about their relationships. I listened for the use of a ‘caring’ voice concerned with the complexities of creating and sustaining relationships. I considered this particularly pertinent to social media use, and concerns about listening and being listened to; and, responding and being responded to came to the fore.

In the final reading, I identified when women situated their experiences within the broader social and cultural contexts. This approach to tracing voice (Figure 5-7) is purposeful as it leads to a ‘trail of evidence’ to later support claims made (Brown, Tappan, Gilligan, Miller & Argyris, 1989; Raider-Roth, 2008; Woodcock, 2010).



I've not been using my normal Facebook account as much since I had cancer. Because, oh I don't really know, it's a bit complex really. I do use it. I haven't been doing as much so that's part of the reason, so I'm not as busy. I don't really have much to say I suppose on my normal account. And I don't really use it for chit chat and things. I don't really just put random stuff on like 'oh woke up this morning and blah blah', I don't really do that. It's more just like events and things that I'll be doing. So I've not been doing as much and then I didn't want a lot of people...obviously a lot of my friends on Facebook are people that I've known for years, school friends and I didn't necessarily want to air my cancer journey with them all the time. I don't want them to think that...whenever I put anything on, so if I put only like three or four posts on, a couple of them about cancer, people are so nice and they are immediately comments and likes and this and that. And I don't want them to think that I'm asking for sympathy and I want them to do that. I don't actually want them to do that really. It's nice, you do feel supported but if my friend was putting, I'd feel like I had to really otherwise it would look a bit bad. So I don't want people to feel they have to. And there are some people I just don't really want them to know really. I don't really want them to know that much about me really in that way.

Figure 5-7 Early testing of use of the Listening Guide

By fusing this approach with the coding already completed, I was able to refine the themes and sub-themes through a re-engagement in listening to the voices of women. I listened for signs of self-silencing, times when a woman buries her feelings and thoughts and manifests confusion, uncertainty, and dissociation. While Brown and Gilligan (1992) explored self-silencing as markers of a ‘psychological resistance’ (p. 30), these markers enabled me to

listen to aspects of women’s experiences of LwBBC that would have gone unnoticed utilising my initial approach to analysis.

I tested out the process of four listening’s with three different interviews using paper-based transcriptions. Having developed confidence in the process as one that supported the refinement of thematic development, I adapted the approach further using Excel.

5.4.3 Stage Three: Using Excel to support interpretation

Through using the four readings approach with three transcripts, the broad themes identified through Nvivo coding (Figure 5-6) – i) support ii) navigating disrupted identities and iii) seeking control seemed to be broadly validated. As I worked through each transcript using the voice centered relational method, sub-themes began to be refined. To aid visualization of themes and sub-themes, I set up an Excel spreadsheet for each participant. I divided the spreadsheet into the three themes. For each theme, I created columns for the sub-themes under consideration with an ‘analysis’/’notes’ column between each subtheme (Figure 5-8).

B	C	D	E	F	G	H	I	J
Rels with HCPS's	Notes	that 'fits with my life'	Notes	Doesn't work for me	Notes	Mining for information	Notes	We gee each other al
Identity								
Looking for someone like me	Notes	Challenges to physical identity	Notes	Challenges to 'social' identity	Notes	Having 'real' conversations	Notes	Managing ongoing ef
Control & expertise								
Want to know what it was like	Notes	Sisters are doing it for themselves	Notes	Protecting self and others	Notes	Knowledge is power	Notes	Seeing the positive

Figure 5-8 Using Excel to refine themes and subthemes

In the first column, I added the key platforms women were talking about through their interview. For instance, for one participant this was Facebook, Twitter, YouTube, Pinterest, Google, WhatsApp, and FaceTime. I then cut and pasted relevant content from the transcripts into the different cells in Excel. This was achieved by moving between the narrow coding

completed in Nvivo with wider sub-themes set up in Excel developed from the initial grandchild, child, adult node coding framework in Nvivo. This ensured a checking of earlier coding against the wider sub-themes. Annotations made in Nvivo during the initial coding process were transferred to the analysis boxes in Excel to ensure my early analytical thoughts remained in relation to the originally coded text. By using Excel in this way I was able to visually see coded data in relation to each theme and in relation to each platform; how these differed across individuals; and across groups (under 12 months, 1-5 years and 5 years plus). I then read through the cut and pasted quotes in each cell and applied the listening guide approach to analysis. I read for three relationships using colour coding as described above: i) reading for the ‘I’/listening for self ii) reading for ‘they’/ listening for the other – self in relationship to other; iii) reading for self in relation to society (Figure 5-9).

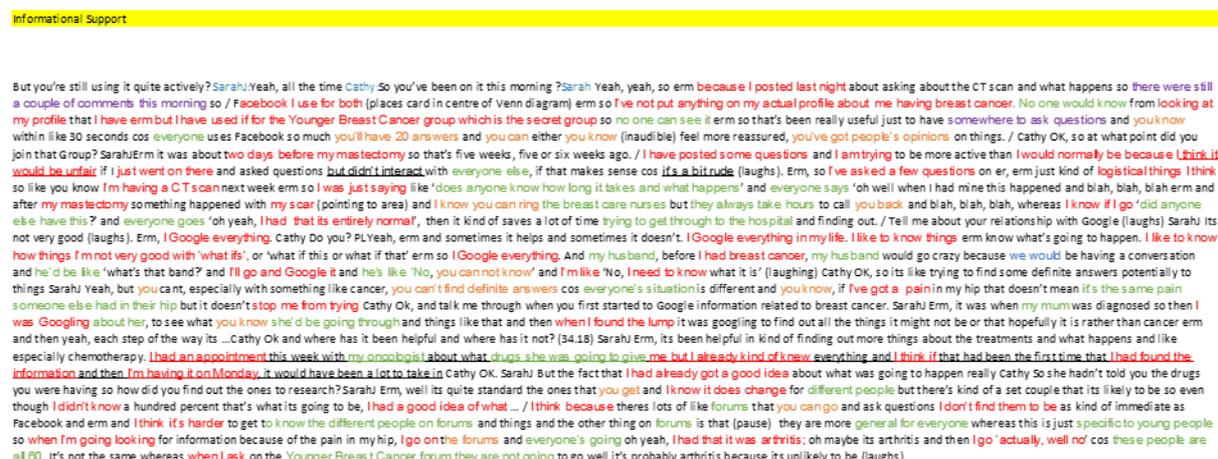


Figure 5-9 Demonstrating the colour coded approach to listening to participants' voice

In the ‘Notes’ column (Figure 5-8), I wrote notes and interpretation. Analysis of the photographs was also noted in the relevant cells. Where there was overlap between sub-themes, this was noted for further consideration as analysis progressed through writing up. As I read, I also reflected on strong and weak ties/ bonding and bridging capital (section 3.1.2) and how voice changed in relation to different strengths of ties. I also noted examples of directed communication, consumption, broadcasting and passive consumption (Appendix 2). This process enabled reflection on the conceptual challenge of ‘what fits where’. It demonstrated the inter-connectedness of sub-themes as women shifted in dialogue between one train of thought and another and the dynamic nature of voice to invoke several themes simultaneously.

The final stages of analysis broadly followed Braun and Clarke's thematic analysis framework, although the dynamic nature of reviewing themes, defining and naming themes was more of a cyclical, ongoing process than the linear process implicated in Braun & Clarke's written framework. For instance, as analysis moved from one group (women diagnosed within the preceding 12 months) to the other groups, changes in how women talked about their social media use led to ongoing reflection on how women's stories of support for instance connected and differed along the 'living with and beyond' trajectory. Analysis continued during the writing up of the findings with the pulling together of the individual analysis made for each sub-theme into a coherent narrative of 'thick description' (Geertz, 1973).

5.4.4 Participant feedback

The process of engaging participants to check 'credibility' (Lincoln and Guba, 1985), post interview, has been discussed in the literature in many different guises including member checking, participant validation, respondent validation and member reflections (Thomas, 2017, p.26) A review of the literature critiques Lincoln and Guba's argument that member checking is essential to establish credibility. (Thomas, 2017). Thomas concludes after reviewing 44 published sources that there is "no evidence that routine member checks enhance the credibility or trustworthiness of qualitative research" (p.37). He argues however, that there is evidence to support member checking as useful to check representation. Given the focus on 'voice', it was always conceived that women would be involved in further considerations of the findings. However, early in the research process, a pragmatic decision was taken to not return transcripts to participants. The interviews used numerous visual materials. Reading the transcripts without access to the video film recording would have not made much sense to participants. During the transcribing process, much use was made of the video footage to check what activity the participant was involved in and what they were talking about as they moved visual images around on the Venn diagram or talked through their photographs.

I did however have email contact with participants between the time of interview and availability of research findings. At different intervals, I would update participants on my progress. On occasion participants would provide an update on their current use of social media. I emailed participants prior to forwarding the research findings to ask them whether

they wanted to receive them. I did not assume that women would want to revisit discussions. As Frith (2011) noted participants may have moved on from or have actively forgotten experiences that were difficult. Eighteen participants (86%) asked to receive the findings. Three photo-elicitation participants did not respond to emails. The summary of findings invited participants' comments and were sent to participants by email (Appendix 26). Participants were encouraged to make contact by phone or email if they had queries regarding the findings or to make further comment. Nine participants (50%) responded. All were supportive of the findings. Some offered comments about aspects of the findings which resonated. A sample of these are included and discussed in the Discussion (Chapter 10: section 10.1). Others offered thanks for being given the opportunity to read the findings:

'Many thanks for allowing me to read your report and also my pen portrait. Very interesting read. I recognise some of the things we talked about and hope it will be a useful and informative read to others. I have no amendments to make to either document' (Photo-elicitation: Millie)

5.5 Conclusion

This chapter outlines how the research was carried out and explains the decisions made relating to sample, data collection, data analysis and disseminating findings to participants. The next chapter begins to provide context by introducing the twenty-one participants and detailing the platforms they use. It concludes with an overview of the themes generated from eleven photo-elicitation and nine photo-production interviews with women LwBBC.

Chapter 6: My participants and their social media use

6.0 Introduction

This chapter introduces my participants and their social media use. It is divided into four parts. Part one introduces each participant through a pen portrait. The second part provides a demographic overview of the participants as a group. The third part discusses the descriptive data gained from the completion of the social media audit (Appendix 18). Finally, the chapter concludes by setting out the three key themes and subthemes identified through the analysis processes.

6.1 Participants' pen portraits

To help situate the analysis, I have adopted the approach used by Edmondson (2013), in her poly-textual thematic analysis of self-harm and introduce each of the women with a short description. These descriptions demonstrate the complicated aspects of women's lives and contribute to giving 'voice' to participants. They give 'voice' in two ways. Firstly, the introductions add rigour and trustworthiness (Elo et al., 2014) in that they provide significant context. Secondly, participants were asked to contribute to and amend pen-portraits as part of the participant feedback process. Most women were happy with the pen portraits they reviewed. Two asked for changes to be made. One wished to use her real name but wanted changes made elsewhere to limit identifiability. Another rewrote her pen portrait in full. These changes were incorporated into the respective individuals' pen portraits as requested.

In the next section, the participants' pen portraits are presented in groups. These relate to time since diagnosis and the type of study participated in (photo-elicitation or photo-production). Each pen portrait is accompanied by a short summary of social media used for general use and platforms used in relation to LwBBC. For those participating in the photo-production study the number of photographs taken is detailed. An image accompanies each pen portrait. For those participating in the photo-production interviews, one image from those provided by the individual was selected. For those that participated in the photo-elicitation study, an image has been included to support the idea of visualising voices through showing the images women 'spoke to' when they talked about social support or their social media use.

6.1.1 Participants: diagnosed in the preceding 12 months³⁷

6.1.1.1 Photo-elicitation study participants

Sarah M



<i>Social media platforms used in relation to LwBBC:</i>	<i>Facebook, FaceTime, Instagram, WhatsApp, Wikipedia, YouTube (6).</i>
<i>Wider social media use³⁸:</i>	<i>Picasa, Pinterest, Snapchat, Yahoo (4).</i>

Figure 6-1 Sarah M - photo-elicitation images used

Sarah (27)³⁹ heard about the study via the YBCN group on Facebook. She is married with two young children, Sarah was an undergraduate at a local University in her second year. We met five months post diagnosis, prior to her final chemotherapy session. Sarah had had a lumpectomy, radiotherapy and was to take Tamoxifen for 'five to ten years and then that should be it'. This was the second interview undertaken and the shortest at 55 minutes.

Sheena



<i>Social media platforms used in relation to LwBBC:</i>	<i>Twitter, Pinterest (2).</i>
<i>Wider social media use:</i>	<i>FaceTime, LinkedIn, Instagram, WhatsApp, Wikipedia, Yahoo, YouTube (7).</i>

Figure 6-2 Sheena - photo-elicitation images used

Sheena saw details of the study on Twitter. Sheena (49) was diagnosed following extension of the breast screening trial.⁴⁰ We met approximately seven weeks post-mastectomy. This

³⁷ At time of interview

³⁸ Not related to LwBBC

³⁹ All ages provided in participant biographies are age at time of diagnosis.

⁴⁰ The NHS Breast Screening Programme (GOV.UK, 2014) starts for women after their 50th birthday, but a trial extension of the scheme to those aged 47 and above, identified abnormalities when Sheena was screened.

followed an earlier lumpectomy. She talked about ‘*feeling in a good place*’ with much of her support coming from ‘offline sources’. Sheena works full time; has four children and a partner.

Sarah J



<i>Social media platforms used in relation to LwBBC::</i>	<i>Facebook, Pinterest, Twitter, WhatsApp, Wikipedia, YouTube (6).</i>
<i>Wider social media use:</i>	<i>FaceTime, Flickr, Hootsuite, Instagram, LinkedIn (5).</i>

Figure 6-3: Sarah J - photo-elicitation images used

Sarah (29) saw details of the study on the YBCN Facebook page. We met five weeks after her mastectomy. She was about to start chemotherapy treatment. Sarah is married and works full time as a healthcare professional. She talked animatedly about her social media use, particularly in relation to maintaining her privacy and managing numerous friendship groups, principally using WhatsApp.

Denise D



<i>Social media platforms used in relation to LwBBC:</i>	<i>Facebook (1).</i>
<i>Wider social media use:</i>	<i>Twitter, Wikipedia, WordPress, YouTube (4).</i>

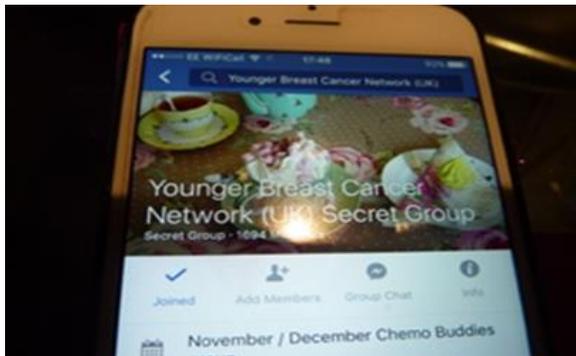
Figure 6-4 Denise D - photo-elicitation images used

Denise (64) is retired and married with two grown up children and three grandchildren. She heard about the study from a colleague of mine. We met in a meeting room local to her home as she lived some distance from Salford and was not keen to travel. She was diagnosed with Ductal Carcinoma in situ (DCIS) in December 2015 and had a lumpectomy in February 2016 at which time she felt the cancer had ‘*left her body*’. She had just had her first chemo session

and her hair was beginning to fall out. Later she was due to have radiotherapy. She was full of energy, talked optimistically about the future and with huge passion about her family.

6.1.1.2 *Photo-production study participants*

Michelle J



<i>Social media platforms used in relation to LwBBC:</i>	<i>Blogger, Facebook, Instagram, WhatsApp, Wikipedia, WordPress, YouTube (7).</i>
<i>Wider social media use:</i>	<i>FaceTime, Picasa, Twitter, Skype, Snapchat (5).</i>

Figure 6-5 Michelle J Image 7

© Michelle / 29.02.16/ University of Salford / Cathy Ure

Michelle (38) saw details about the study on Facebook. Michelle comes from a large family; is a staff nurse on an acute ward; married and has three children. Michelle had a lumpectomy; radiotherapy; and had just finished chemotherapy. She was attending Breast Cancer Care’s Moving Forwards programme⁴¹ when we met. Michelle openly described experiences of fear relating to recurrence and was very articulate about her active seeking of support online and offline. She shared 9 photos during our 89-minute session.

Michelle M



<i>Social media platforms used in relation to LwBBC:</i>	<i>Facebook, FaceTime, WhatsApp, YouTube (4).</i>
<i>Wider social media u:</i>	<i>LinkedIn, Pinterest, Twitter (3).</i>

Figure 6-6 Michelle M Image 9

⁴¹ Breast Cancer Care run The Moving Forwards Programme in partnership with NHS hospitals. The programme usually takes place over half a day for three or four weeks. It aims to provide information, support and professional guidance on how to cope with and adjust to life after breast cancer treatment. Topics covered may include: healthy eating, exercise, managing menopausal symptoms, lymphoedema, cancer fatigue, and intimacy and relationships (Breast Cancer Care, 2018).

Michelle (38) heard about the study via the YBCN group on Facebook. We met for her briefing session and interview between chemotherapy sessions 3 and 4. She had been diagnosed four months previously, just before Christmas 2015. She spoke positively about taking advantage of her time off from her full-time job working to spend time with her two young daughters. She described her diagnosis as “*just a period in my life*” which was not going to ‘define her’. She did not know whether she would need a mastectomy or lumpectomy as initially it had been thought there was one tumour but now “*they can see a scattering across the chest*”. She anticipated being on Tamoxifen for five to ten years’ post treatment. Michelle shared 11 images. She had really thought about what she wanted to represent and why. Our interview discussion lasted for 102 minutes.

Kirsty



<i>Social media platforms used in relation to LwBBC:</i>	<i>Blogger, Facebook, Pinterest, Skype, WhatsApp, Yahoo, YouTube (7).</i>
<i>Wider social media use:</i>	<i>Flickr, Instagram, Wikipedia (3).</i>

Figure 6-7 Kirsty Image 12

©Kirsty /15.03.16/ University of Salford / Cathy Ure

Employed in the creative arts industry, Kirsty was 34 when diagnosed. Her treatment included a lumpectomy, chemotherapy, radiotherapy and Tamoxifen. She heard about the study via the YBCN group on Facebook. Kirsty asked at our briefing session whether she could use her own camera and edit the photos she took. Kirsty used her own camera, for which I provided an SD card. Kirsty took photographs during her third round of chemotherapy. Consequently, we met for interview two weeks after briefing as she began to recover. When we met up again, Kirsty provided a file version of all the photographs taken however, we concentrated entirely on 12 edited images. The interview lasted for 126 minutes.

6.1.2 Participants: one – five years post diagnosis.

6.1.2.1 Photo-elicitation study participants

Liz



<i>Social media platforms used in relation to LwBBC:</i>	<i>Facebook, Twitter, Wikipedia, WordPress, Yahoo (5).</i>
<i>Wider social media use:</i>	<i>Google +, Instagram, LinkedIn, Pinterest, Skype, WhatsApp, YouTube (7).</i>

Figure 6-8 Liz - photo-elicitation images used

Liz (51) had links to the University of Salford through her involvement in the WoMMeN (Word of Mouth Mammography e-Network) Facebook group. She was the first participant within the overall study and we met in the Psychology Department at the University of Salford. Liz was diagnosed in 2013, following a routine breast scan, with primary breast cancer. She had a mastectomy, chemotherapy and was taking Tamoxifen. Employed full time, Liz is married and has two daughters.

Jayne

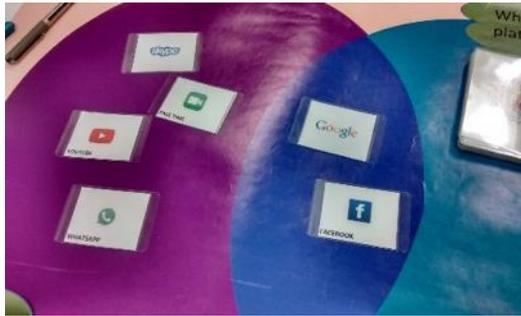


<i>Social media platforms used in relation to LwBBC:</i>	<i>Blogger, Facebook, Pinterest, WordPress, YouTube (5).</i>
<i>Wider social media use:</i>	<i>Delicious, FaceTime, Instagram, LinkedIn, Skype, Tumblr, Twitter, WhatsApp (8).</i>

Figure 6-9 Jayne - photo-elicitation images used

Jayne (44) heard about the study via the YBCN group on Facebook. She was diagnosed with Paget’s disease⁴² of the nipple with high grade DCIS. At the time, she was working full time in academia; setting up her own business; caring for her partner, two children and father (who lived some distance away). She talked at length about the different challenges she faced at that time in her life. She is a prolific user of social media in her professional life.

Jojo



<i>Social media platforms used in relation to LwBBC:</i>	<i>Facebook (1).</i>
<i>Wider social media use:</i>	<i>FaceTime, Skype, WhatsApp, YouTube (4)</i>

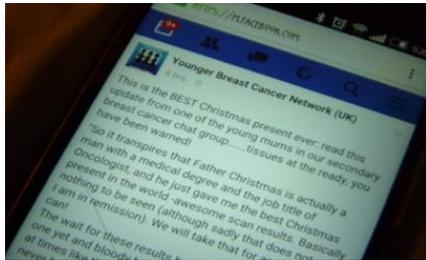
Figure 6-10 Jojo - photo-elicitation images used

Jojo travelled some distance to take part in this study and relied on her sister and niece to bring her as she does not drive. She is part of a large close family. Jojo saw the study posted in the UK breast cancer support group for sufferers and survivors Facebook group. Jojo has Multiple Sclerosis and was in significant pain when walking. Diagnosed with DCIS at 48, she had a mastectomy, chemotherapy and radiotherapy. She is medically retired, single and was, at the time we met largely confined to home because of the pain in her feet. Her role prior to retirement was as a theatre technician where she had helped with mastectomies. She described how she didn’t see women prior to or post-surgery and did not consider how they were feeling. She described focusing on the clinical procedure as a “conveyor belt” with little consideration on the impact and effects on the person. As I said goodbye to Jojo, she commented that I have *“talked to you in a way I haven’t with anyone else. It’s like a weight has been lifted off my shoulders. It’s really good to be able to talk”*.

⁴² Paget’s disease is a sign that there might be breast cancer in the tissues behind the nipple. About half of the people diagnosed with Paget's disease have a lump behind the nipple. In 9 out of 10 cases, this is an invasive breast cancer (Cancer Research UK, 2018).

6.1.2.2 Photo-production study participants

Delphi



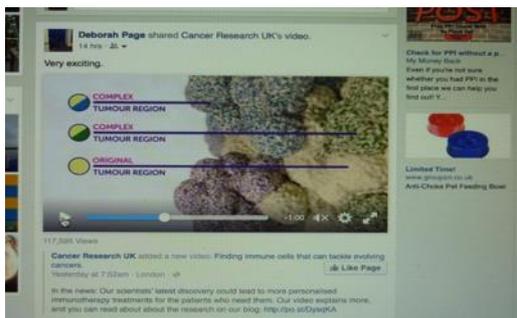
<p><i>Social media platforms used in relation to LwBBC:</i></p>	<p><i>Facebook, FaceTime, Pinterest, Skype, Twitter, YouTube (6).</i></p>
<p><i>Wider social media use:</i></p>	<p><i>Instagram, WhatsApp, Wikipedia (3)</i></p>

Figure 6-11 Delphi Marmaduke Image 9

© Delphi Marmaduke / 05.01.16 / University of Salford / Cathy Ure

Delphi (pseudonym) saw details of the study on the YBCN Facebook page. Delphi has a complex cancer history both personally and within her family. Previously diagnosed twice with cancer (leukaemia and cervical), she was diagnosed with breast cancer at 28, following a misdiagnosis at 27. In relation to her breast cancer, she had a lumpectomy; bilateral mastectomy and chemotherapy. She began to take Tamoxifen but discontinued after three months because of the “*cognitive effects, which is why I don’t take it because I reacted really quite seriously to it. Fatigue is a big one*”. A mother of one, divorced and full time first year PhD student, Delphi described herself as focused on the future and refused, given her extended history with cancer, to be defined by the disease. Delphi described herself as “*not a photo taker*” yet she shared 18 images during our 115-minute discussion.

Deborah



<p><i>Social media platforms used in relation to LwBBC:</i></p>	<p><i>Facebook, Twitter, YouTube (3).</i></p>
<p><i>Wider social media use:</i></p>	<p><i>FaceTime, Pinterest, Skype, Wikipedia, WordPress (5).</i></p>

Figure 6-12 Deborah Image 2

© Deborah / 11.03.16 / University of Salford / Cathy Ure

Deborah (42) is a moderator of the Facebook Breast Cancer group, Younger Breast Cancer Network. She is married with two children (2 and 6 at the time of diagnosis); she is the main

wage earner and works full time as a mental health nurse in a Mother and Baby Unit. Diagnosed in 2013 with primary breast cancer, she had two lumpectomies, radiotherapy and Tamoxifen. Chemotherapy had been offered prophylactically which she declined because of the side effects:

“They said you know, we would still offer it prophylactically and because of your age, but you don’t need it for treatment. Well, then, no, no. Having seen my mum in chemo, I have got a two-year-old, a six year old, I am the main wage earner. I can’t, you know. If I needed the treatment then that is fine, that is a no-brainer. But if I don’t need it...”

At the time of her diagnosis her maternal grandma and her mother were both undergoing treatment for ovarian cancer. Deborah shared 15 photographs in an interview session which lasted 95 minutes.

Nicola



<i>Social media platforms used in relation to LwBBC:</i>	<i>Blogger, Facebook, Flickr, Instagram, Google +, Picasa, Snapchat, Tumblr, Twitter, WhatsApp, WordPress, YouTube (12)</i>
<i>Wider social media use:</i>	<i>LinkedIn, MySpace, Periscope, Pinterest, Skype, Tweetdeck, Wikipedia, Vine, Vimeo, Yahoo (10)</i>

Figure 6-13 Nicola Image 2
 © Nicola /19.03.16 / University of Salford/ Cathy Ure

Nicola (36) and I met on a Saturday morning at The University of Salford building in MediaCityUK. We had spent some time trying to find a suitable date, using direct messaging on Twitter, as she worked part time and had a young daughter to consider in terms of when and how to attend for interview. It has been difficult to meet to pre-brief and so a camera and SD card had been posted out in advance. Nicola had been diagnosed with primary breast cancer four years previously in 2012, and had a lumpectomy, chemotherapy, radiotherapy, Tamoxifen and Zoladex. Nicola is a prolific social media user but unfortunately experienced some issues with taking photographs. Not all the images Nicola had taken were actually captured. She had three images to share in an interview which spanned 109 minutes.

Wendy

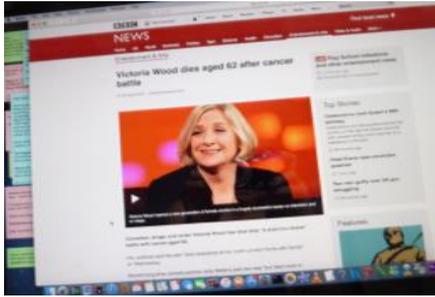


Figure 6-14 Wendy Image 25

© Wendy Northway /28.04.16/ University of Salford / Cathy Ure

<i>Social media platforms used in relation to LwBBC:</i>	<i>Facebook, Vimeo, YouTube (3).</i>
<i>Wider social media use:</i>	<i>Flickr, Instagram, Wikipedia (3).</i>

Wendy (50) contacted me after seeing details of the study in the Macmillan support area at a hospital in North West England. We met for interview in a private meeting room in a community building known to both of us. Through email discussion, when setting up where to meet for the briefing session, Wendy and I realised we knew each other having met once before in relation to a sports club, Wendy was involved with⁴³. She had been diagnosed with primary breast cancer in January 2014, six months after I had previously met her. She had a lumpectomy, sentinel lymph node clearance, chemotherapy, radiotherapy and Tamoxifen. Married, she had taken on a volunteering role at her local hospice post treatment. Wendy shared her social media use through 31 images in an interview which lasted 152 minutes.

⁴³ I had previously escorted Wendy on a tour of a local nature reserve with my Parish Councillor hat on. She came to see if the site could be a suitable location for her sports club to use. She did not know me as a doctoral student interested in social media and breast cancer at that time.

6.1.3 Participants: over five years' post diagnosis

6.1.3.1 Photo-elicitation study participants

Delly



<i>Social media platforms used in relation to LwBBC:</i>	<i>None. Use of the Breast Cancer Care forum.</i>
<i>Wider social media use:</i>	<i>LinkedIn, Wikipedia, YouTube, Yahoo (4).</i>

Figure 6-15 Delly - photo-elicitation images used

Delly contacted me after seeing the study advertised on Breast Cancer Care’s website. Diagnosed with primary breast cancer in 2006, aged 46, Delly was diagnosed nine months later (2007) with primary breast cancer in her second breast. She described limited support except from her mother, limited family, friends and Breast Care Nurses. She attended a breast cancer support group for a number of weeks following, which was helpful in certain respects, but, due to the fact that they were run during the day, it failed to introduce her to women of an alike age or younger. Delly had two mastectomies and has ongoing issues relating to reconstruction. She began to take Tamoxifen six months after her second mastectomy in 2007, however exacerbation of her depression caused her to stop adherence. She is unable to work because of health issues and lives alone. She began using the Cancer Buddy Network, 2014, after picking up an advertising card at the Breast Clinic, found it helpful for support, but it covered many differing forms of cancer, patients/sufferers. She only heard of the Breast Cancer Care forum in 2015, and decided to switch to it, it being more pertinent to her type of cancer, and therefore increased and expanded her contact with other women LwBBC. She very much wished she had joined it sooner, it proving to be “an invaluable source of information, advice and support. I really can’t praise it enough. I’ve advised and encouraged other women I’ve met to join it and wouldn’t hesitate to recommend it” (Delly). But it also presented her with an opportunity to “give something back”, experience, compassion and support wise, to other women “going through similar”. “It’s an understandably traumatic experience, whatever the level, grade, forms of treatment. The more support you can get and

have, the better, and nothing is better than contact with those who've experienced it themselves. I've made many good, and mutually caring supportive friends from the Forum, albeit it's through the ether. Some people actually meet up "in the flesh" and go on to forge strong friendships". (Delly). Delly doesn't use Facebook, she doesn't feel it necessary.

Denise G



<i>Social media platforms used in relation to LwBBC:</i>	<i>Wikipedia (1).</i>
<i>Wider social media use:</i>	<i>Facebook, FaceTime, LinkedIn, Pinterest, Skype, WhatsApp, YouTube (7).</i>

Figure 6-16 Denise G - photo-elicitation images used

Denise contacted me after seeing the study advertised in Breast Cancer Care's 'Voices' magazine. Now self-employed, Denise was 47 when diagnosed in 2007, and teaching music in schools. Diagnosed with DCIS and primary breast cancer she had a lumpectomy, mastectomy, chemotherapy, radiotherapy, and taken Tamoxifen and Arimidex as hormonal treatments. Denise positioned herself at the outset of the interview as 'not really a computer user'. Despite this assertion, Denise uses multiple social media platforms in her day to day life and one in relation to LwBBC.

Eleanor



<i>Social media platforms used in relation to LwBBC:</i>	<i>None (0).</i>
<i>Wider social media use:</i>	<i>Facebook, LinkedIn, Skype, WhatsApp, Wikipedia, YouTube (6).</i>

Figure 6-17 Eleanor - photo-elicitation images used

Eleanor (pseudonym) contacted me after hearing about the study from a colleague. Diagnosed ten years ago, aged 47; Eleanor was diagnosed with a local recurrence in 2010.

She has a lumpectomy, mastectomy, chemotherapy, radiotherapy and hormonal treatments, Tamoxifen, Letrozole and Herceptin. She described herself as ‘not an avid user of social media’, despite this she identified six platforms she has used. Eleanor works four days a week at a University in the North West, is married and has one adult child.

Mandy



<i>Social media platforms used in relation to LwBBC:</i>	<i>Facebook, Skype, WhatsApp, Wikipedia, YouTube (5).</i>
<i>Wider social media use:</i>	<i>Pinterest, Yahoo (2).</i>

Figure 6-18 Mandy - photo elicitation images used

Mandy was coming up to her seven-year anniversary of diagnosis when we met. Diagnosed just after relocating to Manchester and starting an undergraduate course when she was 36, she found herself isolated from a close supportive network when undergoing treatment. She had a mastectomy, chemotherapy and radiotherapy and is continuing to have challenges with reconstruction. Working part time at Christies, as a chemo nurse, in order to ‘give something back’, Mandy is seeking new direction for the future. Mandy was very open and engaging about the challenges she has experienced as a result of LwBBC and her social media use as part of that experience.

Millie



<i>Social media platforms used in relation to LwBBC:</i>	<i>Facebook, WordPress, YouTube (3).</i>
<i>Wider social media use:</i>	<i>LinkedIn, Wikipedia (2).</i>

Figure 6-19 Millie - photo-elicitation images used

Millie (pseudonym) travelled from Yorkshire to participate after seeing details of the study on the Flat Friends Facebook group. First diagnosed in 2002 aged 55, Millie was diagnosed with a local recurrence 11 years later in 2013. She has had a mastectomy, chemotherapy,

radiotherapy and hormonal treatments, Tamoxifen and Letrozole. A single parent when initially diagnosed in 2002, she is now retired and remarried. Millie spoke of the changes that had occurred in the way the NHS shared information between 2002 and 2013 and the differences technological advancements have made.

6.1.3.2 *Photo-production study participants*

Jo



<i>Social media platforms used in relation to LwBBC:</i>	<i>Buffer, Facebook, FaceTime, Google +, Instagram, LinkedIn, Periscope, Pinterest, Skype, Twitter, Yahoo, YouTube (12).</i>
<i>Wider social media use:</i>	<i>WhatsApp, Vine (2).</i>

Figure 6-20 Jo Image 16

© Jo Taylor - abcdiagnosis / 10.12.15 / University of Salford / Cathy Ure

Jo (47) and I were jointly involvement on the University of Salford’s WOMMeN project. Jo is a significant contributor to the group both as its patient representative and as a prolific user of social media. She has 12,300⁴⁴ Twitter followers and an active breast reconstruction information website. Diagnosed in 2007, Jo has been LwBBC for 9 years. Married, her two children were 2 and 5 months old when she was diagnosed. Her treatment has included chemotherapy, radiotherapy, Herceptin, Tamoxifen and Zoladex. In 2014, Jo was diagnosed with secondary breast cancer. She attends hospital every three weeks for treatment and will do so for the rest of her life. When we met for our interview, Jo had been stuck in traffic. We started late and Jo was keen to get to another meeting she was able to be paid for. Despite this, she shared her experiences through 47 photographs during our 86-minute discussion.

⁴⁴ In December 2015, Jo had 6000 followers. On March 20th, 2018, she had 12.3K followers (<https://twitter.com/abcdiagnosis>).

Lizzie



<i>Social media platforms used in relation to LwBBC:</i>	<i>Facebook, Twitter, WhatsApp, WordPress, YouTube (5).</i>
<i>Wider social media use:</i>	<i>FaceTime, Google +, LinkedIn, Periscope, Skype, Yahoo (6).</i>

Figure 6-21 Lizzie Image 7

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Lizzie (pseudonym) was diagnosed with primary breast cancer over 10 years ago, aged 45. She had a mastectomy, chemotherapy and radiotherapy, Tamoxifen and Anastrozole. Prior to being diagnosed she had a senior role in academia; one that was highly pressured but from which she gained considerable satisfaction. When we met, she had just decided to retire. The ongoing effects of treatment meant that her working life had to substantially change and, on her return to work, she moved to a part time role with a much smaller workload. These ‘effects’ continued to create challenges in the workplace. Lizzie described herself as guarded about talking to anyone about her experiences of breast cancer. Lizzie shared aspects of her experiences and social media use through 15 images and in a 78-minute interview. When we concluded she said *‘I’ve talked to you more than anyone else; I haven’t talked about this for as long with anyone’*.

6.2 A demographic overview

Twenty-one women aged between 27 and 64 at time of diagnosis participated in this study. The mean age at time of diagnosis was 39.7 years for women diagnosed within the previous 12 months; 42.7 years for women diagnosed between 1 and 5 years previously; and 44.8 years for women diagnosed over five years previously. Seven women were interviewed in each group. Interviews lasted between 55 minutes and 168 minutes (mean = 99 minutes). 157 photographs were collected from the photo-production study. The total number of images taken by women ranged from 3 – 47 (mean = 17).

Table 7 below suggests potential bias in the study sample, in that the sample is relatively young, with 85.7% of participants under 50. Additionally, the pen portraits (section 6.1)

indicate many women as well-educated and having held professional roles (teachers, professional photographer, healthcare professionals, academics, mature students) although data regarding socio-economic group (based on occupation) and highest educational qualification gained were not captured specifically by the demographic questionnaire (Appendix 17). The pen portraits also indicate the sample to have been predominantly heterosexual, however data specifically identifying sexual orientation was not requested.

Table 7: Participant characteristics (n=21).

	No. of women		No. of women
Age at time of diagnosis		No. of times diagnosed	
<31	3	Once	17
31-40	6	Twice	4
41-50	9	Type of breast cancer	
51-60	2	Primary	11
>61	1	DCIS	4
Marital status		Primary/DCIS	3
Single	5	Local recurrence	2
Cohabiting	2	Secondary	1
Married	13	Treatments received	
Divorced	1	Mastectomy	13
Ethnicity		Lumpectomy	11
White British	19	Chemotherapy	17
Black British	1	Radiotherapy	14
Mixed, multiple ethnicities	1	Tamoxifen	13
Employment status			
Full time employment	7		
Part time employment	4		
Unemployed	2		
Retired	3		
Student	2		
Not working through choice	1		
Unable to work due to health issues ⁴⁵	5		

⁴⁵ When asked 'Are you currently...?' some women selected more than one option, linking their current 'work' status to 'unable to work due to health issues' as an explanation.

6.3 A descriptive overview of social media use

Prior to interview or at the outset of interviews, some women positioned themselves as non-social media users – *‘No, I don’t use Twitter. No. No. No. I am an ignoramus’ (Delly)*.

Indeed, in her pen portrait, Delly described herself as not using “Facebook, she doesn’t feel it necessary”. However, when ‘everyday use’ (see Chapter Three) was recorded, all women used at least four social media platforms. The range and mean of social media use in ‘everyday life’ by participants is detailed in Table 8.

Table 8: Range and mean of overall platform use

Time since diagnosis	Range	Mean
< 12 months (n=7)	5-12	9.14
1-5 years (n=7)	5-22	10.71
5 years + (n=7)	4-14	7.14

While all women used at least four social media platforms for ‘everyday use’, some women were more prolific users of social media platforms. This was the case for women at different times post diagnosis, with 13, 22 and 15 platforms used by a participant within each ‘time since diagnosis’ group respectively.

In comparison, the range of platforms used specifically related to LwBBC was smaller (0-12) (Table 9).

Table 9: Range and mean of platform use specifically related to experiences of LwBBC

Time since diagnosis	Range	Mean
< 12 months (n=7)	1-7	5.00
1-5 years (n=7)	1-12	5.71
5 years + (n=7)	0-12	3.28

All women diagnosed within the preceding five years, used one platform in relation to their experiences of LwBBC. Some women used multiple platforms in relation to their experiences of LwBBC, with eight being used by one women diagnosed within the preceding twelve

months; and twelve by some women diagnosed in the 1-5 year and over 5 years post diagnosis groups. This indicates significant variability in how women engage with social media when LwBBC. For women diagnosed within the preceding 12 months and 1-5 years

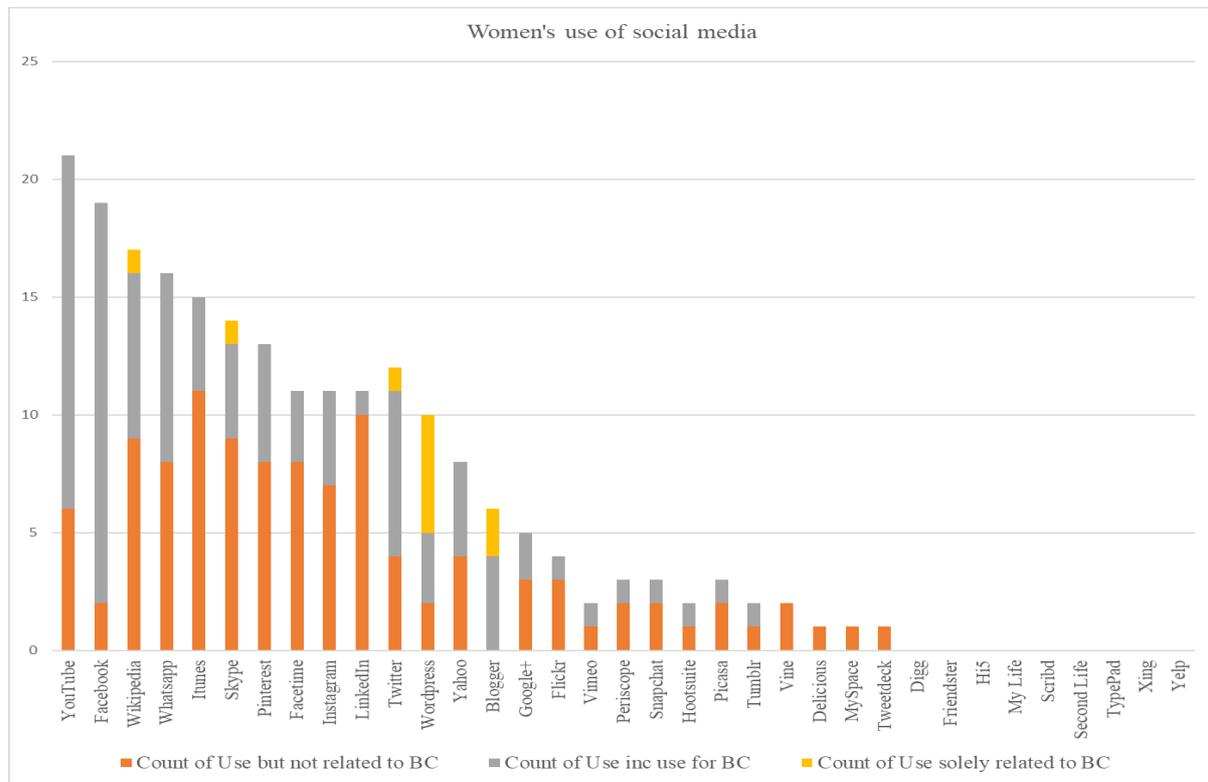


Figure 6-22 Social media use by platform - general use and including use related to LwBBC

previously, the number of platforms used across each group in relation to LwBBC was similar (5.00/5.71). The difference in identifying how women’s ‘everyday’ use of social media platforms differs to how social media is used by women in relation to their experiences provides for the first time a more nuanced understanding of women’s wider social media use. Figure 6-21 provides a graphical representation of social media use by all women participating in this study.

The findings indicate YouTube (n=21), Facebook (n=19), Wikipedia (n=18) and WhatsApp (n=16) to be the four most commonly used social media platforms for ‘everyday’ use. The five most commonly used platforms used in relation to LwBBC were: Facebook (n=17), YouTube (n=15), WhatsApp (n=8), Twitter (n = 7) and Wikipedia (n = 7). Women’s use across all 36 platforms is provided in Appendix 22. In Appendix 22, use is shown in relation to: a) composite use (any use); b) for ‘everyday’ use (not related to LwBBC); c) in relation to

aspects of LwBBC; d) solely related to LwBBC. These descriptive statistics provide one way to explore how women LwBBC use social media. The thematic analysis processes undertaken expanded this understanding.

6.4 Thematic findings

Three main themes were identified (Figure 6-23). These coalesce around three benefits of social media use: support, identity and control. Interestingly, the themes identified early in the coding process and demonstrated in Figure 5-6 remained stable throughout the coding and analysis process. Each theme consists of a number of subthemes, identified in Figure 6-23. Chapters Seven, Eight and Nine will report on each of these themes in detail.

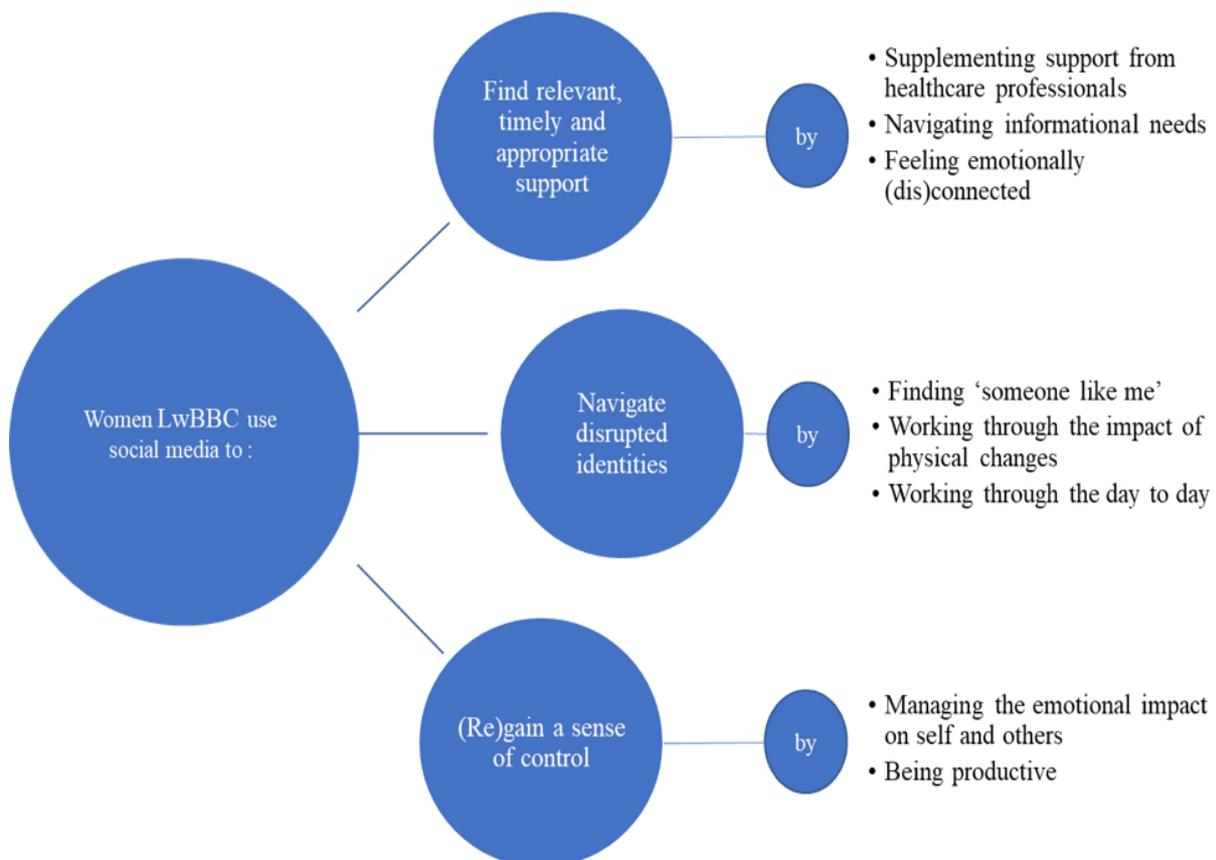


Figure 6-23 Final thematic map showing how women use social media in relation to LwBBC

Chapter 7: Theme One - Finding relevant, timely and appropriate support

7.0 Introduction

This first theme reflects women’s experiences of wanting support, seeking support and finding relevant, timely and appropriate support. Women develop multiple strategies for gaining social support. Support was experienced as both connecting and disconnecting.

Figure 7-1 presents the three subthemes that make up this theme and defines their scope.

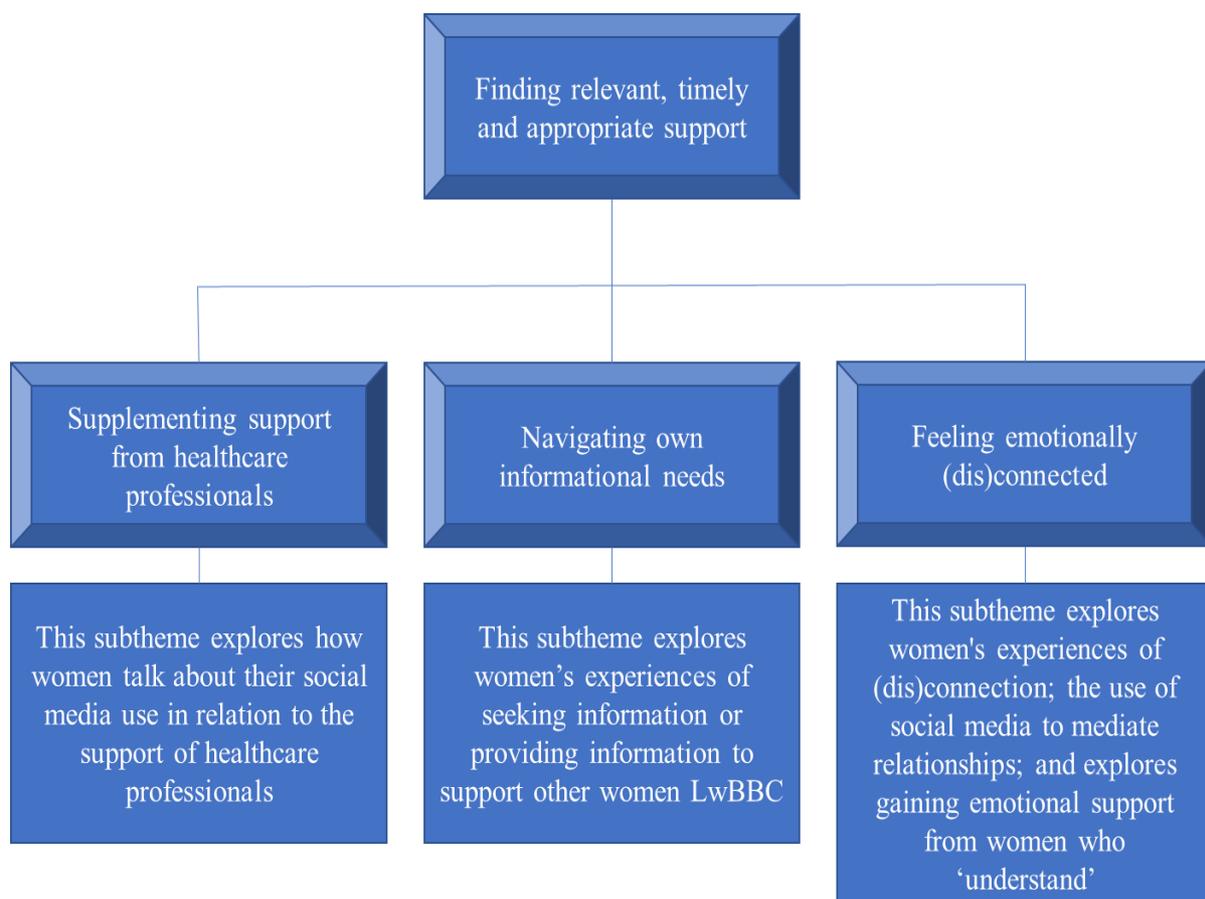


Figure 7-1 Finding relevant, timely and appropriate support - Thematic map

This chapter will explore the three subthemes in detail.

7.1 Subtheme 1: Supplementing support from healthcare professionals



'it's so fast-paced, that um, you know, it's all so clinical, it's like 'in assessment, get the chemo up, next person, in, out, in, out' that's how it is 135 patients a day we have' (Mandy).

This subtheme explores how women talk about their social media use in relation to the support of healthcare professionals.

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Figure 7-2 Supplementing support from healthcare professionals

7.1.1 Introduction

Women talked about accessing support from healthcare professionals⁴⁶. Most of these encounters were in the clinical setting. Women's experiences of access to, and the availability of, healthcare resources relates to women's use of social media for support. This is shown through (i) women seeking to limit demands on healthcare professionals; (ii) photographs de-emphasising the role of the healthcare professional in women's experiences of treatment; and, (iii) the benefits experienced of being able to access immediate support through social media.

7.1.2 Women seek to limit demands on healthcare professionals

Many women talked about contact with their breast care nurses (outside of clinical appointments) as only possible through telephone contact. Women spoke of the restrictiveness of this type of contact: - *'It's always on the phone and I don't like phones so*

⁴⁶ The definition of 'healthcare professional' provided by the World Health Organisation and cited by Smailhodzic et al., (2016) is utilised within this thesis; that is :- 'those who study, advise on or provide preventative, curative, rehabilitative and promotional health services based on an extensive body of theoretical and factual knowledge in diagnosis and treatment of conditions and other health problems' (p. 3).

much (Jayne); *I hate ringing up and mithering the nurses* (Sarah M); *I've only rang twice. They must have lots of other people; women, men, children who need their time and experience, you know, as well* (Denise D). Sarah J voiced concern about not wanting to *'be bothering them with phone calls when they are in clinic'*. The notions of *'mithering'*, *'bothering'* and *'lots of other people who need their time and experience'* demonstrate women negotiating entitlement to care (Sulik, 2007) positioning themselves and their health within a wider cultural framework of publicly funded healthcare provision. Breast care nurses were portrayed as stretched with limited opportunity to support patients. This view was supported by Mandy – a chemotherapy nurse:

'it's so fast-paced, that um, you know, it's all so clinical, it's like 'in, assessment, get the chemo up, next person, in, out, in, out' that's how it is 135 patients a day we have' (Photo-elicitation: Mandy).

Often women only brought their breast care nurses into the conversation after looking at the photo-elicitation photographs (Figure 7-3), they nevertheless expressed strong feelings about the nature of the relationship they had with them.



Figure 7-3 Images of healthcare professionals used in the photo-elicitation study which women responded and 'spoke' to.

Women framed their interactions with breast care nurses as limited by time. *'They never have enough time'* (Jayne); *'they are rushed off their feet'* (Jojo); *'they are really busy'* (Jayne); *'they were there to do their job and go'* (Jojo); *'they didn't have time to talk to you'* (Jojo). Jojo and Millie voiced their experiences of changes in the provision of care within the health service. Jojo drew on personal experience of being an NHS employee to express a view that care provision was universally different *'back in the day'*. Millie supports Jojo's claim. She tracks the changes in her care provision between the time of her primary diagnosis and second diagnosis, eleven years apart:

'I had more contact with my breast cancer nurse then, than I've had this time';

'she used to ring me quite regular to make sure that I was alright. Whereas, the contact has not been the same this time';

'I've just rung when I've got a query, whereas before she rang me' (Photo-elicitation: Millie).

Across the interviews, women were careful to voice support for their breast care nurses despite describing limiting their contact with them outside of the clinical setting:

'Breast care nurses are great, but they never have enough time' (Photo-elicitation: Jayne);

'you've got to understand they are doing their best so I have a lot of time for people like that' (Photo-elicitation: Denise G);

'the breast care nurses but they have a lot...they've got a lot of patients. I didn't like to request too much of them or ask too much of them' (Photo-production: Delphi).

This carefully constructed criticism implicates structural factors as affecting the support provided rather than personal factors. Women therefore take a protective stance towards the breast care nurses employed to support them. By limiting their 'demands' for care by not 'mithering' or 'bothering' and attributing the limited opportunities for interaction to structural constraints, women put others needs including the needs of the breast care nurses before their own. At the same time, there is notable media reporting on 'rationing' or reductions in access to NHS healthcare (Charles, 2017). This includes restrictions to access to drugs, equipment, surgery and other procedures, as well as increased waiting times for treatment. Explicit public messages of pressure on health services frame patients' stories of cautious healthcare use in the primary setting (Llanwarne, Newbould, Burt, Campbell & Roland, 2017). These findings demonstrate women LwBBC as cautious users of secondary⁴⁷ healthcare resources when not physically in the secondary healthcare setting and point to social media as a resource to supplement conversations with healthcare professionals. Rupert et al., (2014) reported that users of online health communities (n = 89) also described healthcare professionals as "too busy for detailed discussions" (p.320). To what extent the wider social and cultural focus on perceived pressures on the NHS influence women's

⁴⁷ Secondary healthcare is sometimes referred to as 'hospital and community care' ("The NHS provider sector", 2018).

choices as to where they source support is not known. Similarly, it is unknown to what extent patient's decisions to access support from elsewhere relieve demands on clinical service provision or how alternative channels of support, via social media, mediates this decision-making. Women's accounts however do suggest that their use of social media platforms is changing aspects of their relationships with primary and secondary healthcare providers:

'I mean I've tried to make appointments with my GP, but you know the way things are going with the NHS and all that, it's like three weeks until my next appointment. I don't need to now I just go on the group and think 'oh, OK, alright yeah' (Photo-elicitation: Jojo).

7.1.3 Photography limits the significance of support from healthcare professionals

The photo-production study provided women with opportunities to acknowledge their healthcare professionals as providers of support. Both Kirsty and Jo chose to take photographs during the week they received treatment. They both commented on how attending clinic was ideal for capturing photographs about how they communicate their experiences of LwBBC to others. Kirsty took two images in the chemotherapy unit (Figure 7-4). Notably, the focus of her photographs is on the processes involved in treatment and the environments in which they take place. These are the focus of her experiences rather than the relationship she experiences between healthcare professional and patient. While Kirsty had been keen to take photographs in the chemotherapy unit she also acknowledged a sense of discomfort in having a camera with her in this particular space:

'There was a lady sitting just here and a couple of other people. There were quite a lot of people in actually. So, I didn't want to get everyone, people were looking at me like why have you got that big camera in a chemo lounge as well, so I felt a little bit, I didn't want to be snapping away. In case people didn't feel well' (Photo-production: Kirsty).

Kirsty describes being concerned about 'people' looking at me. Her comments suggest concerns about other patients - 'there were quite a lot of people in actually' - and her relationship with them. She does not refer directly to clinical staff or suggest that they were unhappy with being photographed or a camera being in the unit. It is almost as though they are not part of the conversation; her experiences revolve around her clinical experience and that of other patients.



Kirsty: Image 1



Kirsty: Image 2

Figure 7-4 Capturing images of the chemotherapy unit
 © Kirsty /15.03.16/ University of Salford / Cathy Ure

Jo's photographs of clinical spaces and equipment also represent experiences as biomedical, institutionalised and isolated or isolating (Figure 7-5).



Image: Jo 4



Image: Jo 13



Image: Jo 14



Image: Jo 16



Image: Jo 18



Image: Jo 3

Figure 7-5 Capturing institutionalised processes

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The visual focus of her photographs is on the processes involved in treatment and the environments in which they take place rather than the relationships required to enable the provision of treatment. The blue sign in Figure 7-5 (Image 16) gives the impression the machine often runs late. By being ‘between numbers’, the observer does not know whether the sign is broken or whether it simply reflects a culture of not being on time, given its focus on being ‘late’ rather than running ‘on time’. It points to an absence of human interaction in sharing information, bringing to the fore the institutionalised setting. Jo included twelve photographs detailing the process of having a mould made for her neck and then receiving radiotherapy – a procedure which is ongoing each day during her photograph taking.



Image: Jo 33



Image: Jo 34



Image: Jo 35

Figure 7-6 Jo receiving radiotherapy to her neck

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She talks through the process of receiving radiotherapy (Figure 7-6: Images 33-35):

‘So you lie on the table, they put the thing on your neck, and then you’re lifted up, down, sideways...so you’re moved about – not physically moved about, I mean on the table – into a position, they have to measure you, they put an actual ruler on your neck, where your...so they have co-ordinates, to set you up in the same position every single time, and they’ve got to be more or less millimetre perfect. Then they go out of the room, zap you for a minute, then they come back in and you’re up, get dressed, out’ (Photo-production: Jo).

Jo’s account voices a lack of agency: ‘you lie’; ‘you’re lifted up, down, sideways’; ‘you’re moved about’. The healthcare professional’s role is described as technical ‘they have to measure you’, ‘they have co-ordinates’ with precision described as the critical goal ‘they’ve

got to be more or less millimetre perfect'; and procedural, with limited opportunity for interpersonal support – 'they go out of the room, zap you'; 'they come back in', 'you're up, get dressed, out'. The absence of clinical staff in these photographs (and in Kirsty's) may be due to staff not wanting to be photographed although their presence is felt through taking photographs for Jo. The complexity of the relationship is expressed by Jo stating that in relation to taking photographs:

'They were fine, yeah, absolutely fine about it. I told them what it was all to do with, and they were fine. In fact, the radiologist came in and she wanted one of my cards'⁴⁸

Which she then complicated very shortly after by stating:

'I don't think I was flavour of them month with them, but they said, 'It's okay, we'll take pictures' (Photo-production: Jo)

The images captured depict radiotherapy as a dehumanising and lonely experience. When talking through their photographs in Figure 7-7, Kirsty and Wendy described their treatment experiences as depersonalised: 'you're on a bit of a conveyor belt of treatment' (Kirsty); 'you feel you are on a conveyor belt and that you are going along with this' (Wendy). Kirsty's image has been crafted to support this discussion. She described 'being faceless' when in treatment. She commented:

'I like this image (Figure 7-7) without this, symbolically because it's faceless and that you do become a bit faceless when you are being treated for cancer. You do lose a bit of yourself, you lose a bit of your own identity, you're on a bit of a conveyor belt of treatment and you can just feel completely, just like not yourself, empty. Just going through the motions so that for me is quite symbolic in that way' (Photo-production: Kirsty).

In contrast, Wendy's photograph of putting dive equipment in to the back of her car juxtaposes normal life with the mechanised, robotic, isolated experience suggested by being on 'a conveyor belt'; and supports Mandy's experience of providing treatment described earlier:

'it's like; in, assessment, get the chemo up, next person, in, out, in, out; that's how it is, 135 patients a day we have' (Photo-elicitation: Mandy).

⁴⁸ Her 'abctdiagnosis' business cards.



Image: Kirsty 6



Image: Wendy 9

Figure 7-7 Images women 'spoke to' when discussing being 'on a conveyor belt'

© Kirsty /15.03.16/ University of Salford / Cathy Ure © Wendy Northway /28.04.16/ University of Salford / Cathy Ure

Wendy describes a sense of losing agency as healthcare professionals take control of her everyday life:

'because you are so used to people saying, 'right you're going to have eighteen weeks of chemotherapy'. You come in, 'we need you to come in for your bloods as well. And then you'll have four weeks of radiotherapy'. You are being told what to do all the time. And you let them tell you and then all of sudden they're no longer there telling you what to do. So, what do I do? How do I do this?' (Photo-production: Wendy).

Wendy voices the notion of taking a passive/submissive role within the clinical encounter, 'you let them tell you'. She voices the notion of loss of agency: 'you're going to have', 'you come in', 'you are being told'. Arguably, women's accounts of their relationships with their health care professionals renders the HCP's 'faceless' too. This depersonalisation of the clinical relationship is in keeping with cancer 'survivorship' narratives posted on YouTube (Chou, Hunt, Folkes & Augustson, 2011; Foley et al., 2015). Rendering healthcare professionals 'faceless' and 'nameless' through use of depersonalised references works to reduce their role to a tangential one and reinforces women's ownership of their experiences (Chou et al., 2011). Wendy voices anxiety at needing to reclaim her agency post treatment

because the clinical support structure is no longer there - *'What do I do? How do I do this?'* This experience of loss or feeling abandoned at the end of treatment has previously been reported (Breast Cancer Care, 2017; Coyne et al., 2006; Drageset et al., 2016; Stanton, 2012; Willems, 2017). However, the end of treatment offers a touchpoint for clinicians to propose ongoing support-based links. Despite this touchpoint, Breast Cancer Care reported in August 2017 that 42% of women surveyed (n=800), did not receive any information from their healthcare team on how to access information or support once hospital treatment ended.

7.1.4 Social media offers immediate support outside the clinical setting

Women feel their relationships with their clinical team are largely based around the clinical encounter and support is principally limited by the time healthcare professionals have with each patient. Sarah J warranted use of the closed Facebook group, YBCN, to supplement the support available from her breast care nurses. She spoke of valuing the immediacy of interaction and response to specific questions as a key factor in her use. She commented:

'and after my mastectomy something happened with my scar (pointing to area) and I know you can ring the breast care nurses but they always take hours to call you back and blah, blah, blah, whereas I know if I go 'did anyone else have this?' and everyone goes 'oh yeah, I had (inaudible), It's entirely normal', then it kind of saves a lot of time trying to get through to the hospital and finding out.' (Photo-elicitation: Sarah J).

Sarah's suggestion that *'it kind of saves a lot of time'* indicates a valuing of own time. This complicates the idea that women limit contact with healthcare professionals because they take *'hours to call you back'*, by indicating women have found opportunities to gain immediate support and 'save' their own time. Specialised closed groups on social media offer the resources to do that. Sarah's use of *'blah, blah, blah'* suggests *'they always take hours to call you back'* as a taken for granted aspect of the relationship between patient and healthcare service provider and one she can change by removing reliance on breast care nurses as the single source of knowledge. Through giving equal status to *'women who know'*, Sarah removes the power differential implicit in the patient-provider relationship and empowers herself through asking 'experience-based experts' (Civan, McDonald, Unruh & Pratt, 2009; Collins & Evans, 2002). In the following extract, Sarah demonstrates that the environments

people inhabit shape knowledge and advice and that professional opinion is fluid and nuanced too.

Cathy: 'Does it (pause). Is there a difference between getting a response from a professional breast cancer care nurse and individuals that have had experience?'

Sarah J: Yeah

Cathy: What's your take on that?

Sarah J: I find, from, I find it really interesting looking at it because a lot of people have asked a lot of different questions and I have found that erm, everyone has been told something a little bit different by their nurse and their doctor. So, although it's better to get a medical professional's opinion I think even their opinions change depending upon what hospital they work for; their experiences are; their Trust policy is and all that kind of thing.

Cathy: Yeah, yeah

Sarah J: So, if someone comes... if I ask a question and I get twenty different answers then, I can ask my nurse or decide which one is best. Or if everyone says exactly the same cos that's what they've been told then (weighing things up in her hands gesture).

Cathy: Ok, so it's giving you a, a broader sense of the information out there related to that particular thing?

Sarah J: And a lot of the time I would still check with my nurse anyway but it's just reassuring because you can get an immediate answer rather than you having to sit waiting for your nurse to ring you back (gesture of holding phone outstretched in hand) saying 'come on' (laughs)' (Photo-elicitation: Sarah J)

Sarah acknowledges that the benefit of immediacy of response is complicated by the range of responses. She identifies that not only do women have different experiences but also that '*medical professional's opinions*' differ and that these are influenced by a range of factors including clinical location and Trust Policy. Immediacy is described as an important factor influencing the relationship between patients and their health care professionals, but is also interconnected with sharing experiences, seeking reassurance from peers and using professional knowledge as confirmatory reassurance. Jayne also highlighted differences in expectations of service provision - from one based on '*waiting*' to one based on '*immediacy*':

'there would be people to talk to rather than having to ring up the nurse, leave a message on the breast cancer nurse line, feeling really bad because

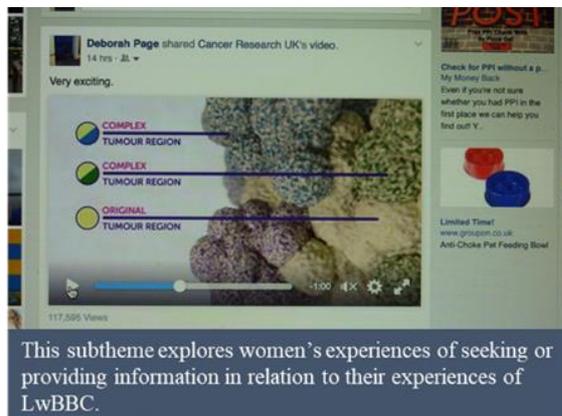
they are really busy, and they are running around doing other things and then waiting for them to ring me back perhaps that same day perhaps not that same day erm, to this was...this immediacy that, you know, we get used to with technology erm...’ (Photo-elicitation: Jayne)

Again, she adds complexity to the notion of drawing on clinical support ‘*feeling really bad*’ because ‘they’ (not she) are ‘*really busy*’ and ‘*running around doing things*’. Through exploring the notion of immediacy of support she frames the Facebook closed group as an opportunity ‘*to talk*’ and to reclaim a sense of control over the information sharing pathway. This is in line with the findings of Ho, O’Connor and Mulvaney (2014). They concluded that adolescents with type 1 diabetes experienced greater autonomy by using social media to supplement or complement the information provided by healthcare professionals.

7.1.5 Summary: Theme One - Subtheme One: Supplementing support from healthcare professionals

Women are using social media to supplement the level of informational support clinical teams can offer. This supports findings from a recent systematic review of social media use in healthcare (Smailhodzic, Hooijsma, Boonstra, & Langley, 2016). Women implicate healthcare professional’s interactions as related to the delivery of biomedical interventions rather than taking a holistic approach to health. Collectively, women describe themselves as cautious users of secondary healthcare provisions and avoid ‘*mithering*’ services they experience as stretched. This is voiced as restricting relationships between healthcare professional and patient. To supplement the support, they do gain from healthcare professionals, women seek support in social media environments they are already engaged in. Women use social media to supplement professional support while also gaining agency through removing reliance on breast care nurses as the source of all breast cancer knowledge. They source from experience-based experts – other women LwBBC. They experience closed groups on Facebook as providing immediate, relevant responses that reassure and inform. By using social media, to address questions and concerns quickly, women demonstrate agency and voice notions of feeling empowered.

7.2 Subtheme 2: Managing own informational needs



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Figure 7-8 Managing own informational needs

'Because there's that much information, you can't possibly take it all in at the appointment. And when they tell you, you're almost kind of shocked anyway. So, you don't digest any of it. Nothing is retained. Absolutely nothing is retained' (Nicola).

7.2.1 Introduction

Women navigate their experiences of LwBBC from an initial position of having no knowledge or limited knowledge about breast cancer (see Chapter 8: section 8.1). Limitations on time with healthcare professionals coupled with a desire to not 'mither' (Chapter 7: section 7.1.2.) leaves women with a range of information gaps. In a metasynthesis of qualitative studies exploring cancer survivors' views and experiences of engaging with adjustment-focused self-management interventions, Coffey et al., (2016) identified that participants were often critical of the limited amount of information they received about cancer. When women talked about managing their informational needs, they did so in one of three ways. Firstly, they talked about the need to Google information. Secondly, they talked about using social media to gain the appropriate level of support they needed at any particular point in time. Finally, they positioned empathetic information sharing from other women who were LwBBC as important. Women described knowledge sharing as enabling anticipatory coping as women had some idea of what to expect.

7.2.2 The need to Google

'Googling' was an online activity participated in by all women (Chapter Six, Section 6.3, Figure 6-22). While not a 'social media', it is pertinent to this thesis to discuss aspects of 'googling' that are relevant to women's experiences of LwBBC. 'Googling' was often

explained by women as a precursor to using social media. Additionally, ‘googling’ and social media were often described as intertwined activities when searching for breast cancer related information. Women talked about how health care professionals discouraged use of Google. Some women were advised by their health care professionals ‘*don’t Google*’ (Liz); ‘*Don’t Google it*’ (Sarah J); ‘*Don’t Google anything*’ (Sarah M); ‘*just don’t do it*’ (Sarah M); ‘*Yeah, they do say don’t Google*’ (Kirsty);

‘I can remember Googling, the breast cancer nurse did tell me off, because it was a few days before I was having an operation, so I Googled to see what the scar would look like’ (Photo-elicitation: Millie).

This shows health care professionals understand the ubiquity of Google to search for information in everyday life (Fuchs, 2014) and in relation to health issues (Prescott & Mackie, 2017), cancer (An, Wallner & Kirch, 2016; Foroughi, Lam, Lim, Sarema, & Ahmadvand., 2016) and breast cancer (Wang et al., 2012). The ‘don’t Google’ narrative stems from a fear that social media use perpetuates the spread of healthcare misinformation (Rupert et al., 2014). Women however demonstrate a complex relationship between taking professional advice and a need to understand more in the immediate aftermath of diagnosis. Despite professional advice, all women used Google in relation to their breast cancer experiences, including the healthcare professionals. When Sarah J talked about her relationship to Google she invoked her professional identity as a health care professional. She described telling people, attending her clinic, not to use Google because they do not know ‘*what is true*’ or what is ‘*real*’. She experienced service users coming to the wrong conclusions by ‘*Googling*’ but then makes her conflict about using Google clear - ‘*but I do it myself*’. She positions Google as synonymous with the internet – ‘*that’s where you find stuff on the internet*’ and demonstrates the strength of her relational tie to Google ‘*I do not know what I’d do without it*’. Sarah’s experience perhaps encapsulates the dichotomy between what clinicians prefer– no Googling - and women’s taken for granted health information searching processes (Prescott & Mackie, 2017). This reflects women’s agency in seeking to satisfy informational needs not met within clinical relationships. Kirsty described a culturally embedded taken for granted use of Google as a ‘*first port of call*’ (Kirsty) for information. Rather than seeking to disempower women through use of a ‘*don’t Google*’ discourse, understanding women’s existing information searching behaviours should be used to guide healthcare practitioner’s advice which should include clear guidance on appropriate online

sources of support. Indeed, a role for nurses in educating patients in how to appraise cancer related information found online, through evidence-based guidelines, has been advocated by Gage-Bouchard et al., (2017).

For some women the need for information begins prior to receiving a diagnosis of breast cancer. Liz and Jayne talked about ‘Googling’ after triple diagnostic testing⁴⁹, prior to receiving a formal diagnosis; meeting their oncologist; and being advised ‘*don’t Google*’. They suggest that comments made by professionals within the diagnostic setting ‘*it does look suspicious*’ (Jayne) and the process itself - ‘*the process took about three hours so I kind of knew there was something wrong, erm in the back of my mind*’ (Liz) - influence their use of Google post diagnostic testing. Jayne describes her responses as she sat in her car after hearing ‘*it does look suspicious*’.

‘I was sat in the car and it was almost like I was being pushed off this merry go round but I was desperate to hang on because I was thinking well it might not be, but actually I really think it is, and I need to get home and get on the internet and find out, cos I’m a Googler, which I know a lot people say don’t Google things like that, but I think because I’m used to an environment where I can use key words in research and that sort of thing erm I felt quite confident that I’d be able to find out and I needed to find out something’ (Photo-elicitation: Jayne).

In the immediate aftermath of testing, Jayne voices the complexity of coping with the forthcoming results of the diagnostic tests through internal dialogue ‘*it might not be*’ and ‘*I really think it is*’. Jayne invokes two identities – a ‘Googler’ and being an academic through voicing her confidence in using ‘*key words*’ to ‘*find out*’. By invoking her professional identity, she is more able to counter the ‘*don’t Google*’ narrative proffered by generalised ‘*people*’. She does not express a need to talk to anyone but to ‘*get home*’ to ‘*Google*’, demonstrating a taken for granted assumption that ‘*Google*’ will provide relevant, timely and appropriate information. Jayne’s recollection prompts questions about how women respond to notions of potential threat; the role of healthcare professionals in supporting women during and following diagnostic testing; and potentially an expectation that women wait for results passively, and obediently ‘*don’t Google*’. Those who utilise Google as part of their everyday

⁴⁹ The triple diagnostic assessment consists of clinical assessment, mammography and/or ultrasound imaging, and fine needle aspiration or core biopsy (NICE, 2017).

professional experiences, and/or part of their daily lives, may gain information for themselves prior to a formal diagnosis. Arguably, given online information seeking is a cultural practice (ONS, 2017) those involved in diagnostic testing should be signposting women looking for further information to useful resources such as the WoMMeN hub (University of Salford, 2017) which can provide information, empathy and support from mammographers and other women involved in breast screening. To my knowledge, work exploring women's information seeking behaviours post diagnostic testing/pre-diagnosis confirmation, has not been explored in the literature and is worthy of further investigation. An absence of clear support processes for women waiting for results suggests a gap in current healthcare provision.

7.2.3 Gaining the appropriate level of information at the right time

Women's need to find further information following their initial oncologist consultation was a common experience. Women report feeling overloaded by the amount of information; lack understanding of the technical language used; or expressed being too shocked to process the information being shared:

'Because there's that much information, you can't possibly take it all in at the appointment. And when they tell you, you're almost kind of shocked anyway. So, you don't digest any of it. Nothing is retained. Absolutely nothing is retained. Everything I know, more often than not, is little snippets of bits that I've remembered from the appointments but then the majority of it I've then gone and found out about it' (Photo-production: Nicola).

Nicola warrants use of other sources to fill informational needs because there is *'that much information'*. The use of *'little snippets of bits that I've remembered from the appointments'* moves this experience from a singular experience at the time of diagnosis to a common experience across appointments. The sense of 'experiencing a void' after receiving an initial cancer diagnosis is reported in the literature (Harkin, Beaver, Dey & Choong, 2017).

In contrast, Deborah, a healthcare professional, rejected attempts to provide her with information before a full diagnosis was known:

'They kept wanting to give me booklets about some recon⁵⁰ and photographs of recon. And I just said, look, don't give me anything until we know exactly what it is. Once I know exactly what it is, what it is feeding on, what stage it is at, what grade it is, then I will sit down and I will read only what I need to read about; what I need to read. Because otherwise my head is going to go bananas' (Photo-production: Deborah).

Deborah's response is that of an informed 'patient'. Her account indicates a knowledge that her cancer will be staged and graded (Greenhalgh, 2017). Her response points to a greater level of knowledge of different stages involved in getting a definitive cancer diagnosis. In response to the experiences of women concerned about receiving a breast cancer diagnosis, and in light of Deborah's experience, it may be useful for diagnostic teams carrying out triple diagnostic assessments to provide patients with a 'pathway to diagnosis flowchart' or similar, to enable online information searching that will support active coping strategies in a personalised way.

While Deborah argued that leaflet-based information was not useful until a full diagnosis was known, other women talked about not reading or skim reading the booklets and leaflets provided to them by health care professionals when diagnosed: -

'I have not read one of them. I didn't have the mindset to even sit down or read a book, in case I saw a word that said 'die'' (Photo-production: Michelle J);

'I have actually got a box full of leaflets and I have skimmed read some of them' (Photo-production: Michelle M);

'Almost straightaway, as soon as I was diagnosed they give you so much bumph, so many leaflets' (Photo-production: Nicola).

'with Breast Cancer Care, unless you're on the forums you've not got... Your leaflets are just leaflets with information' (Photo-elicitation: Millie).

Women seemed ambivalent about the significance of 'the information leaflet'. Comments about the quantity of leaflets received: - 'a box full' (Michelle M); 'so many' (Nicola); 'a lot more' (Millie), when used with terms such as 'bumph'⁵¹, suggest women consider leaflets as information sources of limited value. In contrast, the significance of digital technologies as an informational resource for women LwBBC was demonstrated both in interviews and images;

⁵⁰ Reconstruction

⁵¹ Bumph is defined as useless or tedious information (Oxford English Dictionary, 2017)

as alluded to by Millie above when she commented: *'unless you're on the forums...'*. Women identified websites of UK based cancer charities as respected places to go for information:

'I tended to stick to, but not always, to Macmillan and Breast Cancer Care because other sites you just didn't... I guess I'm not the best critical reader of the research' (Photo-production: Deborah).

'the cancer ones, Cancer UK erm, oh God I can't think of them all now. Cancer Research - I thought they've got to be legitimate, trustworthy up to date honest so that's what I did really' (Photo-elicitation: Denise D).

Deborah and Denise show strong digital literacies using criteria to assess the validity of information sources. They consider charities as trustworthy, legitimate information providers. Women provided images to show the accessing of information via charitable organisations, including Cancer Research UK, Breast Cancer Care, and BreastCancer.org., a US charity (Figure 7-9)

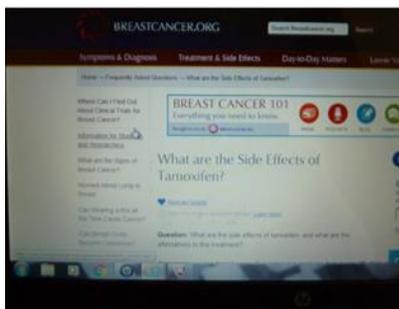


Image: Michelle M 8



Image: Deborah 2

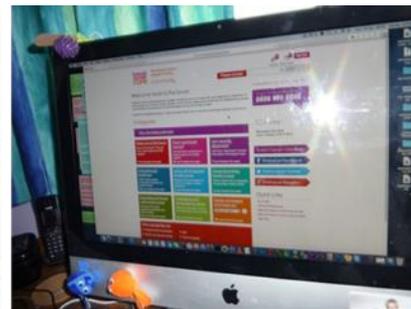


Image: Wendy 13

Figure 7-9 Charities' websites as informational sources

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Women's images and accounts of use of cancer charity websites demonstrate these as key arenas for information searching. Indeed, Scanlon (2013) and Ure et al., (2017) identify breast cancer charities as positioning themselves on Twitter as information providers first and foremost.

Michelle expressed a view that charities are concerned with 'fact based' information about 'proper' things such as income loss and financial management or signposting to other resources, rather than 'trivial' things:

'if it was to talk about something proper, like you know, my money is going down, I don't really know what to do about that, or, you know, where would you advise the best places to get a wig and things like that. That's when I would think 'right, I'll go to Macmillan'. So, I suppose, it's just you don't feel like you should go to them over more trivial things I think. Or talking about your feelings I don't think, so much' (Photo-production: Michelle M).

Here, Michelle articulates a view that Macmillan provides information-based support. In keeping with women's concerns about 'mithering' and 'bothering' health care professionals (Chapter 7, section 7.1.2.), this account voices a concern that Macmillan is not the appropriate 'space' to navigate 'trivial things' and 'feelings'. Michelle's view that she feels unable to go and talk 'about your feelings' points to an additional gap in organisational support provision where informational and emotional needs intersect and demonstrates a gap that peer to peer conversations online fill (Chapter 7, section 7.3).

Some women find that information on 'trusted' charity websites is limited and fails to adequately meet their needs:

'I spent a week (pause) again sort of Googling things but (pause) Googling the drugs interestingly because again I wanted to know exactly what those drugs would be doing to my DNA. What exactly they were going to be doing? I knew, that, because ...on all the breast cancer sites - Breast cancer care, Macmillan, you know, Breast Cancer Now as it is, you can read about you're going to lose your hair, you'll lose your eyebrows, you might feel sick, you might have diarrhoea, you might have constipation you might have a sore mouth, you might have all these things. But it doesn't tell you about what it is doing to your cells and I really wanted to know what it was doing to my DNA' (Photo-elicitation: Liz)

Liz argues that the information available on charity websites focuses on physical changes to the body. To understand the physiological changes, Liz needs to look elsewhere. Spending 'a week' Googling indicates an emotional investment in seeking out this information. Sarah J also described information on charity websites as not going far enough:

'it's hard because erm the things I know you can rely on tend to be quite vague and when you've got symptoms you want to be specific so like, I've got a pain in my hip which I am convinced means that its spread so if you go on the 'proper' websites they go 'well if its spread you'll get pain in your bones' – ok but what kind of pain? I want to know what kind of pain it is. Is it all the time? It doesn't tell you that kind of thing because it can't so that's when you start looking at the forums where people put all the different information

and that's when it's hard to know what's true and what's not because it just people messaging, and everyone's got a different experience'
(Photo-elicitation: Sarah J)

Through limitations on the extent of information made available on charity websites, Sarah J states a need to extend her information seeking into breast cancer communities. This points to a range of different levels of information that needs to be easily accessible and offers women choice in how much they access to meet own needs. This is in line with women's informational preferences identified by Galpin, Meredith, Ure & Robinson, (2017) when designing an informational hub for women in relation to breast screening.

Through proactively seeking out information women felt better equipped in clinical settings. Sarah J talked about the importance of having the right information and enough time to assimilate it:

'it's been helpful in kind of finding out more things about the treatments and what happens and like especially chemotherapy. I had an appointment this week with my oncologist about what drugs she was going to give me but I already kind of knew everything and I think if that had been the first time that I had found the information, and then I'm having it on Monday, it would have been a lot to take in' (Photo-elicitation: Sarah J).

Sarah draws attention to the timing of information provision; suggesting that assimilating information about the chemotherapy she would be receiving would have been more challenging had she not explored the subject online first. Similarly, women experience a disconnect between wanting information to reassure themselves quickly and a time lag in the clinical procedures which may or may not provide that reassurance:

'I know I am having the scans for it but that's miles away and you know I need some reassurance. I either need to know that it is or it isn't and I know you can't find that out from Google but I want to try and find out straightaway' (Sarah J)

Women move between internet use (primarily Googling) and social media use to inform themselves in line with their own needs. Essentially, these tools enable women to wrest some of the control over information flow from their practitioners.

7.2.4 Using social media to learn from experiential experts

Women used closed Facebook groups in active and passive ways. Women reported acquiring a depth of knowledge through ‘lurking’⁵² in closed breast cancer Facebook groups:

Cathy: ‘So you said for the first few weeks you didn’t post anything. Is that right?’

Kirsty: ‘No not really. I just read. You kind of come across a post and there’ll be like 47 comments, by the time you’ve read all of that you’ve had quite an in-depth insight into that particular issue, so I just read a lot.’ (Photo-production: Kirsty).

The sharing of women’s personal experiences in a closed Facebook group provides perceived ‘in-depth insight’ into particular issues. Kirsty shared how her knowledge about PICC⁵³ lines had grown as a result of discussion in a closed Facebook group and watching women’s videos on YouTube:

Cathy: ‘So is that an area of discussion that you had with the Younger Breast Cancer Network?’

Kirsty: Oh yes, big topic about piccs. And ports as well. The Hickman line, which Lara Honner on the video ...so three days after diagnosis she had a nightmare with hers. So, I already knew actually about it. I had an insight into it there, because they couldn’t get the veins and the chemo was delayed, hugely stressful. She had to have this Hickman line and it did not go well. The putting in of the line, it wasn’t good. And then she’s, when she had it out she’s had a big scar and so yeah, I was thinking ‘right, OK, I don’t really know which way I want to go here but I didn’t want one of those’. And I know through my ex-student [via Instagram], she’s had a port in her skin, she went for an operation to put that in under general anaesthetic. I didn’t really want that either. So, the picc is a good happy medium’. (Photo-production: Kirsty)

Lurking is an active participatory process (Han, Hou, Kim & Gustafson, 2013). Through moving across platforms, using women’s experiences from Facebook, Instagram and YouTube, Kirsty builds her level of knowledge. Increasing knowledge has been found to reduce anxiety (Coffey et al., 2016) and learning about other women’s experiences enables

⁵² Lurking is described as non-public participation in online social communities (Preece, Nonnecke & Andrews, 2004).

⁵³ PICC lines are long, thin, flexible catheters, used to give chemotherapy and other medicines. It is inserted into a vein above the bend of the elbow and can stay in place until the course of treatment is completed (Macmillan Cancer Support, 2017).

women to cope more calmly with treatments (Albrecht & Adelman, 1987; Shaw, McTavish, Hawkins, Gustafson & Pingree, 2000). Through having a degree of knowledge about upcoming treatments or procedures women feel better able to ask questions and advocate for themselves:

'I found Twitter really useful in that, because then I started following lots of people, so by the time I spoke to people I was already pretty well informed, or I felt like I was anyway, um, obviously it gave me the opportunity to ask some questions then' (Photo-elicitation; Sheena).

For those most recently diagnosed, engagement in information seeking conversations was positioned around posting practical questions in a closed Facebook group or following 'lots of people' on Twitter. While these information-seeking practices appear very different they both provide bridging capital linking women with others they have had no previous relationship with. Women recently diagnosed reference the significance of being able to draw on experiential informational support from 'patient experts'⁵⁴ related to procedures such as attending for a CT scan 'does anyone know how long it takes or what happens?' (Sarah J); or in relation to experiencing bodily changes - 'what shampoo should I be using?' (Michelle M); 'What happens with your period?' (Michelle J); 'how long does it take for your eyebrows to grow back?' (Michelle J). The benefits women express of learning from other women's health experiences is consistent with the rise in peer to peer health care (Civan & Pratt, 2007, Civan et al., 2009; Galpin et al., 2017; Fox, 2011), yet little is known about how women gather and share information as they move in and out of being an active patient when LwBBC.

Women use YouTube to gain visual information relating to practical aspects of treatment and managing the effects of treatment, including lumpectomy, radiotherapy and mastectomy procedures. Some women used YouTube to watch mastectomies: 'to see what they did' (Sarah J); 'I just wanted to know what they were going to do with my body so I could get my head around it' (Denise G). This demonstrates women's agency in searching for clinical videos to understand the surgical procedures they will experience but not 'know':

⁵⁴ Civan & Pratt (2007) refer to the experiential form of knowledge gained by coping with and managing illness as patient expertise (p. 2).

'YouTube, I've used a lot, looked up a lot of, um, breast cancer operations, yeah "... " certainly, when I was going through the cancer, maybe stuff about chemotherapy, I would look up, um, I'd just type in, you know, uh "Cyclophosphamide" which was one of the drugs that I had, in YouTube and seeing what people were saying about it, because it's more like a visual, rather than reading stuff, which I don't like, reading big, loads and loads of books or whatever "... " so YouTube was kind of interesting, they'd show little films of things or, they'd show little cartoons of like how... breast cancer reconstruction was done, or what happens in your body when cancer is travelling around your body, so I found that very, very useful, as a, as a thing, and I did that through treatment and I still do' (Photo-elicitation: Mandy)

'I did Google a video or YouTube a video of a mastectomy to see what they did "... " it was only afterwards when I had the scar that it was like and I wondered why it was here and not here or there [pointing to parts of her upper body]. I'm sure it will be on YouTube; everything is on YouTube' (Photo-elicitation: Sarah J)

While Tan et al., (2014) explored the quality of videos on YouTube in relation to breast reconstruction, this evidence suggests wider interest in mastectomy but not necessarily reconstruction. Signposting women to approved online resources regarding mastectomy, during clinical encounters, may be beneficial for some women in supporting the development of patient knowledge.

To address the challenges in negotiating the physical changes experienced when in treatment (see Chapter 8: section 8.2) women also viewed videos to learn how to tie headscarves (Michelle M; Nicola; Denise D) and how to apply eyebrows using make up (Michelle M; Delphi). These were described without reference to other people and were individual search activities to meet visual informational needs. All examples were 'remembered' while prompted to think about their use of YouTube when placing the social media card for 'YouTube' on the Venn diagram. There were no examples of the use of YouTube in the photographic data.

The importance of peer-to-peer information sharing was shown through inclusion of photographs promoting use of #bccww; connection with @abcdiagnosis and the homepages of YBCN, The Osborne Trust and Jan's Cupcakes (Figure 7-10). These are reflected in women's use of Facebook messaging to support others diagnosed later than themselves (Image: Deborah 14; Wendy 4) and turned to as 'experts' by others. They not only convey to other women the concept that they are 'experts in their own lives' (Clark-Ibanez, 2004) able

to provide useful insight and informational support to others; but also demonstrate women developing a wider voice.



Figure 7-10 Navigating own informational needs – peer to peer support

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Women’s information sharing on Facebook is embedded in technological and group structures which entwine the sharing of informational and emotional support. For instance, an example is provided of a woman sharing a mainstream news report. She adds her own critical analysis through tweeting a comment relating to the perceived poor reporting of breast cancer related information by mainstream broadcasters. Women therefore act as ‘critical’ readers of public information shared. A BBC news story relating to cancer being caused by the ‘environment’ was shared, accompanied by a challenge ‘*oh, do fuck off*’ in relation to the way the study results were reported. Delphi’s inclusion of a photograph of this post enables her to express feelings of validation when someone else ‘calls out’ misreporting and the impact this has on those LwBBC – ‘*it’s shit enough having cancer without feeling guilty about it too*’. This points to women understanding that information shared through mainstream media can be experienced by others LwBBC as emotionally threatening. Through their online relationships, women can work together to counter the emotional threat (see Chapter 9; section 9.1) or explore it with others through sharing responses. Delphi explains how her own use of social media has changed as she has moved away from the time of her initial breast cancer diagnosis:

‘I’ve stopped using social media to share photographs of my cats about two years ago. And I think if you look back at it, it’s going to be entirely me ranting about the misrepresentation of cancer in the media and also the, I can’t remember what they’re called, but, you

know, like the no-make-up selfies and the ice bucket challenge and things. I think that was much more commendable than the no-make-up selfies, definitely. But, yes, I have rants about those a lot' (Photo-production: Delphi).

Information in the form of 'news stories' were directed through the Facebook closed community as targeted, composed communication (Figure 7-11: Images Deborah 15 & 3) to specific individuals when the relevance of a particular story is observed by one for another. News about research advances were shared through wall posts (broadcast communication) with affective comments drawing attention to particular information (Image 7-11: Deborah 3).

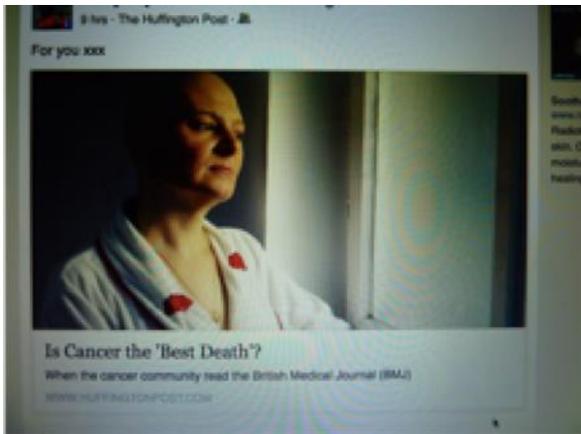


Image: Deborah 15

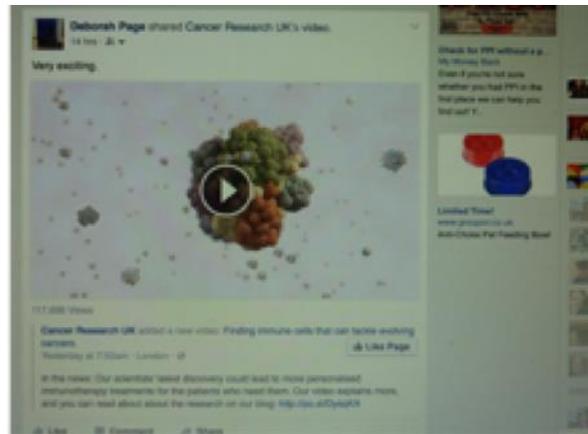


Image: Deborah 3

Figure 7-11 The personalisation of content

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By curating content through adding comments to information released by other organisations, women engage in expressive information sharing⁵⁵ (Smock, Ellison, Lampe & Wohn, 2011) Providing personalised informational support to other women LwBBC and through expressive information sharing entangles the notions of informational and emotional support. The personalisation of a news story with an affective comment (Figure 7-11) shared as a

⁵⁵ Expressive information sharing relates to personalising the sharing of information within posts. Smock et al., (2011) used the following items within a survey to measure expressive information sharing: (i) to provide information; (ii) to present information about a special interest of mine, (iii) to share information that may be of use or interest to others, (iv) to provide personal information about myself, and (v) to tell others a little bit about myself.

targeted, composed communication or masspersonal⁵⁶ communication demonstrates a sense of emotional connectedness (Chapter 7: section 7.3) between women, entangled in information sharing. Women act as informational gatekeepers acknowledging the emotional impact information has on themselves and others, and pass information on with support.

7.2.5 Summary: Theme One - Subtheme Two: Managing own informational needs

Women's accounts demonstrate complex experiences in searching for, assessing, and using information. Initially, women use information searching as a coping strategy. For some women, information searching begins after diagnostic testing and prior to formal diagnosis. Women report experiencing information overload in the clinical setting and use social media platforms to fill knowledge gaps. Women often ignore clinical advice not to Google. Given information retention at diagnosis due to shock is reported (Harkin et al., 2017) social media are used to manage and satisfy women's informational needs in emotionally supportive environments. Women identify gaps in informational follow up and utilise alternative communication mechanisms at key points in their 'patient journey', outside of the formal clinical encounter. Consequently, googling and searching online for further information related to the diagnosis and treatment is common practice. Cancer charity websites, seen as legitimate and trustworthy, are often women's first port of call. The level of information provided however, is not of sufficient breadth or depth to satisfy all women's needs. In addition, many women experience charities' support as signposting or leaflet driven which do not align with their day-to-day information searching practices. Women supplement web-based information through active and passive consumption of 'experiential' knowledge principally using Facebook, YouTube and Twitter. By moving in and out of platforms and different groups on platforms, women gather information at the appropriate time for them, determined by them. This supports women's ability to cope with the amount of information they encounter when newly diagnosed; and supports adjustment and informed anticipation of what the next stage in their cancer experience entails. Through engaging in seeking, sifting, evaluating and sharing information women validate their experiences and become equipped

⁵⁶ 'Communication directed at an individual while simultaneously broadcast to a larger audience'(O' Sullivan, 2005, cited in Smock et al., 2011).

to advocate for themselves (Chapter 9, section 9.2.4). Women's interviews and photographs show the blurring of boundaries between informational and emotional support.

7.3 Subtheme 3: Feeling emotionally (dis)connected



'when I'm talking about things which I kind of wanted to talk about face to face, people feel a bit uncomfortable or people seem like they feel a bit uncomfortable like they don't know what to say or they're like you know, 'are you sure you want to talk about this' and I'm making jokes, but they just don't; they're not responding very well to it' (Sarah J)

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Figure 7-12: Feeling emotionally (dis)connected

7.3.1 Introduction

When women talked about emotional connectedness⁵⁷ in relation to their use of social media, they did so in one of three ways. Firstly, they talked about using social media to navigate feelings of disconnection from strong ties. Secondly, they talked about social media enabling intimate, emotional connectedness with strong and weak ties. Finally, women talked about how their use of Facebook enabled them to assess levels of connection with others and build intimacy.

7.3.2 Using social media to navigate feeling disconnected from strong ties

Women's photographs (Figure 7-13) of family and friends show familial emotional connectedness. The images are of busy domestic lives and invoke concepts of friendship, love, belongingness and enjoyment. They demonstrate LwBBC is not experienced in a cancer vacuum. Four out of seven participants in the photo-production study, showed emotional

⁵⁷ Connectedness occurs when 'a person is actively involved with another person, object, group, or environment and that involvement promotes a sense of comfort, well-being and anxiety-reduction' (Hagerty, Lynch-Sauer, Patusky & Bouwsema, 1992, p. 293).

connectedness as occurring within physical spaces by including photographs taken at home, at their hairdressers, in the nail bar and at a children's party. These facilitated conversations around both positive and negative experiences of emotional connectedness with others.



Figure 7-13 Signs and symbols provided of emotional connectedness

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For instance, some women's use of social media for emotional support were embedded within stories of disconnection. In the photo elicitation interviews Millie, Delly and Sheena talked of family members who 'didn't want to know' (Delly) when they were receiving treatment:

'they've [members of partner's family] been very dismissive. Not interested. Not even visited. Didn't come to hospital. Asked me when I came out of hospital where I'd been!' (Photo-elicitation: Sheena).

The extracts below juxtapose the contrasting experiences of disconnection and connection:

'I don't think my [family member] could really cope. He can't cope with illnesses anyway so, because he kept a low profile... Yes, when I was in hospital he didn't want to really come and see me'(Photo-elicitation: Millie)

'So we can meet. An hour's drive and we can meet, meet for a coffee or lunch or something, which again is nice as you can talk; you've

got that common bond between us. So that's where Flat Friends came in' (Photo-elicitation: Millie).

Millie experienced other people's responses to her diagnosis, treatment and surgery as both disconnecting and connecting. She gained a sense of belonging⁵⁸ from platform use. She states that social media enables connection with women who share a 'common bond' – having had breast cancer and now living 'flat' post-surgery (women she has met through the Facebook Flat Friends group). The degree of intimacy and sense of proximity gained through sharing experiences of LwBBC in closed private spaces frequently leads to 'meet ups' or 'coffee' or 'lunch', indicating supportive relationships moving offline. Michelle J, Michelle M, Kirsty, Nicola, Sarah M, Delphi and Jayne all talked about group 'meet ups'. This absence of boundaries between online and offline life through 'meeting up' was also identified by Harkin (2016) with regard to cancer Facebook groups.

In contrast, Sarah J uses social media to navigate existing friendships complicated by her experiences of breast cancer. Sarah felt disconnected from friends when interacting face to face:

'when I'm talking about things which I kind of wanted to talk about face to face, people feel a bit uncomfortable or people seem like they feel a bit uncomfortable like they don't know what to say or they're like you know, 'are you sure you want to talk about this' and I'm making jokes, but they just don't; they're not responding very well to it' (Photo-elicitation: Sarah J)

Sarah experienced resistance when engaging in face to face dialogue about her experiences describing people as 'uncomfortable' and questioning her when she is 'talking about things' by asking 'are you sure you want to talk about this?'. In response, she adopted WhatsApp as an alternative arena for talking predominately to friends about her cancer. She warrants mediation through technology as providing space within the relationship for the provision and receipt of more helpful supportive exchanges:

'I think it's harder for people face to face to know what to say when you are having a conversation whereas when you say something on social media, because you have a bit more time to think about things you can give like more rounded responses rather than just saying what comes out of your mouth' (Photo-elicitation: Sarah J)

⁵⁸ A sense of belonging was theorised by Baumeister & Leary (1995) as a basic human need.

Sarah J leverages existing groups of friends on WhatsApp to gain support, through chatting about *'my breast cancer'* as part and parcel of every day conversation, in a way that echoes offline relationships (Aharony, 2015). This approach is experienced as less challenging than updating friends face to face. David and Cambre's (2016) work on Tinder suggests simple application interfaces are experienced as less intimidating than face to face encounters. Technological advancement, in the development of simple application interfaces, provides women with more choice and flexibility in how they can draw on the supportive resources of family and friends. This enables *'mediated intimacy'* (Vetere et al., 2005, cited in David & Cambre (2016) which supports the maintenance of social capital. WhatsApp acts as an arena where individual actors (Goffman, 1959) can craft their lines and reflect on their *'performance'* before sending messages. Sarah uses it to sustain and nurture her friendships which are tested by her diagnosis.

While Sarah used WhatsApp to help manage her interactions with friends and family, other women use social media to help navigate feelings of disconnection created by friends and families' unhelpful comments:

'Oh you've got breast cancer, Oh you'll be fine though because it's so good these days' (Photo-production: Kirsty)

'Oh, er well, you know you'll get a boob job' (Photo-production: Michelle M)

'sent it via Messenger I think, and I know they were trying to help and they'd put this - I think it was a picture in Grazia or something of supermodels - all with their shaved heads and gone look 'you know, you'll be in fashion if ever you need a buzz cut anyway' (Photo-production: Michelle M)

'and then people are going 'Oh, Angelina Jolie did it so it's alright isn't it' (Photo-production: Michelle M)

'Oh, your cancer's gone now, get over it. Carry on with your life' (Photo-elicitation: Jojo).

'Like the other day I'd done a WhatsApp to them, just to two of them. And said my head has been so sore, I really hope it's not...[secondary breast cancer] 'I'm just going to punch you, they call me Lecky, because that's my maiden name. Lecky I'm going to punch you when I see you if you keep saying that. It's not in your head. You're stressing yourself out. Get a grip' (Photo-production: Michelle J).

These ‘supportive’ comments are experienced as disconnecting. They *‘trivialise’* (Michelle M) experiences of hair loss and mastectomy (Michelle M) and the ongoing physical and emotional impact (Jojo; Michelle J). They draw inappropriately on media representations such as ‘the Angelina Jolie effect’ (Borzekowski, Guan, Smith, Erby & Roter, 2013; Evans et al., 2014) and being *‘chemo chic’* (Michelle M). They convey the impression that breast cancer is ‘a passing inconvenience’ (Sulik, 2013, p.698). This *‘trivialising’* also assumes women LwBBC are positive recipients of medical progress – *‘it’s so good these days’*. For some, a diagnosis of breast cancer appears to have been reduced inadvertently to a *‘boob job’*. These comments shift away from focusing on the potential consequences of ill health for someone diagnosed with breast cancer, to one ‘informed’ by consumerism and the body project⁵⁹. They demonstrate the differences in experiences and knowledge between women ‘that know’ and women who cannot know what it is like LwBBC. Women LwBBC suggest that outside of the breast cancer community there is limited expression of empathy in relation to the ongoing emotional, psychological and physical effects women encounter. Michelle used Figure 7-14; images 9 and 10 to convey the sense of meaningless chatter, as she contemplated loss of a breast:



Image: Michelle M 9



Image: Michelle M 10

Figure 7-14 Feeling disconnected from 'supportive' comments

© Michelle Mullany / 03.03.16 / University of Salford / Cathy Ure

‘people just saying like really unhelpful things. And just that they, just need to shut their mouth’ (Photo-production: Michelle M)

⁵⁹ Body projects are attempts to construct and maintain a coherent and viable sense of self-identity through attention to the body, particularly the body’s surface (Featherstone. 1991)

She signals a desire to speak out, to silence those – ‘*shut their mouth*’ - who trivialise her experience and create unwelcome anxiety. Michelle took this photograph to portray visually and through telling her story the sense of disconnection felt when people speak without thinking about the impact their words have on others - ‘*you just want to punch people in the face sometimes*’ (Michelle M). Michelle withholds from vocalising these thoughts, excusing people’s comments as being unintentionally unhelpful:

‘I’ve not ranted at anyone. I’ve not said anything back you know or got angry with anybody because I know they don’t mean anything by it’ (Photo-production: Michelle M).

This sense of frustration at silencing how she is experiencing living with cancer echoes the experiences of breast cancer bloggers identified by Ure (2014).

7.3.3 Social media supports intimate, emotional connection with strong and weak ties

Women seek emotional support mediated via social media to access women LwBBC as they ‘understand’: ‘*the group understands*’ (Jojo); ‘*she understands*’ (Wendy); ‘*sometimes it’s fantastic just to find somebody that gets it*’ (Nicola); and enable conversation about the realities of LwBBC - ‘*I can say more to them than I can do to my own family*’ (Jojo). In sharing examples of social interactions, they experience as unhelpful, women relieve their own stress and use humour to bring other women LwBBC into closer relationship with them:

‘oh, we were out in T K Maxx with my mum and my mum saw somebody shaking a Cancer Research thing and she went ‘my da...my daughter’s got it. She’s got it, I’d better put some money, hadn’t I?’ So, so she’s posted ‘I’m going to kill my mother’. But, she probably felt she couldn’t say that to anybody else so you know, [you] go, ‘oh yeah, my mother did this last week’ blah blah blah and you know sometimes it’s quite funny really’ (Photo-production: Michelle M).

Positive benefits of humour in illness have previously been reported (Kuiper, 2012; McCreddie & Wiggins, 2008). Humour provides “an individual and collective sense of empowerment, builds cohesion across a community and reduces feelings of isolation” (Demjén, 2016, p.18).

Women critically assess and integrate helpful channels of emotional support into their ways of coping. The images of family and friends and of ‘being loved’ (Figure 7-13) co-exist in women’s photograph portfolios with images of digital technologies and social media (Figure 7-15). These act as a proxy for emotional connectedness.

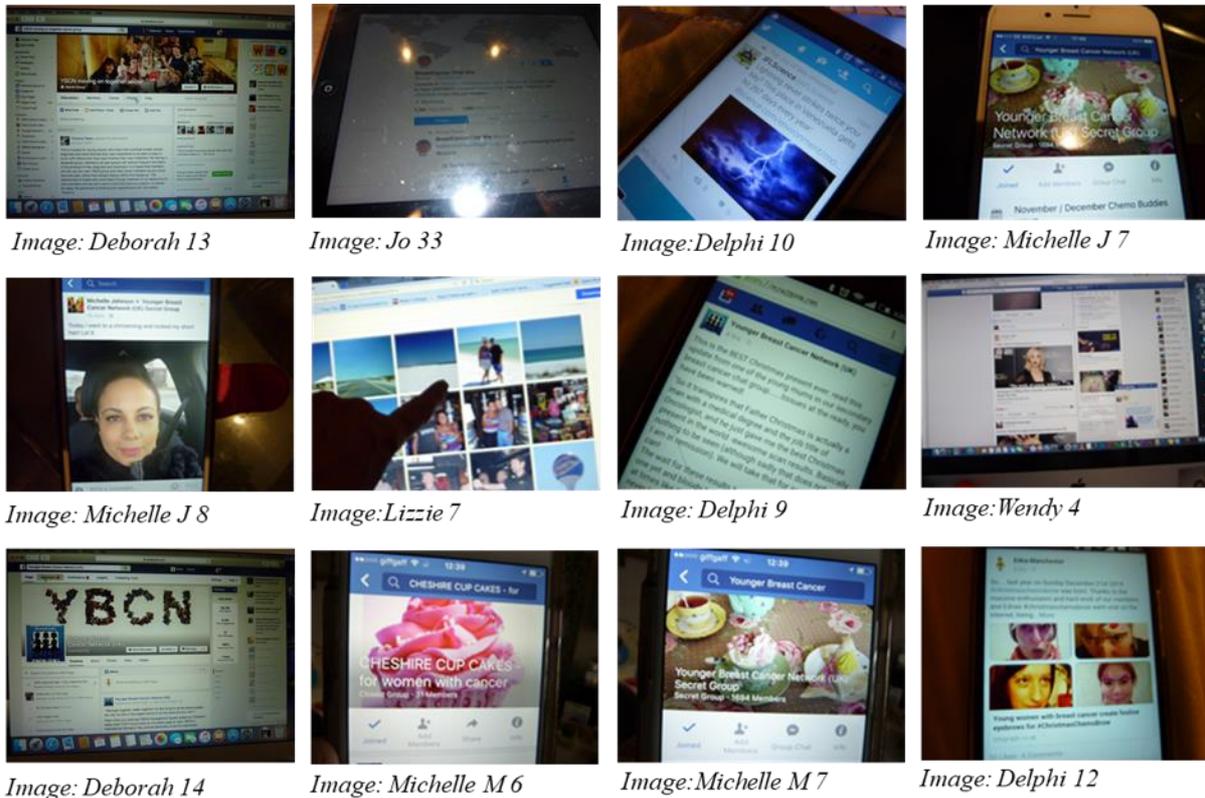


Figure 7-15 Feeling emotionally connected

© Michelle / 29.02.16/ University of Salford / Cathy Ure; © Deborah / 11.03.16 / University of Salford / Cathy Ure; © Wendy Northway / 28.04.16/ University of Salford / Cathy Ure; © Jo Taylor - abcdiagnosis / 10.12.15 / University of Salford / Cathy Ure; © Michelle Mullany / 03.03.16 / University of Salford / Cathy Ure; © Lizzie / 18.11.15 / University of Salford / Cathy Ure; © Delphi Marmaduke / 05.01.16 / University of Salford / Cathy Ure

Women’s narratives and images of Facebook profile pages and posts (Images: Deborah 23, 24; Delphi 9,12; Michelle J 7,8; Michelle M 6,7; Wendy 4), Twitter feeds (Images: Delphi 10; Jo 33) and blogs (Image: Lizzie 7) position these environments as sources of emotional connection. In relation to image Lizzie 7, Lizzie described her joy of receiving a blog from her friends travelling in the US ‘I feel like I do those things with them and they know that.

They know how much I appreciate it'. Other women used emotive language to describe how significant they felt Facebook groups had been for them since diagnosis:

'But I cannot think of a single source that would provide even close to the amount of...even close to the amount of support the YBCN has provided for me. I never looked elsewhere (Photo-production: Delphi)

'it's honestly, it was a lifesaver, for me, absolutely. [Founder's name] group was amazing' (Photo-elicitation: Jayne)

'But this has been a lifesaver for me I think, the Young Breast Cancer Network, most definitely' (Photo-production: Michelle J)

'it's [YBCN] really good. It's really, really, really good. It's definitely the first place I would ask a question I didn't feel I could ask my doctor' (Photo-production: Kirsty)

'Social media is amazing. I nearly said Facebook what's erm oh dear how can I explain it's like a virtual friend. Like your Guardian Angels or your guides. You've never met, and you know they are there for you. You know' (Photo-elicitation: Jojo)

Women describe sharing their experiences with other women LwBBC on social media as being part of a *'sisterhood'* (Liz; Wendy); of *'walking in their shoes'* (Liz) and being part of a *'tribe'* (Nicola).

Often women's communicative preferences signalled a preference for emotional support in environments that provide privacy. This is reflected in the predominance of Facebook closed groups within the photographs provided (Figure 7-15: Images Deborah 13,14; Delphi 9,12; Michelle J 7,8; Michelle M 7, 8) and within women's accounts. Yet, women also provided examples of moving away from the public gaze of 'normal' Facebook and the closed breast cancer groups on Facebook for more intimate conversations. Other platforms, which offer feelings of proximity and intimacy - WhatsApp, Skype, and FaceTime - were used to gain emotional support. This demonstrates women selectively choosing those media environments that best suit their communicative and emotional needs (Madianou, 2015) at any specific time. WhatsApp was also used as it is free (Denise G; Jayne; Nicola; Sarah); a good way of sending photos to one another (Jayne; Lizzie; Nicola); as a space where everyone is *'happy to chat'* (Lizzie); and provides a greater sense of connectivity through seeing someone has read your message (Kirsty). WhatsApp was used with family (Denise G; Eleanor; Jojo) or friends and family (Jayne; Lizzie; Mandy; Michelle J; Nicola; Sarah J; Shenna); and the Uni girls

(Sarah M). Mandy articulates use for familial connectedness which they collectively use when struggling emotionally:

'WhatsApp ... a really nice way of keeping in contact with people, my family now, just my siblings, only my 5 brothers and sisters, are on there, and if we're feeling a bit down, we go on there' (Photo-elicitation: Mandy)

Skype and FaceTime were utilised as visual media to reduce distance and support the development of familial relationships inter-generationally. Examples included Sarah J Face Timing her mum:

'when she's got my nieces around because they are quite small, so I Facetime them then and they show me all their toys and things' (Photo-elicitation: Sarah J)

Women used Skype and FaceTime for emotional support when feeling ill or with family members experiencing declining health. In the following extracts, Kirsty warrants use of Skype and FaceTime as a visual 'checking' tool which enables discussion around 'being OK'. In contrast, Deborah FaceTime's her mum to provide connection and pleasure which could not have been tolerated face to face:

'when I'm really poorly at home, stuck at home, my mum likes to Skype me to just check that I look alright. And invariably I don't. So, she does, she uses that with my grandad as well because he lives in the Lake District. And she says she Facetimes him because she can see his face and if he's okay, so if he says he's fine and he's not fine she can tell. And so, she does the same with me I think. Or I say, she says 'you sound fine' and I say 'I'm not fine' so it's the other way' (Photo-production: Kirsty)

'we would FaceTime quite a bit, because the kids would want to chat and my mum would want to chat to the kids and of course by then she was kind of on the sofa 24/7 [] You know, if you are fatigued and in pain, the noise, it doesn't matter how much, for her it was horrid, because she wanted to hear the noise, she lived for her grandkids, but her body just couldn't tolerate it, and the jumping around, a three year old boy, you can imagine, can't you? (Photo-production: Deborah)

Skype and FaceTime were described as 'the reality of it sometimes' (Kirsty) collapsing the distance between mothers, daughters, grandfathers, grandmothers and children to provide emotional sustenance and facilitate physical proximity. Its beneficial use for people receiving

palliative care or who are isolated with limited access to familial support has been previously identified (Battley, Balding, Gilligan, O'Connell & O'Brien, 2012; Bensink et al., 2009).

7.3.4 Facebook features and feeling emotionally connected

Emotional support may be expressed using 'one-click' communication (Burke & Kraut, 2016) such as 'likes' and 'comments' on Facebook pages. Women articulate different views regarding the significance of 'likes' dependent upon whether they relate to status updates on their 'normal' Facebook page or within closed groups. Kirsty expresses ambivalence to receiving 'likes' to her 'cancer posts' on her normal Facebook page:

'I don't want them to think that...whenever I put anything on, so if I put only like three or four posts on, a couple of them about cancer, people are so nice, and there are immediately comments and likes and this and that. And I don't want them to think that I'm asking for sympathy and I want them to do that. I don't actually want them to do that really. It's nice, you do feel supported but if my friend was putting, I'd feel like I had to really, otherwise it would look a bit bad. So, I don't want people to feel they have to' (Photo-production: Kirsty)

She posits people feel they 'have to' 'like' these posts, suggesting a culturally embedded use of Facebook to acknowledge challenging personal experiences. By stating '*otherwise it would look a bit bad*' Kirsty indicates Facebook 'friends' generally behave in a self-enhancing way (Burke & Kraut, 2016; Eranti & Lonkila, 2015; Goffman, 1959). This concurs with Eranti and Lonkila's (2015) findings. In a small survey of 26 Finnish students, they identified social pressures as influencing user's liking activities; a tendency that was further elevated for sensitive postings. In contrast, after posting a photograph of herself and her daughter 'dressing up' to the YBCN closed Facebook group, Kirsty recalls getting '*83 likes*'. The precision of the number of 'likes' suggests they have social significance. This different sense of emotional connectedness is warranted as related to shared experience and shared identity (Chapter 8, section 8.1) and is valued:

'It gets far and wide and you feel like this big, huge, far reaching set of people, that are the same as you, and that is a comfort' (Photo-production: Kirsty).

This suggests women gain psychosocial benefits from the ‘lightweight’ (Burke & Kraut, 2016, p.269) one click communication actions made by other women LwBBC, potentially because they act as a signifier of belongingness.

Some women used Facebook to explore the extent of support available from ‘normal’ Facebook friends following diagnosis and to see how other people responded to news of their diagnosis:

‘I wonder who might comment and what’ll they say and I wonder who won’t comment and then I thought and also if people don’t comment or don’t like or don’t tick I don’t, I don’t, you know throw my dummy out of the pram it’s like because that is what Facebook is’ (Photo-elicitation: Denise D).

The combination of targeted, composed messages via messenger and one click communications generated feelings that people *were ‘in my corner’* (Denise D) and *‘rooting for you’* (Michelle M) reducing concerns about being isolated. Publicly posting visual images as status updates on Facebook was reported as giving women a sense that their story was being seen and heard.



Image: Wendy 6

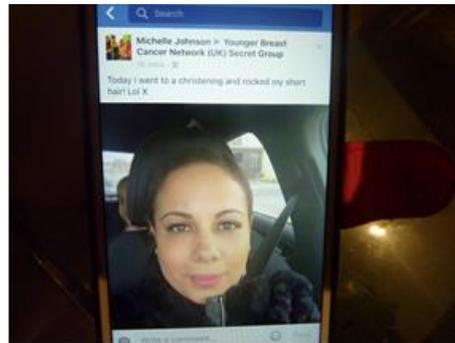


Image: Michelle J 9

Figure 7-16 Using the visual to gain support

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Women used photographs to describe how social media mediated emotional connectedness both at home and on social media (Figure 7-16):

‘My patio (image: Wendy 6). 2014 was the worst year ever (starting to cry). But it was also a lovely year. I had so many people come and visit me. They came out of their way to visit me to see how I was. And there’s lots of photographs on my patio of friends. I posted those.

And I think that encouraged more people to come. It's just lovely'
(Photo-production: Wendy)

'But there's just hundreds of comments. I put that on my Facebook wall as well (image: Michelle J 9) and I've got nearly 200 likes on it and absolutely massive amounts of comments' (Photo-production: Michelle J)

Wendy remains emotionally vulnerable when talking about her diagnosis and treatment. She categorises this period temporally, experiencing it as both 'the worst year ever' and 'a lovely year'. This was warranted by visits from friends 'encouraged' to come because of her posts on Facebook which pictured the same setting (her patio) and the public broadcasting of gaining emotional support from friends. In effect, through the inclusion of a similar visual image, Wendy transforms the Facebook 'like' into a physical visit, visible to all her Facebook friends.

For women going through chemotherapy, closed Facebook groups were described as supporting psychosocial health through reducing isolation and feelings of loneliness. Specific examples of timely, targeted, composed communication⁶⁰ were provided. Sarah M describes using the chemo buddies group of YBCN:

'we gee each other along and stuff like that and so I might not post anything for three weeks but around that chemo week there's a few of us having it at a similar time, just say 'how is every... we might say how is everyone?' And those times when you are sat home for a week, bored out of your brains, feeling like death, it's quite nice to connect with somebody that's going through the same thing, yet you've not got the energy to talk so, you know what I mean, so it's been really good for that because I think I would have felt quite lonely...yeah.' (Photo-elicitation: Sarah M)

Sarah voices conversation with women she has had no previous relationship with as reducing loneliness in relation to a specific experience when LwBBC. Here, Sarah is curating and consuming content through connecting with weak ties. Despite being part of 'chemo buddies July and August' she describes specific psychosocial benefit at a particular time of her chemotherapy cycle, rather than regular involvement in or benefit from chemo buddies

⁶⁰ While Burke & Kraut (2016) define targeted, composed communication as consisting of 'one to one exchanges between a user and another particular Facebook friend that included text' (p. 272). I extend that definition to 'one to several' to reflect the nature of Facebook communications within a sub-group (e.g. Chemo buddies – November and December) or a closed Facebook group where the message is directed equally to all group members.

throughout the period of her chemotherapy treatment. She positions connection to others ‘having it at a similar time’ as one built on empathic understanding as ‘we gee each other along’, when ‘you’ve not got the energy to talk’. Sarah’s invoking of ‘you’ve not’ positions ‘not having the energy to talk’ as a generalised experience after chemotherapy presenting the idea that this engagement with ‘similar others’ does not feel demanding; differs from ‘talking’ and works to reduce feelings of being alone. There is a sense that this Facebook communication fits a specific need at a specific time that cannot be fulfilled by others that have not had a similar experience. It is a highly tailored experience of support from women. She begins to repeat a post she may have made ‘how is every...’ and then pauses, silencing herself. She corrects herself invoking ‘we might say’ giving a greater sense of unity and togetherness as a group of young women going through chemotherapy together.

This represents an intensity of relationships with other women LwBBC. Delphi’s photographs (Figure 7-17) include two photographs of posts on the YBCN closed Facebook page (Images 9, 12) and a retweet posted on Twitter (Image 10).

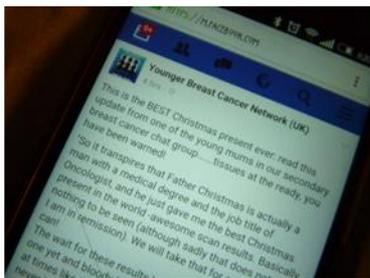


Image: Delphi 9



Image: Delphi 10



Image: Delphi 12

Figure 7-17 Broadcast communication and emotional connectedness

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Broadcast communication⁶¹ in closed groups provides positive affective support to a wider community audience and to a specific individual simultaneously. Image 9 in Figure 7-17 begins:

‘This is the BEST Christmas present ever: read this update from one of the young mums in our secondary breast cancer chat group; tissues at the ready, you have been warned’ (Photo-production: Delphi)

⁶¹ This is known as ‘masspersonal communication’ (O’Sullivan, 2005, cited in Smock et al., 2011)

This post draws attention to a community ‘being there’ for the individual concerned; the emotional ‘work’ that others’ experiences may place on those engaging in this community; the straightforward way being ‘a young mum’ with ‘secondary breast cancer’ is conveyed; the existence of separate ‘spaces’ for women at different stages of breast cancer and the appreciation of the emotional resonance of the Christmas period for women LwBBC. This sense of ‘being there’ is supported in a separate image by a different photographer (Image: Deborah 13). A request by moderators of the YBCN for women in the ‘Moving On’ group to offer support to women recently diagnosed and in treatment is captured. This demonstrates a proactive, community approach to the emotional support of others.

‘...it’s so heart-warming that as soon as somebody’s introduced into the group they’d be ‘likes’ and you’d get 20 or 30 ‘likes’ and the next sort of hour or couple of hours... and they’d be people saying ‘welcome’ or if they’ve said which region they are they’ll say ‘oh yes I’m in that region too’, or ‘I’m going through chemo’ or ‘I’ve just been diagnosed’ (Photo-elicitation: Jayne).

Women’s sense of community and affective positive response is also encouraged through moments of fun and collective camaraderie. YBCN created #christmaschemobrow, to encourage members to share photographs of their Christmas themed ‘eyebrows’ (Figure 7-17: Delphi 12):

‘It was entirely taking the piss out of ourselves for having no eyebrows and making the most of the things we could do. There’s a lot of that that happens internally in the group’ (Photo-production: Delphi).

Delphi captures how women become intertwined in each other’s lives in Figure 7-17, image 10. Women build attachments with other women beyond the experience of LwBBC - ‘you kind of make friends who become friends on a personal level’ (Deborah). Delphi’s image references the extension of sharing experiences to including women’s children too.

Developing this sense of connectedness was warranted by having the ability to curate content and forward posts which would be of interest to friends LwBBC or their children. This moves focus away from centring exclusively on ‘cancer’, to cancer in the wider context of their lives:

‘She’s about six and she’s really into storms and storm chasing and things. And it was something we’d talk about on the group, completely unrelated, but we’d all share that. And one of the things that we do is (pause) people...women that I know, and I’ve got to

know their children and certain traits of their children and equally the same for all of us, when we spot things we'll share them with each other' (Photo-production: Delphi).

Blogs posted on The Huffington Post website were shared in a Facebook wall post. Women curate information with affective gestures to provide and deepen personalised support e.g. signs in the form of kisses (xxx) (Figure 7-18: Image: Deborah 15)⁶² suggest love and care. 'For you' demonstrates targeted, composed communication signalling personal connection; a knowledge of the intended recipient and their likely response:

'somebody had sent that back to me saying 'for you'. One of my friends had sent that back saying don't worry, you're not the only one who has got a bit cross about this'. (Photo-production: Deborah).



Image: Deborah 15

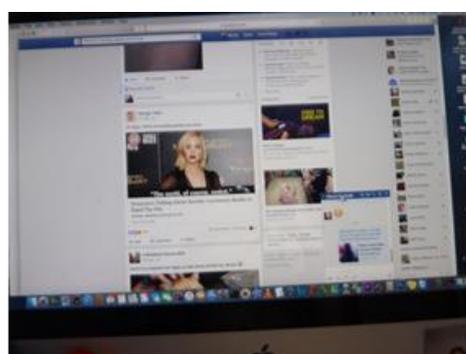


Image: Wendy 4

Figure 7-18 Targeted composed communication and emotional connectedness

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Many women employed direct messaging on Facebook as a one to one emotional support mechanism (Figure 7-18: Wendy 4). Sharing content indicates a tailoring of support and offers psychosocial support through demonstrating someone is thought about and loved.

7.3.5 Summary: Theme One - Subtheme Three: Feeling emotional (dis)connected

Feeling an emotional connection to other women LwBBC was a significant factor in using social media platforms. Different social media are used to navigate feelings of disconnection from others; to mediate relationships to gain emotional support when and how women need

⁶² This image was also included within the previous subtheme – managing own informational needs. This shows the entanglement of affective responses, targeting communication and sharing information.

it; and to connect with other women who share similar experiences and ‘understand’. Some women found WhatsApp supported the continuation of relationships post diagnosis that had begun to feel disconnected or strained face to face. This enables ‘others’ to provide emotional support and to reduce social embarrassment about how to talk about cancer. By integrating dialogue about everyday experiences of LwBBC into WhatsApp group conversations, women succeed in attending to their need to talk about their experience and ‘other’s’ are able to craft effective supportive responses normalising conversations about cancer. Additionally, women LwBBC use social media to ‘test’ existing friendships by gaining a sense of the availability of support and by encouraging that support to be physically present through sharing visual evidence of ‘friendship’ visits. Women show highly tailored approaches to accessing emotional support, at times which are particularly challenging, including specific moments within the chemotherapy cycle. These reduce women’s sense of isolation and feelings of loneliness. Women curate content to deepen relationships through targeted communications developing reciprocity through mutually beneficial exchanges. Women’s stories suggest positive experiences of targeted, composed communication; one click communication and broadcast messaging suggesting that all can support the development of a sense of belongingness, unity and togetherness. Through using different platforms simultaneously women can scale how private or public they are about different aspects of their experiences. Different platform functionality therefore enables women to scale and reduce distance between themselves and others to suit their needs.

Chapter 8: Theme Two - Navigating disrupted identities

8.0 Introduction

Women experience significant challenge to their sense of identity when LwBBC. Previous research has found that a diagnosis of breast cancer can be experienced as ‘biographical disruption’ (Hubbard & Forbat, 2012; Liamputtong & Suwankhong, 2015; Trusson, Pilnick & Roy, 2016). Biographical disruption occurs when women experience disruption to their taken for granted expectations of their life trajectory (Wilson, 2007). This is manifested by experiencing a ‘critical break’ between past (pre-diagnosis), present and future lives (Bury, 1982; Frith, 2011). This theme explores the disruption women experience post diagnosis; how it is experienced in their lives generally and through social media specifically. Figure 8-1 presents the three subthemes that comprise this theme and defines their scope.

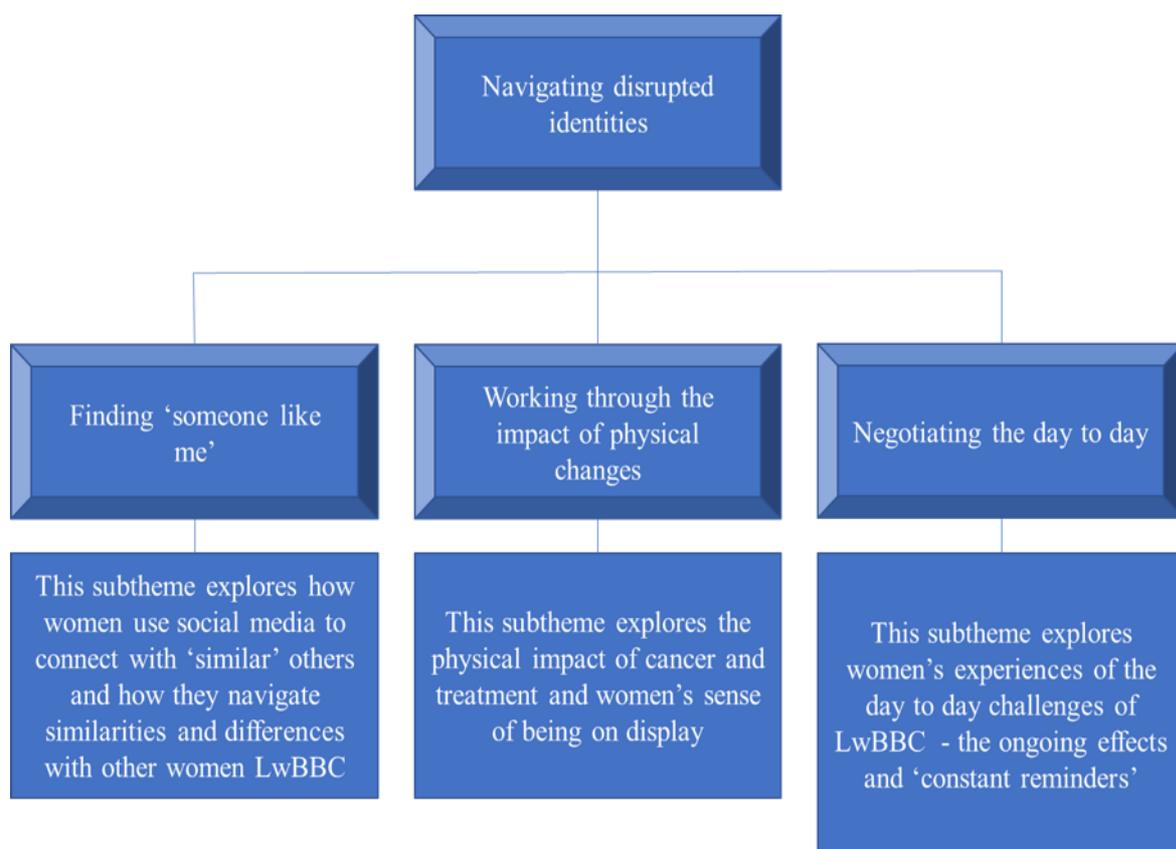
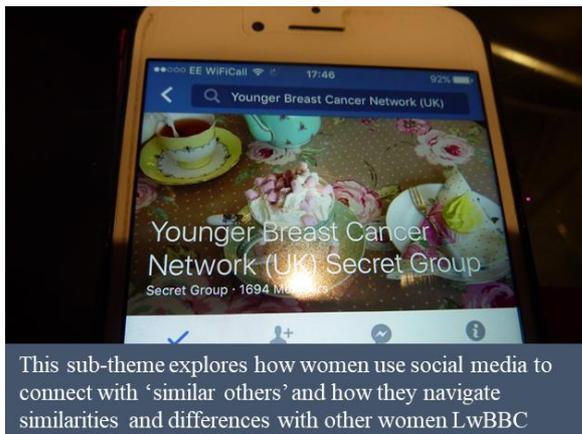


Figure 8-1 Navigating disrupted identities - Thematic map

8.1 Subtheme 1: Finding someone like me



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‘I suppose I was looking for somebody like me. Somebody my age, somebody who had, was going through or had just recently been through what I was about to start. So that’s what I was looking for really. Somebody similar to myself’ (Kirsty).

Figure 8-2 Finding someone like me

8.1.1 Introduction

Previously it has been reported that most cancer patients typically do not have anyone within their personal networks who share a similar experience (Han, Hou, Kim & Gustafson, 2014). Similarly, in this study, most women had no previous experience of breast cancer:

‘I don’t know anyone else who’s had it. Or if I do, it’s older people’ (Photo-elicitation: Sarah M)

‘there was no one on my Facebook that had had breast cancer, I don’t think’ (Photo-elicitation: Liz)

‘I didn’t know of anybody else who had had breast cancer’ (Photo-elicitation: Jojo)

‘I don’t know anybody with breast cancer. It’s not something I know about or have anyone I feel I can talk to about it’ (Photo-production: Michelle M)

‘I hadn’t come across anybody before’ (Photo-production: Nicola)

‘I’ve never met anyone who has had chemo’ (Photo-production: Michelle Mu)

Not knowing people who shared the same experience led to women searching online to find other women who had been diagnosed with breast cancer.

Women’s success in identifying ‘similar others’ was shown across interviews. She was the ‘same as me’ (Kirsty); ‘she was just like me’(Kirsty); ‘we were all in the same boat’

(Delphi); 'we were both in the same boat' (Wendy); 'everyone's in the same boat' (Kirsty); 'we've all been in the same boat' (Mandy); 'we have all been in the same boat at some time' (Jojo); 'we're all going through the same thing' (Michelle J); 'same as you' (Kirsty); 'other people being in the same situation' (Jojo). All those in the photo-production study, under 12 months since diagnosis, had searched online for 'young breast cancer' (Michelle J); or 'young people with breast cancer' (Kirsty) either through Google or Facebook:

'I was just on Facebook and typing breast cancer; 'young breast cancer'. I didn't know they existed and then stumbled across it' (Photo-production: Michelle J).

Women diagnosed over five years previously described a longer timeline before they found 'similar others'. For Mandy this was six months post diagnosis; for Jo, two years post diagnosis; and for Delly, nine years post diagnosis. The speed with which women are now able to locate 'similar others' could be explained by rising use of smartphones, the embeddedness of social media in women's lives, and an increase in breast cancer groups on social media platforms.

8.1.2 Who do women search for?

Women used different criteria when looking for 'someone like me'. For many, this related to age and being at similar life stages. At diagnosis, younger women struggled to identify with the other women that they met in clinic: 'everyone looked really old' (Michelle J). Jayne felt isolated within clinic waiting rooms and when attending a local support group. She identified herself as younger than most women attending and was therefore 'not one of them':

'honestly just sitting in those waiting rooms with all these people around me that were worried out of their minds and a lot of them would look at me because I was in [names of local and specialist hospitals], erm a lot of them would look at me and I sometimes felt they were looking at me and 'she's here with her mum', 'she's just waiting for her mum'. And I would get these almost derisory looks, or I felt that. That was my reaction to the environment. So, whether that was to do with my feeling that well 'I'm not one of them' because I'm not old. That feels really mean. Because I know they are not old either. But I just felt completely isolated from them. So, going online and being in this Facebook group - the fact that it says that it's Younger Breast Cancer Network...' (Photo-elicitation: Jayne).

Jayne felt isolated from *'all these people'*. Jayne imagines that *'they'* think she was in clinic to be *'with her mum'*. She distances herself from the other women she meets in the waiting room *'I'm not one of them. I'm not old'*. In contrast, being in a 'Younger' Facebook group which she perceives as relevant to her experiences removes that sense of isolation.

The disconnection Jayne felt relates to differences in age and life stage. Sarah J also found it difficult initially to navigate getting the 'right' type of support. She talked about using the closed Facebook group (YBCN) and online breast cancer forums specifically in relation to finding out more about a pain in her hip. Sarah found online breast cancer forums unhelpful, as those participating were women of all ages:

'I'm going looking for information because of the pain in my hip. I go on the forums and everyone's going 'oh yeah, I had that. It was arthritis'. 'Oh, maybe it's arthritis'. And then I go, 'actually, well no', 'cos these people are all 60. It's not the same. Whereas, when I ask on the Younger Breast Cancer Forum they are not going to go 'well, it's probably arthritis, because it's unlikely to be (laughs)' (Photo-elicitation: Sarah J).

Sarah conveys the sense that she did not feel appropriately listened to or responded to (Brown & Gilligan, 1992) by members of a more general breast cancer forum. Sarah (aged 29) dismissed these comments *'cos these people are all 60. It's not the same'*. Issues of relatability to others therefore influence women's use of social media platforms. Sarah J and Sarah M were positive about finding a Facebook closed group of 'younger women' because it was *'just specific to young people'* and not *'general to everyone'* (Sarah J). These searching practices show age as an important facet of identity for women diagnosed with breast cancer. Women did not convey a sense that 'age' was an issue discussed within the clinical setting or that being a younger woman at time of diagnosis was 'different'. Rather, the experiences of being in clinical settings with older people appears to lead women to seek 'similar others' in different environments. Some women were frustrated at not being able to join the Younger Breast Cancer Network because at 50, they were too 'old':

'there's a young women's breast cancer group. I'm not allowed to join it because I'm too old "... " I don't feel great right there (laughs)' (Photo-elicitation: Sheena)

The significance of being a member of YBCN was brought to the fore through photographs captured of the YBCN profile page on Facebook by two women recently diagnosed (Figure 8-3: Images Michelle J 5; Michelle M 7).

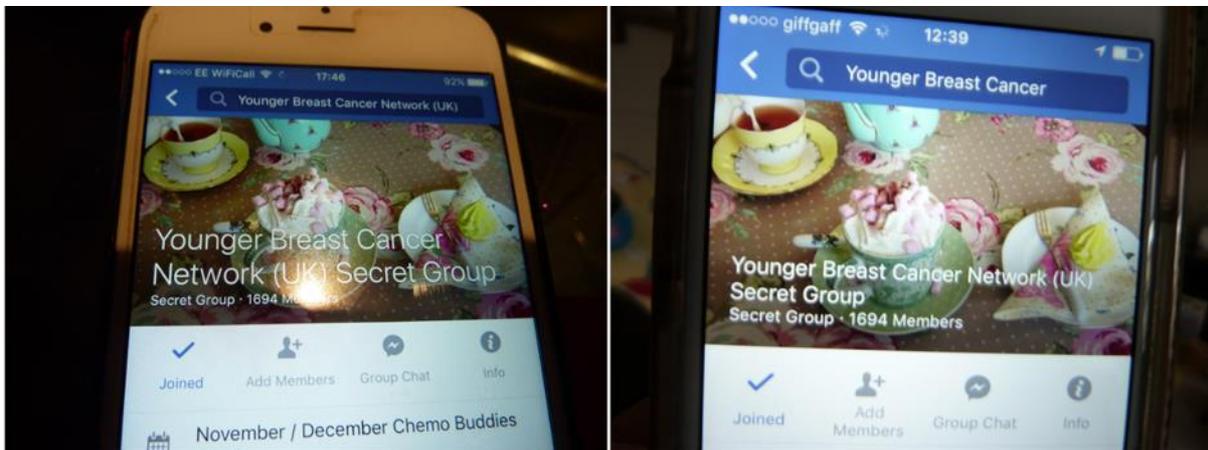


Image: Michelle J 5

Image: Michelle M 7

Figure 8-3 The Younger Breast Cancer Network secret group on Facebook

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The almost identical images of smartphone screens mirror the accounts of ‘finding someone like me’ and the similarities women are looking for in others diagnosed with breast cancer. Both phone screens (Figure 8-3) report YBCN as ‘a secret group’ having 1694 ‘similar other’ members. This informs younger women that they are not alone and are part of a network of women like them. The images used for the homepage by YBCN suggest women are joining a vibrant social space focused on chat and relaxation (tea and cake). Michelle J’s photograph (Image: Michelle J 5) gives insight into her also being part of a closed group (November/December Chemo Buddies), within the wider YBCN group, leading still further to greater homophily within special interest Facebook groups.

For some women, being able to see similar others in ‘*the same boat*’ enabled adjustment. Kirsty described watching a YouTube video:

‘There is a girl called Lara Honner who has done this video called ‘Get Your Tits Out’ and I suppose that makes you like, when you come across it you think ‘what’s that’ and I watched that video about three days after I was diagnosed and it was like a brace yourself and watch this type of

experience so I suppose I was looking for somebody like me. Somebody my age, somebody who had, was going through or had just recently been through what I was about to start. So that's what I was looking for really. Somebody similar to myself.' (Photo-production: Kirsty).

Kirsty casts this YouTube video as providing both a visual mirror and a view of a possible future. Kirsty's view '*it does make you think that you can do it*' suggests YouTube content offers women vicarious experiences⁶³, which can work to reduce uncertainty and develop greater understanding, enabling women to adjust and be prepared for what lies ahead.

For some women, finding '*somebody like me*' was not simply related to age but also related to type of breast cancer⁶⁴. Michelle J talked about her early use of YBCN and her interest in other women diagnosed with triple negative breast: '*I'm on the triple neg group*⁶⁵', '*I was just obsessed with everyone that had triple neg breast cancer*'. She gave voice to the challenges of negotiating similarity and difference when a 'triple negative' member of the community found shadows on her lungs:

'and people were saying 'I've got another scan coming up. They've seen shadows on my lungs and they were maybe at the same stage as me. And I was thinking 'oh gosh, is this going to happen to me?' (Photo-production: Michelle J).

Michelle demonstrates significance given to type of breast cancer for her. Indeed, the psychosocial needs of women living with Triple Negative Breast Cancer may be unique due to its aggressive nature, with high recurrence and mortality rates (Turkman, Kennedy, Harris & Knobf, 2016) potentially indicating a need for increased support. Michelle describes her anxiety when confronted with other 'similar' women's experiences soon after diagnosis. Michelle M stated that women's stories were '*bordering on the unhelpful actually*', while Michelle J commented:

63 Bandura (1993) contends that vicarious experiences – observations of other people, particularly those seen as role models – increases self-efficacy by raising individual beliefs that they too can master a similar activity or situation.

64 There are different types of breast cancer including (but not restricted to) invasive; non-inflammatory; triple negative; ductal carcinoma in situ (DCIS); lobular carcinoma in situ (LCIS); invasive lobular; and Paget's disease. (Types of breast cancer and related conditions, Cancer Research UK, 2017)

65 Triple Negative Group.

'sometimes I find it quite overwhelming when I've read it all because I can relate to it obviously first hand []⁶⁶ it just makes me feel a bit low when I read it, even though I know everybody has got a different journey. It still scares me when someone says it has come back or they've got a secondary. My mind is not really attuned yet to kind of just, I don't know, it just scares me actually' (Photo-production: Michelle J).

Women can (and do) seek out personalised support. They also get benefit from connecting to women at the same stage of 'the journey': *'You become aware of who is at the start of the journey as well' (Michelle J).* Kirsty talked through a photograph (Figure 8-4) she had taken in the chemotherapy unit of someone she knew via YBCN, on the same chemotherapy cycle; she commented:

'social media has forged that relationship. I saw her sitting in a chair, and recognised her and went and spoke to her because I'd seen her on the internet' (Photo-production: Kirsty).



Image: Kirsty 2

Figure 8-4 Meeting Facebook 'friends' in the chemotherapy unit

© Kirsty /15.03.16/ University of Salford / Cathy Ure

Here, Kirsty warrants the use of Facebook to identify other women at the same stage of treatment and same hospital as her.

⁶⁶ Square brackets indicate the removal of some text to reduce the size of the overall quote. This has been done to aid the reader. Care has been taken to ensure no material changes to the meaning of the topic under discussion occurred

'I knew what she looked like and also I'd seen there were a couple of girls who said they would be treated at [hospital]. So, you have a better look at them and think oh I might see you. And then, so I went and spoke to her because I'd seen her on the Facebook group. So, she's there every time I go, you see, because we are on the same cycle. So, I speak to her every time. But I wouldn't have spoken to her normally because of the distance [between chemotherapy chairs]' (Photo-production: Kirsty).

Kirsty shows how social media use makes the distance in the chemotherapy unit smaller. Through 'knowing' someone in a different context, a relationship is already established through membership of the Younger Breast Cancer Network leading to conversation that would not have happened '*normally because of the distance*'. Aspects of breast cancer treatment have become digitally mediated phenomena.

Exploring how to live with a changed body was also digitally mediated (and relates to Chapter 8; section 8.1.3. Managing the challenges of physical change). For Millie, after two diagnoses of primary breast cancer, in 2002 and 2013, and a bilateral mastectomy, it was important to connect with other women who were 'flat' and who saw living breast free as a positive life style choice;

'a lot of us didn't want reconstruction and some were thinking about going flat completely and one of them mentioned the Flat Friends group cos I, I wear a (pause) prosthesis; I didn't have reconstruction I decided to join that group cos at one stage I thought erm do I go flat completely?' (Photo-elicitation: Millie).

Here, Millie demonstrates that 12 years after initial diagnosis (now aged 67), she has joined a new Facebook group – Flat Friends (established 2014) – to negotiate her decision as to whether to go '*flat*'. Observing other women's experiences supports growing self-efficacy (Chapter 9: (Re)gaining a sense of control) in how to be 'flat' and offers an alternative paradigm for body confidence post mastectomy. Millie shows the longer term biographic disruption of breast cancer diagnoses; the ongoing navigation of LwBBC; and the benefit of joining new groups to support that navigation as women change and age.

While age, cancer stage, being at the same stage of 'the journey' and post-surgery body adjustment, were all reasons given for seeking out similar women on Facebook, life perspective was identified as another important search criterion. Mandy voiced a need to do

'what the other positive people are doing' and to find 'other likeminded people'. Mandy makes a clear distinction between what she found helpful and what she found frustrating:

'I wanted to find other positive social media sites that were promoting maybe exercise, because I wanted to get into that, and I wanted to find other like-minded women that weren't just kind of having cancer and just kind of, you know, withdrawing into themselves, blah, blah, blah, and then kind of not changing their life, I was like "no, my life's, got to change, it's going to change" and so I was looking for those kind of things really, so I found a few of those, and, so you'd get posts every day, you'd see those and um, and um, I also looked for other things to do, like singing groups, 'cause I'm in a singing group at the moment' (Photo-elicitation: Mandy).

Mandy uses social media sites to help make changes to her life. This suggests her agentic use of social media has transformative potential supporting positive psychosocial benefits. Mandy is dismissive of people 'just kind of having cancer' and states her desire to 'find other positive social media sites' after initially using a 'positive' American triple negative breast cancer Facebook group. Mandy voices a positive, optimistic approach to life 'my life's got to change, it's going to change' with a more holistic approach to supporting her well-being – exercise and mindfulness - gained through singing. Facebook enables Mandy access to similar women who model positive life styles and provide focus on positive change through posting every day.

8.1.3 Managing the challenges of 'being similar yet different'.

As outlined, previous literature has not explored women's accounts of difference within the online breast cancer community or the impact this has on women's ongoing participation. In this study, it was found that women find social media interactions challenge their developing sense of identity as part of this community. For instance, when Denise picked up the photo-elicitation photograph relating to cancer charities in our interview, she commented that she had not looked at any charity forums online.

Cathy: Have you read any of their blogs?

Denise D'A: No. No, I haven't. Erm, probably because erm my side effects have been I think, I am coping very, really really well and I feel erm when you read the side effects they're horrendous and I haven't felt horrendous. However, that doesn't say that when I, and I don't know, and I still don't know how my body is going to cope but if it does become horrendous then I know they are there.

Cathy: OK

Denise D'A: Because if people are going through, say a horrendous experience, they really don't want me saying 'I'm really well and I've not' you know. I think you need to share the same level that you are on so that, so that ... Or share the level that they are on, you've got through it and look at how life is now. I'm doing a marathon. So, I didn't feel as though I was there yet, to share with somebody' (Photo-elicitation: Denise D).

Denise did not read blogs because she considers blogging as an inherently reciprocal process – ‘you need to share’ - aimed at achieving mutually beneficial exchange (Lewis, 2015). In line with the concept of a hierarchy of cancer suffering (Ennis-O'Connor, 2013; Stordahl, 2016), Denise reflects on her experience in relation to others potentially having a ‘horrendous experience’. She comments: ‘They really don't want me saying, ‘I'm really well’’. Sheena also experienced disconnection in relation to the politicisation of breast cancer on Twitter and how women’s interactions demonstrate a hierarchy of suffering. Sheena states, ‘I followed a lot of people initially’ and engaged actively in directed communication ‘I got involved in a lot of conversations’, yet found the political undercurrent resulted in a change in her level of involvement. Sheena shared: ‘I have ... done less’; ‘I probably pulled away’; comments ...put you off really’. Both Sheena’s experience and Denise D’s view that forum use and reading blogs is reserved for those who can ‘share the same level’, is problematic for women wanting to explore their own and other’s experiences. This notion may result in missing the benefits found in lurking or reading others’ posts (Setoyama, Yamazaki & Namayama, 2011; Van Uden-Kraan et al., 2008). Notably, the evidence relating to the benefits of lurking in breast cancer communities are reported from questionnaire-based studies and explore posting and lurking in online breast communities, not social media platforms. The literature needs extending, to understand whether differences in motivations for posting and lurking in closed breast cancer Facebook groups and the psychosocial benefits achieved from these interactions align with the online community literature. Decisions to not engage with other women because they are not at the ‘same level’ may potentially impact psychological well-being by working to invalidate the experiences of those who are not ‘on the same level’. Similarly, Denise assumes her contribution would not be valued however, bloggers gain benefits from a sense of perceived social support (Baker and Moore, 2008).

The news that women would need to have chemotherapy was often reported as significantly challenging. Greenhalgh (2017) asserts that sociological accounts of chemotherapy tend to focus on 'its dramatic dark side' (p.5). Women felt they were unable to post about their chemotherapy experiences if they were not 'horrendous'. Michelle M had a different experience of chemotherapy than the 'horrendous experience' she had been anticipating yet felt that telling others about this 'different' less traumatic experience was not one she could share easily online:

'people aren't posting on there 'oh, I had my chemo. Actually, it wasn't that bad. OK, I felt a bit rough for a few days but I'm quite perky now'. People don't post that' (Photo-production: Michelle Mu).

This suggests that discussions of 'horrendous' chemotherapy experiences can silence other women's experiences within the breast cancer community. These narratives give weight to the view that negative stories are more prolific in online breast cancer communities than positive stories (Batenburg & Das, 2015; Wen, McTavish, Kreps, Wise & Gustafson, 2011). This may be a response to women feeling they cannot share fully how they feel about their experiences with close family and friends (Chapter 9; section 9.1) and that their experiences are silenced by wider cultural discourses (Ure, 2014). In comparison, it is interesting to note that recently 'horrendous experiences' of childbirth have been found to be silenced in online discussions about childbirth (Das et al., 2017). The evidence that women's interactions in online communities can give voice to and silence particular narratives is of cultural and societal significance. The inability for all voices to be heard works to invalidate some women's experiences and impacts on self-esteem and adjustment. Consideration should be given to the potential impact the dominance of 'horrendous' discourses relating to chemotherapy has on women's adjustment to a diagnosis of breast cancer. As Greenhalgh (2017) argues medically, breast cancer is heterogeneous with a range of chemotherapy regimens employed dependent upon the stage, grade and molecular profiling of the cancer. Wider public understanding of the range of responses to chemotherapy may work to reduce anxiety in the immediate aftermath of diagnosis, while staging and grading work is completed.

The use of Facebook, for some, supported reflection of their current position in relation to others living with cancer. This comparison led to Denise D telling herself '*get a grip*' after reading accounts of children online going for proton treatment. When Jojo arrived for

interview, she was concerned that having MS (Multiple Sclerosis) would impact on her ability to participate in the study. She walked with a walking stick and struggled with pain in her ankles during our interview. Despite this ongoing pain and challenges to her own mobility, she commented:

'in the past month or so I've heard about so many that have died in the [Facebook] group, that sort of like ...And some of the comments some of the ladies put, it's just heart-warming. And I just think 'oh gosh'. You know, what, I'm moaning because I've got a bad back. I'm moaning because I've got a sore ankle and look at these other people who have got to face harder situations than what I am in' (Photo-elicitation: Jojo).

Observing the challenges other women face results in Denise and Jojo expressing more optimistic perspectives. They feel lucky to be in a better position *'I felt I was very lucky' (Denise D); 'I'm ok; I've got no problems' (Jojo)*. This sense of being lucky in comparison to others was voiced by nearly all women including Jo who is living with secondary breast cancer:

'I'm lucky in a way, because I have the secondary breast cancer where it is, it's not affecting me as much as it could do. I go to clinic and I see people with walking sticks. People in wheelchairs, and that is a worry for me. The progression of things. What could be' (Photo-production: Jo).

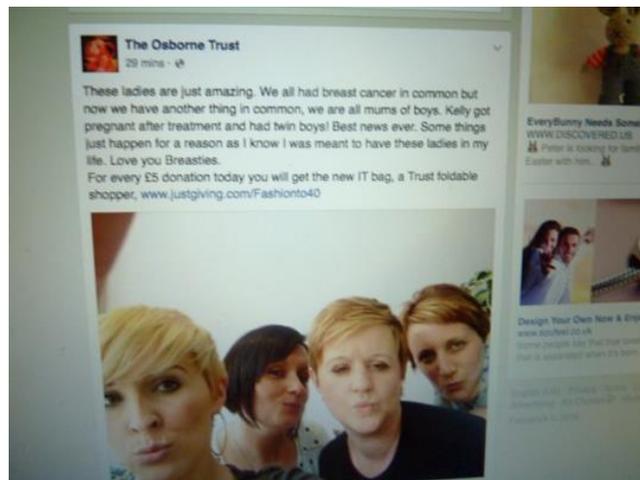


Image: Deborah 7

Figure 8-5 The Osborne Trust
© Deborah / 11.03.16 / University of Salford / Cathy Ure

Deborah provided images which enabled her to reflect on being the same but different through identifying with other women's experiences. Deborah highlighted the work of The

Osborne Trust⁶⁷. As Deborah talked about Figure 8-5 (Image: Deborah 7), she challenged the viewer to consider any preconceptions they may have of the women pictured:

'you look at them...they could be walking down the street. You would never know, would you? You would think that they were young girls, out on the town. Taking their selfies. Having a good time...and wouldn't have had to contemplate dying, leaving a young baby behind. You wouldn't know, would you?' (Photo-production: Deborah).

Under 45 when diagnosed, Deborah was and is a younger woman LwBBC. Her reflection on seeing a group of young(er) women diagnosed with breast cancer vocalises her own experience: *'you would never know, would you?'* She employs taken for granted social norms *'walking down the street'*; *'taking selfies'*; *'having a good time'* to highlight the disconnect between the social expectation of biographical continuity and having *'had to contemplate dying'* and *'leaving a young baby behind'*. As a member of YBCN, she is similar yet different to the women pictured. The visual construction of the image – four women in their late twenties/early thirties, with similarly styled on trend hairstyles, posing for a group selfie proffers a strong visual group identity which works to construct this group as both similar and different to other women LwBBC.

While Deborah voiced a sense of similarity and difference with other younger women LwBBC, Nicola and Michelle also articulated notions of this difference in relation to other members of YBCN. They are both part of YBCN and a 'rebel' invite only secret group 'The BBB's' – The Bad Arse Booby Bitches. Initially set up as resistance to the moderation of the YBCN group - *'we're rebelling'*; *'we swear a lot'*, Nicola describes the group aims as being different to the aims of YBCN:

'it was never meant to be a support group as such, in the way that Younger Breast Cancer Network is and what have you. It was more a case of we were a group of friends that had met through the Younger Breast Cancer Network. We still wanted to keep in touch with one another and talk about our experiences, but we didn't want it moderated as such []. It's more a group of friends that can come on there and we can...: Like you get

67 The Osborne Trust provides children aged 16 years and under whose parent/s have cancer access to recreational activities during a parent/s treatment by funding up to 3 activities such as a cinema trip, play centre visit or a meal out. Activities are supervised by an adult family member or friend. The aim is to offer the parent/s some rest and the children some time away from all that cancer entails (The Osborne Trust, 2018).

...sometimes people put on announcements that they don't want to put on their main Facebook, We call it Big Face' (Photo-production: Nicola).

Nicola describes this 'alternate' group as related to focusing on 'a group of friends' – individuals who have come together through participating in the YBCN group:

'I'm in this group because I've got a friend and her sister had breast cancer the year before me. And she is too old for the younger one [YBCN]. So she said Michelle I'm in a group that's called BBB, so why don't you join it, because I know you directly and then it's a laugh and it's not all about breast cancer. So, I said OK. So, I've joined it. And it's a lot of swearing, people having breakdowns of relationships, husbands have been cheating. And they look at themselves in the mirror and they've had a double mastectomy and they are no longer confident. And we talk about all things like this but there's a lot of swearing and light- hearted humour in there. So, it's doesn't always have to be about cancer, which is nice' (Photo-production: Michelle J)

Michelle J comments 'it's a laugh and it's not all about breast cancer' where women don't have to 'hold back'; implying limitation on what is appropriate to post on YBCN. Its creation reflects the dynamic emergence of a multiplicity of niche groups in which women seek greater connection with people who they see as likeminded. The ability for anyone to establish alternative groups (Chapter 9: section 9.2.2. Being Productive) enables women to navigate similarities and differences by moving between groups simultaneously in multiple online spaces.

Some women actively avoid participating in face to face groups or online groups as a coping strategy. Eleanor, diagnosed twice in 2006 and 2010, is a lone voice in articulating a view that sharing experiences would be unhelpful to her: 'I would never join a group er in person or online'

'because even when you are in hospital and you're surrounded by other people who are having mastectomies, even after 24 hours I was, you start off by thinking 'oh well everybody knows how we all feel' because you know you talk about your history and when did you get it and what did you have done and blah blah blah and is this your second time? And you know but after 24 hours of that you just want to run away and have a normal conversation. So, I certainly didn't want to go to a group or join anything on Facebook where the communication was all about your experiences and you know, and how are you today? and 'oh, that happened to me' and you know' (Photo-elicitation: Eleanor)

Eleanor describes a notion of ‘how women talk about their mastectomies’. Her use of ‘*blah blah blah*’ indicates these historical accounts as repetitive and as ongoing relational work from which she gains little benefit. She needs ‘*normal conversation*’ rather than communication ‘*being all about your experiences*’ as the most appropriate coping strategy for her. While Eleanor rejects conversations centred on sharing experiences, Lizzie (diagnosed in 2006) brought forward the challenges of meeting other women LwBBC. She commented:

‘some of the women that I have met who have had breast cancer, that’s the first thing they want to tell you. And sometimes if you have a conversation with somebody else who has had breast cancer, it feels like a competition because they say, ‘I’ve had this and have you had that’ and I find that really hard to deal with to be honest’ (Photo-production: Lizzie)

As women move further away from diagnosis, it seems the notion of the hierarchy of cancer suffering remains ever present when women meet other women LwBBC. Rather than embracing ‘similarities’, as was seen in the approaches of women diagnosed within the previous 12 months, Eleanor and Lizzie adopt strategies that distance themselves from other women LwBBC. Eleanor comments: ‘*I wouldn’t tell you*’ [*that she was LwBBC*] while Lizzie states ‘*I don’t tell people unless I have to*’. Despite this apparent reluctance to share aspects of their breast cancer identities with others, both Eleanor and Lizzie approached me to participate in this research. This potentially suggests women seek out specific audiences to share their experiences, where they sense they will have the opportunity to share, in a non-competitive environment.

8.1.4 Summary: Theme Two - Subtheme One: Finding someone like me

In the immediate aftermath of a breast cancer diagnosis, many women use social media to find ‘similar others’. The opportunity to see women who are in the ‘same boat’, look similar and are experiencing similar treatments reduces uncertainty, enables adjustment and increases women’s self-efficacy. Significantly, the need to find ‘similar others’ can continue along the ‘survivorship’ trajectory with women joining new social media groups as they seek out individuals from whom they can learn to support decision making. Relatedness is a key factor in supporting relationship building on Facebook and Twitter. When women felt ‘different’

between themselves and others, either in relation to age or sometimes treatment regimes, they sought out other women in other groups they more closely identified with. This shows greater selectivity in relation to sourcing social support through social media. As breast cancer groups become more ‘niche’ – for younger women or for ‘bad arsed’ women, women are increasingly able to find a supportive environment of likeminded women. That said, some women find interactions online more challenging and suggest evidence of a hierarchy of suffering. When women move away from discussions on Twitter and Facebook because they feel their experiences are invalid, the community they seek to be part of and contribute to is silencing them. Women’s experiences encapsulate the ongoing debate about the “internet’s potential to create and diminish community” (Batenburg & Das, 2015, p.585) with women experiencing participation as both positive and negative, sometimes simultaneously. This indicates that many women LwBBC begin complex relationships with ‘similar others’, however they decide to construct ‘similar others’, across the timespan post diagnosis.

8.2 Subtheme 2: Working through the impact of physical change



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'I think as well with my daughter sort of saying, "you don't even look like my mum anymore" that's hard' (Michelle M).

Figure 8-6 Images taken a few months apart to show 'physical change'

8.2.1 Introduction

Women treated for breast cancer can experience marked changes in their physical appearance (Coll-Planas & Visa, 2016; de Boer & Slatman, 2014; Doh & Pompper, 2015). Women used the photo-production methodology to produce materials to enable conversations about

physical appearance. Women provided ‘selfies’ knowing they were presenting their body in a way that can/could be observed as they invited me to observe and explore their photographs with them. These photographs led to considerable conversation around the impact of treatment on women’s bodies. Common to these accounts is a sense of ‘being on display’ or being visually ‘different’. Sometimes these challenges were navigated using social media but not always. This subtheme initially establishes some context by exploring how women talk about the biographical disruption experienced through changes to their physical appearance. Then, women describe how social media enables them to ‘out’ the challenges of living with significant changes to their appearance and to incorporate changes into daily conversations. Finally, women’s use of selfies to explore these changes is discussed. Their descriptions indicate social media can be used to help women navigate their responses to physical changes and support adaptation.

8.2.2 Hiding changes

Women at different stages of LwBBC, who had received chemotherapy, provided detailed accounts of the impact of hair loss. These included the fear of anticipated hair loss:

‘Every time I went to see my breast care nurse I would be crying. I don’t want to lose my hair. I don’t want to lose my hair. I was so upset. Anyway, those are the only people that knew how upset I was over it, as well my husband.’ (Photo-production: Wendy)

Wendy hid the anticipated impact of her hair loss from most of her friends and family and demonstrates her need for emotional support from her breast care team. Other women at the early stages of treatment shared graphically their emotional responses to losing their hair – *‘I feel sick’*⁶⁸ (Michelle M). While Eleanor, ten years post initial diagnosis, reflected on how her normally stoic composure was also affected by hair loss:

‘For the whole of the time I’d been...I’d had breast cancer so, if you call it say ten years, I’d only cried once. I cried when my hair started falling out’ (Photo-elicitation: Eleanor).

While women show ongoing reflection on losing their hair, they also show the emotional challenges inherent in supporting their own families who are also living with the experience

68 iPoems used to ‘hear’ women’s voices formed part of the analysis process. Appendix 21 provides an example of an iPoem. Here, Michelle shares her experience of losing her hair during chemotherapy.

of their hair loss. Michelle M’s young daughter challenges Michelle regarding her continuing identity as her mum; signifying the importance of external physical appearance to others too:

‘because of my hair and she’s been sort of saying ‘you don’t look like my mummy any more’ and crying. And the breast cancer nurse when I first got diagnosed gives you like a storybook called Mummy’s Lump which we read and obviously there’s the 3 year old and she doesn’t get it but then there was a picture in there of a women with no hair and a wig on the side and she screamed her head off and ran out of the room, which is part of the reason I am doing the cold cap⁶⁹ because of me thinking if I keep some hair then it is easier for her to cope with’ (Photo-production: Michelle M)

Michelle demonstrates instrumental and emotional support being provided by breast cancer nurses through the provision of a tool - ‘a storybook’ - to support women in talking to their young children about the physical impact of chemotherapy. She highlights the complexity of navigating her own reactions, as a women and mother, and others emotional reactions to her hair loss. She indicates that the complex relationship women and girls have with (their) hair is established from a very young age.

Women describe the emotional impact of the physical changes brought about by treatment: ‘I just don’t feel like me’ ‘I hate the way I look’ (Michelle Mu)); ‘I don’t recognise myself’ (Kirsty); ‘everyday it’s a shock’ (Delphi). Below a ‘timeline’ of women participating in the photo-production study is reproduced chronologically. Each of these women raised hair loss as an issue. The timeline begins with the participant most recently diagnosed at time of interview.



Figure 8-7 Using hair to talk about loss, adaptation and growth

69 Cold caps can be worn during chemotherapy treatment to try and reduce hair loss. They work by reducing the amount of chemotherapy drugs that reach the hair follicles (Macmillan Cancer Support, 2018).

© Michelle Mullany / 03.03.16 / University of Salford / Cathy Ure © Kirsty / 15.03.16 / University of Salford / Cathy Ure © Wendy Northway / 28.04.16 / University of Salford / Cathy Ure; © Michelle / 29.02.16 / University of Salford / Cathy Ure © Delphi Marmaduke / 05.01.16 / University of Salford / Cathy Ure

One interpretation of this photo-analysis is of hair as a metaphor. Biographical disruption is not only visible through hair loss but women’s continuing focus on their relationship with their hair many years after treatment. Each of the five images is a form of selfie. The women centre themselves in each photograph. The majority of the images present each individual looking directly at the camera almost expressionless. This is in keeping with autopathographic portraits and pictures stemming back to the 16th Century (Tembeck, 2016). Autopathographic portraits, Tembeck reports, typically show a recurring theme; the subject facing the camera in a frontal pose, gazing directly towards the viewer “with the wilful intent to show oneself as being ill or in treatment” (p.4). In contrast to this ‘recurring theme’, Kirsty includes an image with her back to the camera (Figure 8-7: Image: Kirsty 10). This also demonstrates ‘wilful intent’ to show herself as ill and in treatment. She uses the image to discuss issues of anonymity and to reflect on her loss of identity ‘I don’t recognise myself it could be anyone’. Through her account and images, Kirsty represents the notion of herself as stripped back or stripped bare through the absence of distinguishing features such as hair and clothes. Both Michelle M and Michelle J included photographs taken pre-diagnosis to ‘remember’ a past self and an up to date image taken in the week of photo production (Figure 8-8).



Image: Michelle M 5



Image: Michelle M 11



Image: Michelle J 6

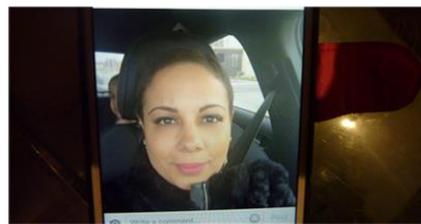


Image: Michelle M 7

Figure 8-8: Images of anticipated biographical continuity and disruption

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In all four images, they have presented themselves in the centre of the image and on their own. The second images provided by each participant are each taken in familial spaces – a bedroom and the family car. These give rise to a sense of the significance of spaces in which women feel secure from which to share vulnerabilities created by changes to physical appearance. The inclusion of pre-diagnosis images suggests significance in visually representing themselves from a time when they anticipated biographical continuity⁷⁰. These photographs both anchor women within their pasts (Harrison, 2002); connect the present with other “spaces, places and times” (Frith, 2011, p.63) and work to demonstrate change in biographical narratives.

Michelle M describes how taken for granted aspects of everyday life are disrupted when having treatment for cancer; *I hate my photos at the moment. I hate my hair. I don't like to look in mirrors*. Looking in the mirror is experienced as distressing, leading to avoidance (hiding), because *this does not feel like me*. The statement *this does not feel like me* contrasts with the more typical description of *this does not look like me*. The juxtaposition of *feel* with *look* shows women’s experiences of identity as multisensory and enlarges the idea of biographical disruption from one related to the ‘external’ look to disruption of the whole self. She asks, *will I ever like, not look ‘normal’ but ‘look like me’ again?*. Through including *not look ‘normal’* one interpretation is that Michelle rejects the idea that Figure 8-8: Image Michelle M 5 is now an image of her ‘normal’ self, potentially suggesting acceptance of a changed or changing self. She had already conveyed a view that Figure 8-8: Image Michelle M 11 is one that she does not recognise as her. In orientating to asking whether she will ever *feel like me again. I think that's what it is* she voices complex identity work in play; by not recognising ‘past’ or ‘current’ self as ‘me’ either in the way she looks or feels.

The complexity Michelle describes is visually captured by Kirsty (Figure 8-9). She explains that in Image 1 she was trying to capture the idea of struggle.

70 ‘Biographical continuity’ is under defined in the literature. Bury (1982) defines biographical disruption as ‘the structures of everyday life, its taken-for-granted features, and the tacit stocks of knowledge upon which they rest are profoundly disrupted (Williams, 2000, p.43). Williams (2000) suggests ‘timing and context, norms and expectations, alongside [sic] commitment to events, anticipated or otherwise, are crucial to the experience of our lives’ and establish a basis with which to understand biographical continuity.

'and this turmoil I suppose. And then I wanted to hide the bald, hairless image in amongst all that. Because it represents how complex you feel really and how complex your feelings are about how you look and what you're going through' (Photo-production: Kirsty).



Image: Kirsty 1



Image: Kirsty 7

Figure 8-9: Visually capturing the complexity of the struggle with hair loss

© Kirsty /15.03.16/ University of Salford / Cathy Ure

Kirsty changes from speaking as a professional photographer *'I wanted to hide the bald hairless image in amongst all that'* to her response as a women LwBBC - *'It represents how complex you feel really and how complex your feelings are about how you look and what you're going through'*. She says the complexity is related to *'how you look'* and *'what you're going through'* positioning disruption to visual appearance as the primary issue affecting how she feels about herself. She uses Figure 8-9: Image 7 to describe wearing wigs *'because for me that represents normality I suppose and the before'*. This is a complex explanation expanded further by her comment that these photographs of her wearing wigs

'are about the kind of outward exterior and the outward appearance and being normal, and fitting in and having hair and all of that' (Photo-production: Kirsty).

In contrast, Delphi talked about being unconcerned about hair loss as a result of chemotherapy because of *'the wigs'*:

'But I really like wigs. I love the wigs. I've got lots and lots of wigs. So, I could change my look and be completely different.....which I really, really, really enjoyed because I do that quite a lot'

anyway.....and fancy dress. I very much like fancy dress. So it was an excuse to do fancy dress every day and I had nothing else to do'(Photo-production: Delphi)

Kirsty feels wearing a pink wig is more 'normal' and more acceptable than 'the shock of a bald woman'. While, Delphi describes the opportunity to use wigs as an opportunity for identity exploration – a performative act (Goffman, 1959) - through 'fancy dress' which she 'really, really, really enjoyed'. Biographical disruption is therefore taken up by some women as an opportunity to explore their creativity in relation to their physical appearance⁷¹. It points to adaptive coping strategies through positive reappraisal. Playing around with aspects of visual identity is described by Kirsty as more acceptable than being bald 'It's not socially acceptable in this western society I suppose'. Denise also raised the social and cultural barriers to be a bald woman. Her comments followed on from a question I had posed about her Facebook use. I was trying to gauge what content she would upload, what she wouldn't upload and why?

Denise: Yeah, I find there's some things you don't share on Facebook, I think, you know. There's certain, I think you should have a boundary of what you share with family and friends

Cathy: Because you said you didn't want to upset other people?

Denise: No, you see

Cathy: Are you more concerned about how other people will respond to it?

Denise: Yeah someone said to me the other day – tomorrow, I'm going for my hair cut to have it cut short - and somebody said, 'oh why don't you just shave it off?' Well, not yet (shaking head) you know it will come erm because people do react to you when you have got no hair and I won't be walking round either with no hair cos er

Cathy: Say that again, I didn't quite understand that

Denise: Pe, people, I've seen people react to people with no hair

Cathy: Yeah?

Denise: Erm and I won't be doing that because I think it puts people in an awkward position, if you are in their company or even if you're at the till or anywhere where you are interacting with that person erm I think they may feel that they have to comment. Maybe. I don't know. I don't want to put my, what I am dealing with on to other

71 Arguably this is practically manifested in women's participation in the photo-production study.

people. Yeah. So, I am going to have it cut short and then eventually, tomorrow I'm hoping they're⁷² going to show me some scarves and things and I'll be ready for when I am, you know, for when I am bald. (Photo-elicitation: Denise D).

Denise describes her Facebook audience as her family and friends and states the boundaries she has in relation to what she shares with them. Denise is anxious about how she will be responded to by others. She shifts our conversation from navigating boundaries on Facebook to how being visibly different may result in people feeling *'that they have to comment'*. This shows a universal concern about how people will respond to her as she visually changes as a result of treatment. Kirsty when discussing image 8-10 adds to this sense of wrestling with visual change. She discusses wrestling with not wanting to *'hide the fact'* that she has no hair and going *'incognito'*.

'I don't really like, obviously I've not worn my wig here, I don't really wear them that much because I don't really want to hide the fact that, I don't...sometimes I want to go incognito but not really. I prefer to just be as I am really' (Photo-production: Kirsty).



Image: Kirsty 7

Figure 8-10 Going incognito
© Kirsty /15.03.16/ University of Salford / Cathy Ure

In contrast to the earlier discussion of wearing wigs *'being about the outward appearance and being normal'* Kirsty states a preference for not wearing wigs and argues attending the interview without a wig as supportive of this claim. In contrast to much of Kirsty's account, her struggle with physical changes to her appearance is shown with the movement between

72 Here, Denise is referring to Look good, Feel Better™, an organisation which helps women manage the visible effects of cancer treatment <https://www.lookgoodfeelbetter.co.uk/>

not hiding *'the fact'*, wanting *'to go incognito'* and preferring to *'just be as I am really'*. The inclusion of *'but not really'* after incognito draws to the fore the ongoing negotiation she is involved in with herself. This followed by *'I prefer to just be as I am really'* shows a tension between being able to be *'as I am'* and perceived social pressures to claim a healthy identity (Dua et al., 2015) by hiding her cancer status from view. In relation to Figure 8-11: Image 5, she comments:

'So, I didn't quite get this one right which was very annoying but because I was using the wrong exposure and lighting that I had I couldn't quite get it sharp. I would prefer that to be really sharp on my hand and softer at the back. So obviously the message is clear with that one I would have thought, but that's my scar from my lumpectomy. And so it's just a bit more straight forward really in terms of the symbols that are in the image and again it's faceless, intentionally faceless. You can't really tell if it's a boy or a girl, really can you? Not really. You probably can just about but it's genderless, faceless, just like very bloke, human, sort of condition I suppose' (Photo-production: Kirsty).



Image: Kirsty 5

Figure 8-11 Treatment scars and identity

© Kirsty /15.03.16/ University of Salford / Cathy Ure

She acknowledges *'my scar'* from *'my lumpectomy'* indicating adjustment to visible evidence of the impact of treatment on her body. Kirsty's visual imagery aligns with Tembeck's (2016) perspective of autopathographical images who contests that images which

“feature or announce illness as integral to their subject matter – operate as statements confirming that these experiences should be regarded as integral parts of the subject’s life” (p.4).

Kirsty then distances herself from considering this as an image of herself and rather studies it objectively as a professional photographer. While she appears to invoke external perspectives through inviting comment from myself ‘*you can’t really tell if it’s a boy or a girl really, can you?*’ she answers her own question rather than waiting for a response ‘*Not really*’. This suggests a multi-voiced, multi-layered negotiation between exploring aspects of physical change mediated through her professional role identity and role as a research participant.

The concept of someone’s physical appearance making people ‘*feel like they have to comment*’ needs further investigation as social norms relating to visual difference results in women silencing their experiences by ‘fitting in’ and hiding visible evidence of physical change. In exploring women’s anticipated responses to hair loss, it is as important to understand what aspects of LwBBC women don’t post about in public spaces online as those they do. Significantly, neither accounts by Denise or Kirsty invoked not wishing to be identified as a ‘person with cancer’ (Frith & Harcourt, 2007) rather, they both position a lack of social acceptability of being a bald woman in contemporary society suggesting stigma related to an absence of hair, not having a cancer diagnosis. The images shared, and stories told within this study demonstrate that women continue to feel uncomfortable in society using props (wigs and headscarves) to ‘fit in’. Michelle M question’s why this becomes the focus of her attention.

‘why am I just not worried about the cancer? Why am I so worried about my hair and my boobs and actually, I’m not even thinking about the cancer much that’s the most ridiculous thing, because I just sort of think ‘they’ve got that under control’ I’ve got some Doctors dealing with it’ (Photo-production: Michelle Mu).

Women present this individual and cultural focus on external appearance as dominating the physical aspects of their experiences of LwBBC.

8.2.3 Using social media to explore changes to physical appearance

Interestingly, both Wendy and Kirsty use photography to help navigate how they feel about the physical changes to their bodies yet seem undecided as to whether sharing these experiences have a place on social media. Part of their move towards reclaiming a sense of

who they are physically is enacted through a creative process of photographing the body and reflecting on what role the images have taken in supporting adjustment. For instance, Kirsty talked about the tension between the quality of her imagery when considering it from a professional perspective and the limitations perceived in posting the images on social media because of her professional role:

'and I've been thinking about whether or not I will share them. I don't know whether I would or not, I can't decide. The most likely place I would share them is on the YBCN that's the place I feel I could easily share them. I feel like if I put them on my own Facebook, every Tom, Dick and Harry will be there having a good nosey, and I don't think it's professional either. I can't...I couldn't share that because of my job. It's too much skin in that image' (Photo-production: Kirsty).

While Kirsty uses the images taken for this study to reconcile aspects of her physical self with her professional identity, she struggles with whether 'socially' sharing photographs would be beneficial to her. Similarly, Wendy talks about using time lapse video to capture bruising developing on her body after sentinel node removal and her dilemma in whether to upload the content:

'there is a film that I am toying with the idea of uploading. And I don't know whether to upload it or not. I will probably run into copyright issues⁷³ with it. Basically, when I had my second operation, I had a horrendous bruise all the way down my side there. And again, time lapse photography, I got my husband to take a photograph of that every day and I put that, really corny actually, to 'I will survive'. I don't know whether to upload that film or not.

Cathy: That's really interesting. What is your concern about uploading?

Wendy: It's because I'm semi naked if you like. Hiding all my bits. So, I'm not wearing a bra but I'm holding my bits. So there's no nipples or anything like that. But the idea is that I am semi naked. I am not sure about it at the moment. But I find it very interesting to see how the bruise faded.

Cathy: And over what time did that take for it to...?

Wendy: About eight weeks' (Photo-production: Wendy)

73 Because Wendy used copyrighted music as an underscore.

Wendy, supported by her husband, spends considerable time and energy in a creative project capturing unanticipated bruising. She has developed a permanent memory through capturing the imagery of the bruise fading through time lapse photography, giving it further emotional significance through underscoring it with ‘I will survive’⁷⁴. Her suggestion that she may not upload it initially seems to be related to issues of copyright. Wendy later indicates her concerns relate to others’ potential reactions and a sense that others would interpret her reasons for posting as being focused around seeking sympathy or empathy (emotional support). In line with Kirsty’s struggle of how to gain the most benefit from her creative photographic work, Wendy describes interest in herself as both subject and object; and as having ‘a voyeuristic fascination’:

‘I guess another reason for not uploading it, is going down to this pity thing as well. I don’t want people to pity me. It’s not about oh poor me. It’s a fascination if you like, a voyeuristic fascination and the artistic element of it’ (Photo-production: Wendy)

These narratives of creating content and determining whether or not to upload them, indicate the benefit women experience from using photography as a navigational tool when experiencing biographical disruption. The creative process of creating visual content to share therefore may increasingly be and become a significant component of how women navigate the complexities of changes to their body. Exploring further this visual component in future work could extend the literature on autoethnography and the uses and gratifications of social media use to reclaim positive self-image.

In contrast to women feeling anxious about being in the public gaze when losing their hair, examples of social media use to provoke comment and invoke support related to hair loss were provided. These came to the fore in two ways. Firstly, women integrated social media into the ‘moment’ of the chemo-head shave - as something to be captured and shared - indicating the ‘head shave’ as one of significant biographical disruption. Secondly, through posting selfies women specifically used social media to narrate a story of physical change.

Using Facebook, some women enact support from ‘similar others’ when deciding whether to shave their heads after starting chemotherapy:

74 I will survive’ a 1978 disco classic by Gloria Gaynor.

'there is this horrible period in time when you make a decision whether or not you're going to shave your head and some people do and some people don't. Cold cap and all that. And it's a bit of a big deal really for most people and the times, there's been a few girls who've said they are really upset. They're devastated. And they're like 'right I'm going to do it', and you're like 'go and do it now. Just do it. You'll feel better, I promise you'll feel better' and then they come back half an hour later, 'right I've done it' (Photo-production: Kirsty).

Kirsty shows women empowering and supporting other women within a closed Facebook group to take control of the timing of shaving their head, making the event an impromptu 'social' occasion with weak ties in a peer led group. Sharing anxieties, concerns and thoughts relating to this decision within a closed Facebook group supports women taking action and facing their immediate fears. Some women's accounts showed 'the head shave' as a real time 'social' event where support was enacted from generalised 'others'. In these accounts, women are opting to put themselves centre stage (Goffman, 1959) in a public demonstration of actively engaging in personal change. The sense of emotional work experienced by women actively engaged in their 'head shave experience' is conveyed in the following extract by Wendy. Here, she talks about finding her 'old' hairdresser (who had moved away) because she wanted her to shave her head when 'the moment' came.

'I contacted her on Facebook. That's right. I private messaged her and said 'I've got cancer. I need somebody to shave my head'. And she was lovely. She came round to the house. And it was a lovely evening, (Wendy begins to get upset) it really was, it was such fun. I cried all the way through my first haircut.

Cathy: You're making me go. So what happened? Why was it such a joyous or fond occasion if you like?

Wendy: Because I set up a JustGiving page. I set a target of £100. (Wendy starts to cry). Within that first hour it was broken (crying). And I raised £1,000. It was amazing (crying). And when...I had so much support. Sorry. I really did. I had so much support I couldn't cry at my loss. I just couldn't, and I never regretted that shave. Never regretted it. In fact, the following day I went out without any hair covering on as well' (Photo-production: Wendy).

Here, Facebook enables reconnection between weak ties (a hairdresser and previous client); supports intimate one to one directed conversation 'I've got cancer' and enables requests for instrumental support 'I need somebody to shave my head'. Yet, Wendy also constructs 'social' fundraising as connecting her 'loss' with improving her own self-esteem through

engaging others in actively supporting her (and others) at a time of significant emotional work and distress. The act of posting publicly online about her ‘shave’ enabled Wendy to begin to nurture a new sense of self; demonstrated in her act of acceptability and adaptability *‘the following day I went out without any hair covering as well’*.

Michelle J proactively uses WhatsApp and Facebook as communicative resources to share different selfies with different audiences. Michelle uses a WhatsApp group called *‘My Journey’* to direct conversation *‘about her breast cancer’* with her ‘best friends’. She shares photographs *‘all the time’* enabling a real time ‘look at it now’ sharing of experience.

‘They’ve got a diary of my hair. Or like when I’ve had new eyebrows, I’ve uploaded ‘look girls, this is what’s happened’. Or ‘look I’ve got a hair today’. So, I’ll use it to upload pictures. When I had the operation, the lumpectomy, I was taking pictures and sending it to them showing them how my scar was healing and so they’ve seen... And one of my friends Jackie [pseudonym] said ‘I’ve never seen your...for someone who has always been shy about her boobs, I’ve never seen them so much in my life’. So, it was things like, ‘look at it now’ (Photo-production: Michelle J).

Michelle uses WhatsApp with her ‘best friends’, those who were emotionally and geographically close and seen on a regular basis. The sending of an image accompanied by a short message *‘look, I’ve got a hair today’* suggests an intimacy and understanding of each other’s day to day lives created through frequent encounters (O’Hara, Massimi, Harper, Rubens & Morris, 2014) which enable and support the intimate sharing of personal photographs. These work together to produce an ongoing narrative, which was originally started *‘because I didn’t want to keep just texting everybody individually’*. Michelle’s account suggests frequent posting, referring to the WhatsApp group as having *‘a diary’* and warranted through Jackie’s comment relating to frequently seeing Michelle’s *‘boobs’*. The setting up of a ‘My Journey’ group dedicated to exploring the intricacies of changes to Michelle’s physical self creates an ongoing conversation. O’Hara et al., (2014) posit that the thread of encounters on WhatsApp *‘are about being together or having a sense of being together through the ebb and flow of lives lived as a piece’* (p.1141). Here, WhatsApp as a communicative resource in a health context enables an intimate sense of privacy and support. In effect, it is the sharing of a ‘live’ life; a lived life and being alive.

In comparison to the intimacy described through frequent postings to WhatsApp, Michelle describes her preference for Facebook use with family.

'For family I used Facebook. So, I put a lot of things on Facebook, like when I went bald. I thought 'oh God somebody is going to see me if I go to the shops I've got this hat on, they're going to know I've got no hair'. And even though everyone was lovely, at first, I used to feel really paranoid because I could tell it was a wig. And all the kids and my husband were like, 'you can't tell it was a wig'. You could tell it was a wig. And I thought I'm just going to have to brave this. So I took a picture of myself with a bald head. And my friend said just put it on Facebook, everyone is going to see it. You've got it out of the way, so they're not going to ask questions then when they see you. And I thought I will just do that and I did. And then I had hundreds of comments. 'Wow. I didn't know'. Or just things like that. And it did make it easier for me that. And then my family, a lot of my family are on Facebook, so they've seen it as well. Yeah. It's like an icebreaker really' (Photo-production: Michelle J).

Michelle talks about hiding her bald head *'I've got this hat on'* and being *'paranoid'* *'because I could tell it was a wig'* indicating that these strategies to conceal hair loss did not work well for Michelle. Interestingly, Michelle appears to ignore the supportive comments of her family *'you can't tell it was a wig'* and warranted her friends' intervention as the prompt which encouraged her to post an image on Facebook. She describes her Facebook use as different to her WhatsApp use – moving from controlled intimacy into the public gaze *'everyone is going to see it'*. She reflects on posting the image *'of myself with a bald head'* as changing her relationship with both herself and her family in relation to how she managed being bald. Posting actively online to a wider audience shows Michelle's agency in adjusting to her changing physical appearance. She described the posting as an icebreaker, suggesting a *'getting to know you'* between two or more people who do not know one another. Given this conversation focuses on Michelle showing and telling her family about her cancer *'Wow, I didn't know'*, her comments gives a real sense of that dissonance for all when someone is experiencing and living with a cancer diagnosis. Michelle finds the intervention – the posting of a broadcast communication of an image of her hair loss on Facebook – as making *'it easier'* and as emotionally supportive *'I had hundreds of comments'*. She uses Facebook strategically to try to ensure or prompt positive interactions and demonstrations of social support by forewarning people of changes to appearance prior to physical interaction (Williamson, Harcourt, Halliwell, Frith & Wallace, 2010). It is as an action that would reduce *'questions' from 'others'* and operates in contrast to unknown others *'feeling as though they have to make comment'* (Denise D). It also indicates a taken for granted assumption that Facebook use is prevalent and that she is connected with a significant number of people,

included those that visit *'the shops'*. There is a sense that by putting it on Facebook, any social inhibitions Michelle experienced related to baldness are removed; *'you've got it out of the way'*.

8.2.4 Using the selfie

Interestingly, across all interviews, only Michelle J provided an example of a selfie she uploaded to the Younger Breast Cancer Group and her own Facebook page in which she *'rocked'* her new hair. Michelle explains taking the picture *'to show that I've put it on there'*; as visual evidence of her engagement with Facebook. She actively uses social media to give encouragement to others experiencing hair loss and to gain encouragement from others. She enlarges the experience of uploading this image by commenting:

'but there's just hundreds of comments. I put that on my Facebook wall as well and I've got nearly 200 likes on it and absolutely massive amount of comments' (Photo-production: Michelle J).

For Nicola, the inclusion of a 'selfie' taken for the project facilitated a conversation about her current ongoing negotiation of physical changes to self and of her use of selfies to support that negotiation. Nicola described beginning to take *'a lot of selfies'* since being in treatment despite never being *'one to do it really before treatment'*. She talked about when she would take a selfie:

'I did go through phases of taking quite a lot of selfies, just to kind of, I don't know, reinforce my sense of self like in the moments when I thought, yeah, I look quite nice, I'd take a picture of it. But then I'd also kind of document it. I'd take pictures of myself looking dire as well. So, I've got umpteen photographs on here (pointing to her phone), on Facebook, on Twitter, on Instagram of me with absolutely no hair or eyebrows, what have you' (Photo-production: Nicola)

Nicola's account positions selfies as a taken for granted social practice in contemporary culture (Iqani, & Schroeder, 2015; Sung, Lee, Kim & Choi, 2016), warranting their use to reinforce 'sense of self'. She invokes relationships with others indirectly through referencing her phone and social media platforms. Nicola therefore warrants platform use as multi-purpose: to document self; to reinforce sense of self; and, to communicate sense of self to different audiences – Facebook, Twitter, Instagram. This documenting of experience of looking 'nice' and 'dire' suggests an active engagement in perceiving physical identity and

change as dynamic. Kozinets, Gretzel and Dinhopl (2017) suggest that through uploading images to publicly accessible sites, individuals write an online narrative:

'about the self which must be read in the entire context of a person's posting behaviour on the medium to be fully comprehended in context' (p.7).

Nicola describes herself as *'happy to share everything, I over share'*. Discussing her use of 12 social media platforms, in relation to LwBBC, Nicola positioned her sharing of selfies as a typical way of communicating with others (Barry, Douette, Loflin, Rivera-Hudson & Herrington, 2017); and her selfie posting as a form of life writing (Morrison, 2014; Tembeck, 2016). The posting of photos 'looking dire' challenges taken for granted interpretations of Facebook for portraying the desired self and censoring content that threatens image (Madden & Smith, 2010, cited in Sumner, Ruge-Jones & Alcorn, 2017). Selfies, *'when the eyelashes were coming out and the eyebrows were going'* were posted to her normal Facebook page. She conceptualised these as *'a kind of document for myself and for my friends'*, prompted by requests for information on *'how was I getting on with treatment'* and *'how was I feeling'*. Purposing Facebook as a connected contemporary photo album for the longitudinal provision of memories is supported by the literature. For instance, archiving memories has been identified as one of the key motivations for selfie posting online (Sung et al., 2016). Nicola reflected on her 'illness' selfies as representing a moment in her life from which she could later take stock:

'it's just nice to be able to look back, so maybe when they pop up in a few years' time and I've been five years with no evidence of disease, I can look back and go, Christ, I went through that didn't I, but I'm alright' (Photo-production: Nicola).

Additionally, Nicola warrants other women posting images of hair loss on Facebook in a closed group setting, as normalising the posting of hair loss selfies for those more recently diagnosed

'So the first ones were really quite empowering, then when I was taking the pictures and they weren't so nice, I was still sharing it because by that point I'd been on the Younger Breast Cancer Network and lots of the girls had posted various different pictures of the stages with their hair loss, but then you notice as well people at the other end where they were getting the hair regrow. And so it was nice to see, to have an idea of how long it might take. And to have a record of it and because people are curious and because people

would be asking me question about how I was getting on with my treatment, how was I feeling, you know, what was going on, it was just easier to kind of document it for myself and for my friends, to just document it on Facebook (Photo-production: Nicola).

The role of posting selfies in public online spaces and closed peer led spaces to support psychosocial health is therefore ripe for further investigation.

While Nicola's account reflects on her historical account of social media use, she uses a selfie taken for the project (Figure 8-12: Image: Nicola 1) to prompt a reflection on how she currently feels about her appearance.



Image: Nicola 1

Figure 8-12 Reflecting on changes to own appearance

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'I look at that and I really like that picture of me. It's grainy [], but I've lost the chemo weight, I've not got the bloat, my eyes look healthy and although it's just a simple straight on, I'm not even particularly smiling or anything, I think I look happy, I'm in a good place' (Photo-production: Nicola).

In contrast to Tembeck's (2016) notion of an 'illness selfie', Nicola provides a 'wellness selfie' to reflect on the visual physical impact of chemotherapy (*'I've lost the chemo weight', 'I've lost the bloat',* and unhealthy-looking eyes). By so doing, she brings to the fore her ongoing self-assessment in relation to the physical changes created by treatment a number of years previously.

While Michelle J and Nicola used social media platforms to post selfies to document experience and negotiate relationships with others, Delphi takes a number of selfies to explain how she found YouTube empowering (Figure 8-13: Images Delphi 6 and 7). At the end of treatment, Delphi lost her eyebrows permanently. In response, she used YouTube to watch videos to teach her how *'to get around the obvious steroid moon face and lack of eyebrows and things'* through the use of cosmetics. Her account gives voice to the daily psychosocial impact of living without eyebrows:



Image: Delphi 7



Image: Delphi 8

Figure 8-13 Living permanently without eyebrows
©Delphi Marmaduke / 05.01.16 / University of Salford / Cathy Ure

'And the way I see myself in my head I have eyebrows, so looking in the mirror, it's a shock and it's, ...every day it's a shock and I look and I find it very depressing (pause) actually. And I realised that I cannot get dressed and I cannot do my hair or do anything that would involve making moves to sort of go out or be existing for the day until I have my eyebrows on...

Cathy: Right.

Delphi: ...because it would take an awful lot longer because nothing looks right. I'm not comfortable with anything. It's...everything's wrong until they're on. And as soon as they're on, I'm fine' (Photo-production: Delphi).

Delphi brings forward the ‘shock’ of her own reflection ‘*every day*’ demonstrating the assimilation of eyebrows into an intrinsic sense of self. She describes the experience as ‘*depressing*’ and an inability to carry out taken for granted daily tasks (dressing) until she has physically drawn her eyebrows on. Delphi talked about using YouTube ‘*an awful lot actually when I was having active treatment*’ because she was ‘*very focused on not looking like I had cancer*’ and wearing ‘*the cancer badge*’. The notions of ‘*nothing looks right*’ and ‘*everything’s wrong*’ set against a strong desire to not ‘*wear the cancer badge*’ necessitates for Delphi a daily psychological, emotional and cultural struggle with her own identity but one which she has learnt to master through access to other’s skills and experience on YouTube.

Wendy also includes in her photos ‘treatment impact selfies’ (Tembeck, 2016). She describes her use of time lapse video (Figure 8-14: Image: Wendy 24), composed of taking regular selfies, to document her hair growth post chemotherapy.



Image: Wendy 24

Figure 8-14 Using social media to post time lapse video

© Wendy Northway /28.04.16/ University of Salford / Cathy Ure

Wendy’s account describes the production of a time lapse video for eventual posting on YouTube. Wendy plans to capture images over three years, to explore change and regrowth. The use of time lapse video to construct autopathographical narratives on social media has received limited scholarly attention to date. Tembeck (2016) proffers such videos are

uploaded for “the benefits of peer education” (p.2). In contrast, Wendy states her interest in uploading time lapse videos has a single purpose: *‘just to get so many hits. I’m pretty vain like that’*. Time lapse video offers women a practical opportunity to engage in self-monitoring changes in physical identity which may have positive outcomes for psychological adjustment and acceptance. An opportunity exists for further scholarly work exploring the uses and gratifications of uploading time lapse photo autoethnographies on social media and how this supports psychosocial health.

8.2.5 Summary: Theme Two – Subtheme Two: Working through the impact of physical change

Most content in this subtheme emerged from the photo-study, indicating the power of women narrating their own stories through photography. Women brought photographs to the photo-production interviews which empowered them to have conversations about the impact breast cancer treatment has on the body. The visual changes this brings to women through hair loss is a source of anxiety and numerous strategies are employed to reduce the impact hair loss has on other people. Social norms often result in women hiding the extent of the changes they are experiencing and the realities of the emotional challenges arising from the physical ‘biographical disruption’ experienced. The concentration on stories and images relating to hair loss suggests the visible changes to self may be more challenging for women to negotiate than those that can be hidden from public view. It suggests concern about stigmatisation due to visibly having or having had cancer. Previous research suggests visibility is an important predictor of stigmatization that can impact interpersonal relationships and psychological well-being (Crocker, Major & Steele, 1998; Knapp, Marziliano & Moyer, 2014).

Yet, some women described using photography to explore their feelings about changes in appearance that are not visible to others, including the impact on the body of a side effect of surgery (bruising). Women take a reflective approach to determining visual content to post on social media. Some women flex communicative practices, using WhatsApp for intimate targeted communication of images of body changes with close friends combined with broadcast communication using Facebook to signpost being visually different as a pre-emptive communication strategy from which they can lever support. These differences in approaches indicate the need for further research. Rasmussen et al., (2010) proffered there is ‘existence of a shared secrecy [between women and society] in relation to bodily changes and

post-modern society' (p.157). Arguably this theory is upheld in many women's public social domains given the selectivity shown in the visual images of physical change posted online.

8.3 Subtheme 3: Working through the day to day



This sub-theme explores women's accounts of the day to day challenges of LwBBC - the ongoing effects and 'constant reminders'.

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'It can take me three quarters of an hour to an hour, but it was just absolutely manic when I was travelling there, and I was doing that for two weeks, every day there and back, there and back, there and back "... " you used to...when I had the first lot of radiotherapy eight years ago, you used to get a specific parking place, so that it was quick, because the treatment is quick, and now you don't. So I'm on bloody Level 12...I thought, 'Oh great!' (Jo).

Figure 8-15 Working through the day to day

8.3.1 Introduction

Women at all stages of LwBBC describe having to work through aspects of their experience on a daily basis. Women describe contending with other's reactions because they are not seen to be following the cancer 'script'⁷⁵ (Silverman, 2011). They detail ordinary day to day interactions with strangers as unhelpful. For those further along the cancer continuum, many accounts describe the ongoing day to day impact of the side effects of treatment. Women describe these ongoing physical, emotional, psychological and social challenges as '*constant reminders*': '*so that is kind of a constant reminder, as you know, you start just feeling really tired and really old*' (Deborah); '*I mean I have got constant reminders of everything*'

75 Silverman describes a 'script' as the way in which participants construct events as 'scripted' (Edwards, 1997) that is to say, they describe routine characteristics of events to 'imply they are features of some general pattern' (Silverman, 2011, p.310).

(Wendy). Women also talk about the challenges of digital mourning⁷⁶ and the complexities of negotiating their own mortality, loss and grief.

8.3.2 Normal interactions disrupted by cancer

As part of their discussions about social media use, women talked about normal day-to-day activities disrupted by the way other people responded to them. Both Denise D and Michelle M received uninvited comments, from undefined ‘others’, within their existing social networks. These comments suggest social expectations of how to do cancer:

‘I think I was messing about and we were running around and people were like should you not be taking it easy? Should you not be having your feet up? And stuff, and you know, cos I think people do sort of think that that is how things should be’ (Michelle M)

Denise D posted a message on Facebook a week after having her lumpectomy:

‘I put erm just spent £100 in John Lewis and all this kind of thing like you do’ (Photo-elicitation: Denise D)

With the use of ‘like you do’ Denise positions Facebook as a taken for granted site for broadcasting consumerism. Denise positions the responses to her post as focusing on ‘others’ views - that she should be at home and recuperating - rather than reflecting on the pleasure achieved through the retail therapy engaged in. In response to her post, Denise states,

‘people kept saying to me you can’t be out. What are you doing out?’ (Photo-elicitation: Denise D)

implying criticism of Denise’s own management of her health and well-being. The interactions described by Michelle M and Denise D suggest that members within existing networks begin to redefine women’s previously ‘normal’ behaviour as no longer appropriate, and through vocalising ‘concern’, impact on individual’s sense of self through positioning them as ill. Women become encumbered by moral assessments made about their everyday interactions when they have cancer (Gibson, Broom, Kirkby, Wyld & Lwin, 2017).

Denise D talked hypothetically about potential interactions ‘at the till’ after she had lost her hair. She was concerned that:

⁷⁶ Wright (2014) argues that the expansion of people’s digital lives has brought about new mourning practices which have irreversibly complicated our cultural understanding of death when mediated through the Internet and social media.

'anywhere you are interacting "... " I think they may feel they have to comment' (Photo-elicitation: Denise D).

Her comment suggests a taken for granted assumption that women with visible signs of experiencing cancer treatment are public property. This was a notion taken up by Kirsty and Wendy. Kirsty used her photographic skills to create a visual metaphor (Figure 8-16: Image Kirsty 5) related to the feeling of being 'public property'. She explains the image as representing 'transparency':

'Yeah, transparency I suppose is part of it isn't it. Other people knowing all of your business as well and knowing all this really personal information, you do feel that you are a bit transparent when you've got cancer' (Photo-production: Kirsty).



Image: Kirsty 5

Figure 8-16 Feeling transparent

© Kirsty /15.03.16/ University of Salford / Cathy Ure

Wendy talked about the challenges of everyday interactions with people she would meet in the supermarket, when dog walking or when attending an outdoor show. She describes almost a sense of violation - *'I felt very much like public property that they felt they had the right to ask these questions'*, - as she was stopped by *'strangers'* and *'shop assistants in Asda'* and asked *'are you on chemo'*; *'what's wrong with my arm'*; *'what have you done to your arm'*. The use of active voicing (Hutchby & Wooffitt, 1998) suggests these were uninvited

questions. In her account, Wendy expresses her emotional response to these interactions; *'I don't like strangers coming up to me and asking'; 'I really hate that'; 'I don't like...'; 'It's none of your business'*. Wendy describes wrestling with her own responses: *'I have got to explain. Or I feel I have got to explain'* suggesting social norms in responding to enquiries from others. In part she warrants this response as related to the institutionalised interactions with medical teams:

'I was so used to answering the questions of the medics that this was just another manifestation of it. So, I was answering the questions without thinking, I don't need to answer this to you' (Photo-production: Wendy).

Here, both Kirsty and Wendy articulate a notion of a loss of control of personal privacy and own identity as generalised others change the social norms of social interaction. As answering 'others' questions (medics) has become normalised, Wendy recognises her vulnerabilities *'I was answering the questions without thinking'*.

Some women reported the challenges of navigating the demands of their everyday lives as they sought to 'return to normal'; combine motherhood; the demands of work and the ongoing effects of treatment. Deborah works as a mental health manager for a group of vulnerable adults and children. She described her own challenges four years post diagnosis:

'my job is quite full on, you know, I have the staff going nip, nip, nip. I have all the referrers and the regional stakeholders, nip, nip, nip. A 100 emails going flash, flash, flash, if you do not respond, the world will implode. And you get home, you have got two young children, nip, nip, nip. Because they have to be. I remember sitting down, I feel like I am swimming down a river full of piranhas. I remember sitting there one day and just going I can't take anymore' (Photo-production: Deborah)

Jayne described trying to keep her working week to 40 hours but described her co-workers extending the working week into Saturday and Sunday as a 'pressure':

'because they're doing it I should be doing it' (takes a deep intake of breath and sits back in chair)' (Photo-elicitation: Jayne)

Jayne articulates conflict between her own experience of work, and how others in the YBCN group have chosen different paths post diagnosis:

'people have really changed their lives dramatically and for me seeing all that through the social media does make me still question what I'm doing' (Photo-elicitation: Jayne).

Jayne positions Facebook as enabling insight into women transforming their lives. ‘*Seeing all that*’ creates dissonance for Jayne as it makes her ‘*still question what I’m doing*’. There is a sense that Jayne continues to work through that dissonance. In contrast, Deborah utilises a photograph of a Breast Cancer Care blog post (Figure 8-17; Image 9) to explain how this type of article supports her ability to cope by providing validation to how she is feeling.



Image: Deborah 9

Figure 8-17 Blogs provide validation
 © Deborah / 11.03.16 / University of Salford / Cathy Ure

‘when you read something like that, it kind of validates it. But you are never going to get that in an outpatient appointment. No doctor has got time to sit, you know. And even the breast care nurses, they haven’t got time to sit and go through all that. So where do you get that from? That is where I got it from. And stuff like that I will put on my page and I sort of think yes, you know, actually it is a bit shit. Because otherwise you are just left with it and you feel – well, certainly the way my brain would work, it would just say you are just failing’ (Photo-production: Deborah)

8.3.3 The impact of treatment

One way some women chose to identify themselves in the photo-production interviews, were as women ‘*doing cancer everyday*’ (Kirsty). This is in keeping with Mukherjee’s (2011) contention that ‘cancer’ becomes women’s ‘new normal’. The emphasis for Mukherjee

therefore remains on the cancer as the core to women’s new normal; ever present and ‘a constant reminder’. The extant research has described how the biographical disruption women experience is followed by a ‘new normal’ (Trusson, et al., 2016). Trusson et al., (2016) defines the ‘new normal’ as ‘a continual renegotiation of identities, daily lives and futures as time passes and lives evolve’ (p. 121). Both Kirsty (primary breast cancer) and Jo (secondary breast cancer) chose to take photographs when they knew they would be receiving treatment. Kirsty’s account gives voice to the shock of treatment. Kirsty took photographs in the chemotherapy lounge and talked about the clinical significance of her PICC line⁷⁷ and the need to carry the paperwork in the red folder around with her ‘*anywhere I go*’ (Figure 8-18; Image Kirsty 1)⁷⁸ as the PICC line is ‘*flushed and dressed once a week and then blood is taken out of it and everything*’. She manoeuvres in her photography from supporting the institutionalised clinical need to monitor the cleanliness of the PICC to the emotional experience of living with a PICC line – ‘*a line in your body for months on end*’. When talking about Figure 8-18; Image Kirsty 7⁷⁹ Kirsty describes trying to communicate the idea of pushing cancer away:



Image: Kirsty 1



Image: Kirsty 7

Figure 8-18 Chemotherapy and the PICC line

© Kirsty /15.03.16/ University of Salford / Cathy Ure

78 This image was previously discussed in relation to the institutionalised presentation of receiving chemotherapy (section 8.1).

79 This image has previously been discussed in relation to ‘being faceless’ (section 7.1.3).

Cathy: 'And the hand being up, obviously it's blanked the face out but is there...'

Kirsty: 'It's actually to push things away, that's why I did it yeah. It did blank my face out, so I took quite a lot of those and I did like the ones where the face was missing but yeah, it's all to do with this idea of putting distance between you and what's happening to you. That's very much how I feel. I would very much like to push all of this out of my life. I would love to be able to do that, and I can't. But that is what I would really like. Just manhandle it back where it came from. And there's things about that image that I find, I hate that, the way the picc looks, I don't like the scar, I just think it looks so medical and horrible' (Photo-production: Kirsty).

These two images when considered together give significance to the everyday monitoring of chemotherapy drug administration. They show dissonance between the image of formalised, personalised medical intervention (Image: Kirsty 1) and the emotional and psychological impact experienced when living with a picc line inserted into the body throughout treatment that acts as an embodied reminder (Image: Kirsty 7).

Jo presents a more embellished narrative of 'doing cancer everyday'. Her 47 photographs and accompanying narrative demonstrates her treatment as an everyday activity. Jo shows herself as a patient receiving radiotherapy and chemotherapy (Figure 8-19: Images Jo 1, 3, 5 and 37) and as hospital visitor - summed up by institutionalised approaches to car parking and catering (Figure 8-19: Images: Jo 20, 29, 35, and 17).



Image Jo: 1



Image Jo: 3

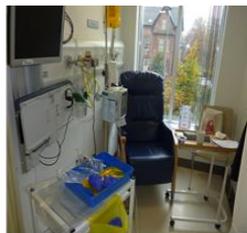


Image Jo: 5

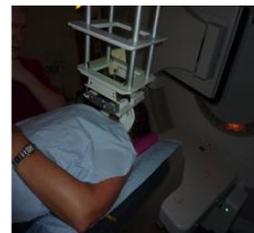


Image Jo: 37



Image Jo: 20



Image Jo: 29



Image Jo: 35



Image Jo: 17

Figure 8-19 "Doing cancer everyday"

© Jo Taylor - abcdiagnosis / 10.12.15 / University of Salford / Cathy Ure

Through use of photography, Jo presents the normality of treatment as a component of her everyday life by juxtaposing the children going to school (two photographs were provided of her son and daughter before school) and the children's friends coming around to play and to have tea after school (Figure 8-20; Images Jo: 11 and 34):

'so it was just showing that life carries on, it doesn't stop because you're having treatment, it was just to say I've now got all these kids to feed!' (Photo-production: Jo).

Jo navigates the impact of treatment in a matter of fact way. For instance, Jo removed her scarf to show me the area where she had received radiotherapy to her neck:



Image: Jo 34



Image: Jo 11

Figure 8-20 "Life carries on"

© Jo Taylor - abcdiagnosis / 10.12.15 / University of Salford / Cathy Ure

'Have you seen this? I look like I've been attacked with an iron; 'they said [the radiographers] that I've got to leave a scarf on, even through the day, even in the winter' (Photo-production: Jo).

Jo describes a pragmatic approach to attending hospital for treatment every three weeks:

'I can't have somebody coming every three weeks with me, it's...who's got time? Who's got the energy? Who's got the effort? I don't mean that in a bad way, I know that it's a drag' (Photo-production: Jo).

Jo reflects that practically people are unable to attend clinic with her because she is there so regularly – every three weeks. She comments *'who's got time'*. But, she also raises the

psychological and emotional commitment required to attend too - *'who's got the energy? Who's got the effort?'*. However, Jo's account raises a contradiction. Jo has extensive social media networks. While Jo physically does not have *'somebody coming every three weeks with me'* because of time constraints and the emotional and physical commitment involved, she uses social media to extend the clinical encounter to her *'networked publics'*⁸⁰ (boyd, 2010). She uses her iPad to connect with her Twitter followers during treatment, drawing on support in real time as and when she needs it (Figure 8-21: Images Jo: 4 and 33).



Image: Jo 4

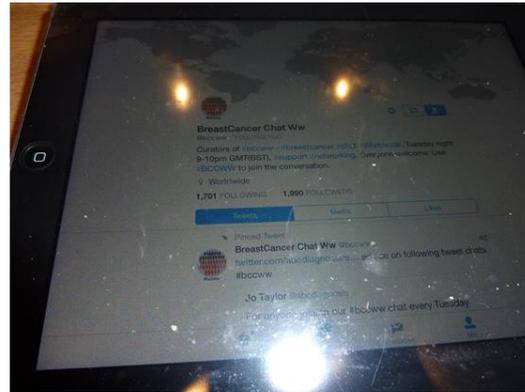


Image: Jo 33

Figure 8-21 Using Twitter and #bccww during treatment⁸¹

© Jo Taylor - abcdiagnosis / 10.12.15 / University of Salford / Cathy Ure

Embodied reminders of treatments⁸² (Trusson, et al., 2016) were frequently provided of examples impacting on daily lives. Mandy, nearly seven years post diagnosis, reflected on the treatment being *'very harsh, very difficult, mentally very difficult, ended up on antidepressants, which I'm still on'*. She stated: *'it never leaves you'* as she discussed significant ongoing issues with body image following reconstructive surgery:

'it never leaves you and I think that's the, I'm going through reconstruction, this has been going on for seven years, it went wrong, it's been awful, it looks awful, so I've got real issues with body image' (Photo-elicitation: Mandy).

⁸⁰ boyd (2010) defines *'networked publics'* as publics restructured by networked technologies. They are simultaneously: the space constructed through networked technologies and the imagined collective that emerges as a result of the intersection of people, technology and practice (p. 1).

⁸¹ © Jo Taylor - abcdiagnosis / 10.12.15 / University of Salford / Cathy Ure

⁸² These act as ongoing reminders of cancer and include scars and changes to the body from surgeries such as lumpectomies and mastectomies.

Women, diagnosed between 1-5 years and 5 years plus, raised lymphedema⁸³ as causing significant ongoing issues (Figure 8-22).

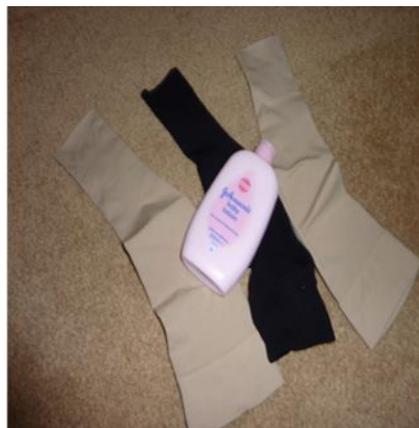


Image: Wendy 5

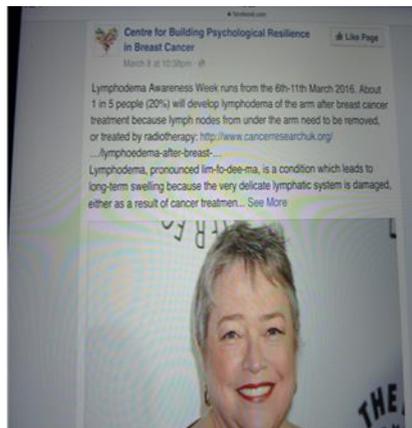


Image: Deborah 11

Figure 8-22 Living with lymphedema

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Women used images to highlight issues related to living with lymphedema and to demonstrate identification with other women living with lymphedema. For Wendy, needing to wear compression sleeves (Figure 8-21: Image Wendy 5) is a visible and ‘constant reminder’. She comments:

‘I look at that arm, there is nothing wrong with it, but as soon as I see the sleeve then it is a reminder that I have had this and this has gone on in my life’ (Photo-production: Wendy).

Lizzie, some ten years past diagnosis, comments: *‘I’ve got lymphedema, so I have to have voice recognition technology’* at work, to avoid pain experienced when typing. She comments that lymphedema has caused the sensation in her fingertips to change:

‘you don’t feel the keys the same and particularly if I’m on my iPhone trying to send a message on Facebook, you know. Amy [pseudonym] put a message on once saying ‘I love your messages, you need to go to Specsavers’ and it’s because I make so many mistakes and she doesn’t understand it’s because my fingers don’t work. It’s not my brain, my fingers don’t work the way that they did’ (Photo-production: Lizzie).

⁸³ Lymphedema is swelling of the arm, hand or breast/chest area caused by a build-up of lymph fluid in the surface tissues of the body. It can occur because of damage to the lymphatic system, for example because of surgery and/or radiotherapy to the lymph nodes under the arm and surrounding area (Macmillan Cancer Support, 2018).

Lizzie explains the numbness she still has in her finger tips *'you don't feel the keys the same'*. Her challenges of struggling to *'send a message on Facebook'* brings forward wider cultural implications for those affected by peripheral neuropathy⁸⁴. With communication increasingly mediated through screens and keypads, the advantages of portable, flexible technologies remain a challenge for those with physical limitations or who become more limited physically because of treatment. She receives 'jokey' comments from friends, *'I love your messages, you need to go to Specsavers'* and broadcast publicly. Lizzie does not criticise this public 'outing' of her ability to type but rather warrants it as a comment made from a position of ignorance *'she doesn't understand it's because my fingers don't work'*.

Deborah includes a photograph of a Facebook post raising awareness of Lymphedema Awareness Week (Figure 8-22: Image Deborah 11) which included an image of the American actress Kathy Bates. She comments that someone had posted this post on the Younger Breast Cancer site and that *'it is just one of those invisible, longer term effects'*.

'And I think there is often a feeling of well, you know, it is all done now, and you are better. It is really hard for people who are struggling with some of the longer term emotional or physical effects, to feel as though they are allowed to say yes – but still, yes, I am alive and of course I am grateful for that and yes, it could be much worse. But there are still bits of it that are really a bit rubbish, you know' (Photo-production: Deborah).

Here, she uses a social media post to raise issues about women's ongoing well-being and being identified by undefined 'others' as 'sick' or 'well'; *'it is all done now, and you are better'*. As shown, Wendy and Lizzie's accounts voice their reality that it is not *'all done now'*. Significantly, Deborah does not claim that living with lymphedema impacts emotional and social well-being but rather orientates her emphasis to *'people'* not feeling they are *'allowed'* to *'say'* *'bits of it [] are really a bit rubbish'*, indicating a silencing of experiences. This links with women's ability to have real conversations about breast cancer contrasts with women's experiences of *'horrendous'* posts relating to chemotherapy; and supports women's presentation of themselves as *'heroic survivors'* (Hollenbeck & Patrick, 2016). This finding reinforces the notion that the more visible the physical impact the more *'horrendous'* it is and

⁸⁴ Peripheral neuropathy occurs when nerves, most commonly in the fingers and toes, are damaged. Symptoms include pain (burning or shooting; numbness; pins and needles; a feeling of warmth or cold; increased sensitivity; difficulty doing fiddly tasks (Breast Cancer Care, 2017).

the more voice it is given. Wendy's account supports Deborah's assessment. When talking about her compression sleeves, Wendy stated:

'I explored the lymphedema support groups. Because there's the lymphedema support network I think it is. And (pause) I was able to go on there and probably could say on there actually...Right....I was having a bad day. So, I did use it then' (Photo-production: Wendy).

Wendy feels able to express her real feelings about lymphedema in a Facebook group demonstrating relatedness and emotional connectedness (Chapter 7: Subtheme 3). This interaction supports embodied talk: *'my sides, I can never describe it. It just doesn't feel...there's a pulling on me'*. Wendy moves across social media platforms as she works out how to manage lymphedema. As well as sharing her feelings in a Facebook group, she uses YouTube to help alleviate the discomfort experienced. She suggests a degree of risk in taking matters into her own hands:

'I used it [YouTube] to find manual lymphatic draining massage.⁸⁵ I was very naughty. Whilst I was undergoing chemotherapy they wouldn't give me a massage to do for my lymphedema. The feeling is that the lymph could carry the cancer cells. However, I was having a lot of trouble with it. And so I went onto YouTube and I found a massage. So, I have used it from that point of view' (Photo-production: Wendy).

Wendy is agentic in trying to resolve the *'trouble'* she was having with her *'lymphedema'*. Her account indicates that the discomfort was so great that she went against medical opinion - *'the feeling is that the lymph could carry the cancer cells'* - suggesting that future risk was over-ridden by immediate physical discomfort. Wendy describes the use of You Tube as goal directed and warranted because *'they wouldn't give me a massage to do'*. Rather than creating a supportive environment to help relieve ongoing effects, the positioning of healthcare professionals as *'not listening'* results in Wendy using Facebook and YouTube (support groups and video information) as an empowered media consumer to enable her to alleviate the discomfort experienced.

⁸⁵ Manual lymphatic drainage is a hands-on therapy that is commonly used for breast cancer related lymphedema and often as part of complex decongestive therapy (CDT). CDT consists of manual lymphatic drainage, compression bandaging, lymph reducing exercises and skin care (Ezzo et al., 2015).

Women's accounts also raised ongoing effects resulting from Tamoxifen⁸⁶ adherence. Liz talked about the psychological challenge of Tamoxifen adherence related to the length of time *'it's worse than chemo for me because five years is out there'* and the physical challenges:

'It makes me sick. It makes me yeah, I've been physically sick. Sometimes it just gets your tummy it's weird, you just, your just sick it makes me have diarrhoea. It makes me have hot flushes that I can't bear. I get migraines. It's really weird. It's worse than chemo. I would rather have another 8 cycles of chemo than 5 years of Tamoxifen' (Photo-elicitation: Liz)

Tamoxifen use was categorised as a *'constant reminder'* by Deborah as *'you start feeling really tired and really old'*. An extensive body of literature has reported the physical challenges Tamoxifen adherence⁸⁷ creates (Bowles et al., 2012; Bright, Petrie, Partridge & Stanton, 2016; Grunfeld, Hunter, Sikka & Mittal, 2005; Kahn Schneider, Malin, Adams & Epstein, 2007). Recently, 44% of UK patients (n=777) completing a cross-sectional questionnaire were non-adherent despite non-adherence being associated with poor clinical outcomes. (Moon, Moss-Morris, Hunter & Hughes, 2017). A recent study by Milata, Otte & Carpenter (2018) argues more decisional supports are needed to help support women experiencing adverse effects from Tamoxifen use. Eleven women, at all stages of LwBBC, mentioned Tamoxifen use within their interviews. Two included photographs in relation to aspects of LwBBC and Tamoxifen use (Figure 8-23: Image: Michelle M 8; Image Jo 8 and 24).



Image: Michelle M 8



Image:Jo 8



Image:Jo 24

Figure 8-23 Tamoxifen use

⁸⁶ Tamoxifen is an adjuvant hormone therapy prescribed to women with oestrogen receptor positive (ER+) breast cancer to reduce the risk of recurrence. About 75% of breast cancers are ER+ (Moon, Moss-Morris, Hunter & Hughes, 2017).

⁸⁷ The extent to which patients take their medication as prescribed (Sabate, 2003, cited in Moon et al., 2017).

Jo's images and narrative pragmatically conveys the reality of living with secondary breast cancer and the daily requirement to take 6 tablets every morning (Figure 8-23: Image: Jo 8) and 3 tablets every evening, including Tamoxifen (Figure 8-23: Image: Jo 8 and 24). The daily repetitiveness of this routine is portrayed by the filled tablet box accompanying the tablets laid out on the counter. In contrast to Michelle (below), Jo does not appear to worry about whether taking Tamoxifen is 'a good idea'. She talks matter of factly about the tablets as a taken for granted requirement of her day to day life:

[Figure 8-23: Image Jo 8] It's one morning's worth. Aspirin and...one's an antibiotic, one's an antihistamine, paracetamol I always have, and that is a drug for...it's actually a vitamin, but it's for...when you're taking certain tablets, it can make you really achy, so it stops all the aches and pains, and it's actually for runners as well, so it's Chondroitin and something else, I've forgotten again [laughter]. Anyway, it's a vitamin that helps your joints. Oh, and that's calcium, that's for my bones, because I have bone mets. []. I have those two big ones twice a day, then another one of them at night, then I have my Tamoxifen at night, so I have three tablets again at night [Figure 8-23: Image Jo 24] (Photo-production: Jo).

In contrast, the image provided by Michelle (Figure 8-23: Image Michelle M 8) of the American website breastcancer.org.uk was utilised within the interview to share her concern about discussions taking place on the YBCN Facebook group about Tamoxifen use. As a new entrant to a peer led group, Michelle voices tension as she tries to navigate medical expertise, patient expertise, uncertainty⁸⁸ and her sense of self.

'After I have surgery, I have then five to ten years of this drug because my cancer is the one which is fed by my oestrogen level. So this is supposed to control my oestrogen levels. So, again I sort of think when you're first told this is the process, this is what will happen – OK, I don't like the idea of being on a drug for a very long time - but I just, I think I just passed it off as well that's what they think I need to do. And then I look on the YBCN network and quite a few people say 'why are you having Tamoxifen?' 'I'd put up a fight

88 To date, no studies of online support groups have measured 'uncertainty' (McCaughan et al., 2017).

against that.’ I’m not on Tamoxifen I don’t think it’s a good idea.’ I’m having this drug instead and erm so again that YBCN is, now I am having a bit of a worry and a bit of a wobble about being on this Tamoxifen’ (Photo-production: Michelle M)

Michelle warrants acceptance of taking ‘a drug for a very long time’ because ‘that’s what they think I need to do’. The challenges of membership of peer led support groups is then brought to the fore ‘I then look on the YBCN network’. Michelle does not say she is specifically looking for information relating to Tamoxifen use but that the subject of use is one frequently talked about: ‘quite a few people say’. Her use of ‘they’ meaning her clinical team and ‘that YBCN’ suggests a feeling of lack of control and a sense of ‘being told’ rather than partnerships with either her clinical team or YBCN. ‘That YBCN’ positions YBCN as a collective body rather than identifying some women within YBCN as a potential source of disconnection. Michelle suggests challenges to the clinical voice as ‘a bit of a worry’ and her having ‘a bit of a wobble’, rather than experiencing different opinions as empowering. She voices a sense of disconnection, anxiety and lack of control in relation to Tamoxifen use.

As well as physical changes, brought about by surgery (lymphedema) and ongoing hormone therapy (Tamoxifen and Letrozole use), women described how their day to day lives were impacted on by long term effects including anger, fatigue, and declines in cognitive ability. These were particularly brought to the fore by women taking part in the photo-production study (Figure 8-24).



Image: Delphi 1

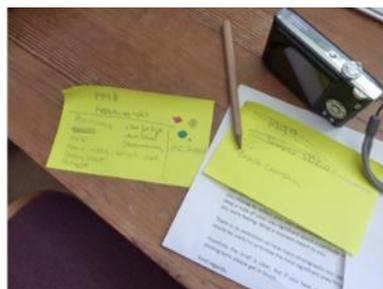


Image: Wendy 22



Image: Wendy 31

Figure 8-24 Experiencing ‘Tamoxirage’ and cognitive decline

© Delphi Marmaduke / 05.01.16 / University of Salford / Cathy Ure; © Wendy Northway / 28.04.16 / University of Salford / Cathy Ure

The images in Figure 8-24 represent issues related to anger and cognitive impairment (Bender et al., 2006) post treatment in private spaces. Delphi describes being angry after her

kitchen work surface was accidentally stained (Figure 8-24: Image Delphi 1). Her ‘anger’ is validated by drawing on the experiences of other women she speaks to online:

‘And that’s something that we’ve got in common in the group. It originally was considered ‘tamoxirage’. But the majority of us have found that we...our patience, our tolerance of things and generally our ability to remain calm about stuff and actually look at the little things as little things, massively reduced’. (Photo-production: Delphi)

Delphi describes changes in her emotional responses – ‘patience’, ‘tolerance’ and her ability to ‘remain calm’ as a common response to breast cancer treatment, experienced by ‘the majority of us’. By claiming a group identity in relation to ‘tamoxirage’, she validates her day to day responses. Women’s accounts described modifying aspects of their lives in order to cope with fatigue whether they were in their thirties ‘I don’t do things that will exhaust me to that level’ (Delphi) or their fifties:

‘Friday, I spend in my pyjamas recovering from Wednesday and Thursday⁸⁹. People at work see what they see as a healthy person so they don’t know had hard it is’ (Photo-production: Lizzie).

Delphi, Wendy and Lizzie all described changes to their cognitive abilities ‘Cognitively, my decline was extreme’ and ‘I completely lost my ability to think about anything’ (Delphi); ‘my cognitive skills are not as good. I feel like somebody drilled holes in my brain, so I have to work really hard to make my brain work’ (Lizzie). Wendy included photographs of making lists (Figure 8-24: Image Wendy 22) and a photograph of her cat⁹⁰ (Figure 8-23: Image Wendy 31) to highlight the impact of becoming easily distracted and unable to process information in the same way:

‘It’s all about attention span. And my attention span was absolutely broken. I didn’t read at all, all through that year. I just couldn’t follow a book. I was watching films on the television, kept having to pause them, have a little nap. Watch them again and it’s just general attention span-which is quite shot really’ (Photo-production: Wendy).

89 Lizzie works part-time. .

90 Wendy used the photograph of a cat to share an anecdote about staying in a hotel and talking to the receptionist – “the receptionist was lovely. She was telling us all about what we could do and what to see. And then all of sudden she said, “oh the pussy cat”. And then it became just a bit of a standing joke with me and my husband, oh pussy cat. It’s all about attention span. And my attention span was absolutely broken’.

One notion in relation to social media use is the ability to engage, as and when, in line with cognitive capability. Wendy found reading and watching traditional media (books and films), when recovering from surgery and treatment, was often beyond her capabilities. While cognitive impairment is a recognised and well-reported side effect of chemotherapy (Boykoff, Moieni & Subramanian, 2009; Brezden, Phillips, Abdollell, Bunston & Tannock, 2000; O'Shaughnessy, 2003; Wefel, Saleeba, Buzdar & Meyers, 2010), women did not directly describe social media use in relation to coping with these changes. However, the immediacy, and flexibility of social media for women - in terms of when, how and for how long to engage - may be beneficial as avenues for support and entertainment when cognitive abilities are experienced as limited.

8.3.4 Navigating mortality, loss and grief

This sub-theme, so far, has explored women's accounts of the day to day challenges of LwBBC, created by social interactions as part of their everyday living and side effects of treatment regimes. However, women also voiced concern about issues relating to mortality, grief and loss which impacted their day to day lives. Across many interviews, women raised fears that they will not survive cancer. For those recently diagnosed this fear was in relation to their current diagnosis and treatment: *'am I going to die? Will I see next Christmas?'* (Michelle Mu); *'I've got a pain in my hip which I am convinced is that it's spread'* (Sarah J); *'I could be dead next year. It could happen. That's a fact to me'* (Kirsty); *'I think about that every day'* (Kirsty). For women living 1-5 years and five years post diagnosis, the fear expressed relates to recurrence. *'I live with the fear of the cancer coming back every day'* (Mandy); *'will this come back?'* (Millie). *'I'm hoping I haven't got secondaries'* (Delly); *'I was getting back ache; side ache. I automatically thought 'oh gosh, I've got secondaries'* (Jojo); *'every twinge or bump you worry that it has returned and it's returning. Do I have to go through the same process again? Is it secondary? In which case, there is no hope really'* (Wendy). Fear of cancer recurrence (FCR) defined as "fear, worry, or concern about cancer returning or progressing" (Lebel et al., 2016) is one of the most common and most distressing outcomes post diagnosis (Cohee et al., 2017). Women diagnosed before fifty, with early invasive breast cancer, lower social support and elevated anxiety are predictors of higher FCR at two year follow up (Liu et al., 2011). In a recent comprehensive review, Simard et al. (2013) identified that FCR across cancers does not reduce over time. Eight-two per cent

(n=18/22) of the longitudinal studies in the review showed no change over the periods assessed, ranging from 3 months to 6 years.

Women negotiated their own fear of cancer recurrence while adjusting to the public/private nature of other women with breast cancer dying. Across 21 interviews, only one example of how women grieve together online was provided, despite numerous women discussing ‘friends’ made in social media groups passing away. Little is known about the psychosocial benefits experienced from grieving in closed health groups. Women’s accounts included narratives of friends who had died from breast cancer:

‘She was only a biscuit older than I am. Died suddenly in the summer’ (Photo-production: Delphi);

‘my friend Suzy (pseudonym) who I had become very close to she got secondaries and she died, so that was another ‘whoa’’ (Photo-elicitation: Denise G);

‘so I have heard about so many that have died in this group’ (Photo-elicitation: Jojo);

‘Caroline’s (pseudonym) since died because hers came back’ (Photo-elicitation: Mandy);

‘I find that the more other women I was meeting with breast cancer. The more inevitably some of them died and the more upset I became’ (Photo-elicitation: Mandy);

‘and sadly, three died, two very quickly after we started the group and then one died this April’ (Photo-elicitation: Millie);

‘she was hilarious, she was brilliant and when she died it was really, really upsetting. Really, really sad and I think it was hard because it was the first one’ (Photo-production: Nicola)

‘it’s not so good seeing all the people that have died or I find a blog and I think ‘oh, this is nice and then the next page will be ‘oh, and then she died’ (laughs)’ (Photo-elicitation: Sarah J)

‘and they obviously post when somebody’s died and I don’t think I’d really thought about that that much’ (Photo-elicitation: Sarah M).

Liz and Delphi talked about the challenge experienced of ‘friends’ tweeting online hours before their deaths. These examples show end of life as a ‘social’ space no longer restricted by isolation, secrecy and infirmity:

'two days before Janice (pseudonym) died she tweeted. So how, you know, how two days and then you're dead. How was she putting something rational and then she's no longer with us? And that's a puzzle for me' (Photo-elicitation: Liz).

'She died suddenly in the summer. I'd been talking to her in the morning, she died an hour later, yeah, which I could not do. I just...I couldn't...it was horrific' (Photo-production: Delphi).

Women are therefore engaging in a 'social' experience of death both as 'friends' and as women who have been living with breast cancer interconnected in life and beyond life. McEwen and Scheaffer (2013) describe Facebook as "a virtual global locale for commemoration, bereavement and public expressions of emotion" (p.64). While many women spoke of their individual feelings of loss, Michelle J gave insight into a closed Facebook group mourning process when Diane [pseudonym] died. This narrative supports Marwick and Ellison's (2012) contention that "mourners experience the desire for openness and publicness, as well as tendencies towards communications contexts that are more private and closed" (p.379). A closed Facebook group supports openness and publicness in a space which is also private, shared and intimate with a bounded membership. Participation in online grieving enables the expression of emotional community and enables women to 'move on' (Chapter 9: section 9.1.4) in their day to day lives:

'Her funeral is on Friday. And we all lit a candle and we've all put a picture on the site. Some were toasting like a glass of wine and the comments there are just hundreds of them. But it just brings the reality, because I think she was about 34. And it just seems, you know ...not everybody gets out of this alive. At the time it made me feel ill because she had triple neg breast cancer. And it's awful, someone has passed away and I'm thinking of myself, but it's, that's just what happens with your emotions, you can't...and she's got two young children and I dwelled on it for a good week. And now you know I can move on you know' (Photo-production; Michelle J).

Michelle's account provides insight into a collective memorial through the actions of lighting candles, uploading individual photographs 'to the site' and the posting of 'hundreds' of memorial comments. She acknowledges the dissonance between her own reaction and the death of a group member '*and its awful, someone has passed away and I'm thinking of myself*' comparing herself in terms of age (34), number and age of children (*two young children*) and type of breast cancer (*'triple neg breast cancer'*). Women using social media have to negotiate the life and death 'realities' of LwBBC from a point of limited awareness

when they initially join groups (Chapter 7: section 7.2.1.). ‘Loss’ becomes an inevitable outcome as a member of the breast cancer community.

8.3.5 Summary: Theme Two – Subtheme Three: Working through the day to day

Women describe doing ‘cancer everyday’. The accounts within this subtheme demonstrates the interconnectedness of physical, psychological, emotional and social factors impacting on women across the cancer continuum and over time. When in treatment, women encounter challenges in everyday environments through invasions of privacy from strangers. Women share these encounters in closed groups and often find humour through shared experiences. For those further along the cancer continuum, daily challenges created by the side effects of treatment are supported through social media use. Women proactively use Twitter and Facebook to bring support to them by broadcasting hospital visits and treatments in situ. YouTube is used for practical guidance on how to alleviate challenging side effects. Some women use multiple social media platforms to draw on different types of support – informational, emotional and instrumental - when trying to alleviate the effects of lymphedema, for instance. While some women are agentic in using social media to find solutions to alleviate the discomfort caused by side effects, others experience anxiety when treatment regimens are rejected by women LwBBC. Challenges to medical knowledge shown by women LwBBC by not following treatment regimens can create dissonance and anxiety for others. Others feel validated when reading posts that express LwBBC as ‘a bit shit’. Some of the commentary points to wider society being relatively immature or under developed in the way it talks with those newly diagnosed and those seeking to continue to contribute to society after treatment. This is a significant educational issue given the expectations that 1 in 2 will experience cancer at some time in their lives (Cancer Research UK, 2015). Finally, women who are members of closed Facebook groups describe social media use as enabling women to process their thoughts about their own mortality collectively and separately; in public and in private.

Chapter 9: Theme Three - (Re)gaining a sense of control

9.0 Introduction

The third theme explores how women LwBBC use social media to gain a sense of control at different stages of the cancer continuum. Women seek to (re)gain a sense of control using social media to i) navigate the ongoing emotional impact of diagnosis, treatment and ongoing effects on self and others, and ii) by being productive. Figure 9-1 presents the two subthemes that make up this theme and define their scope. This chapter will explore the subthemes in detail.

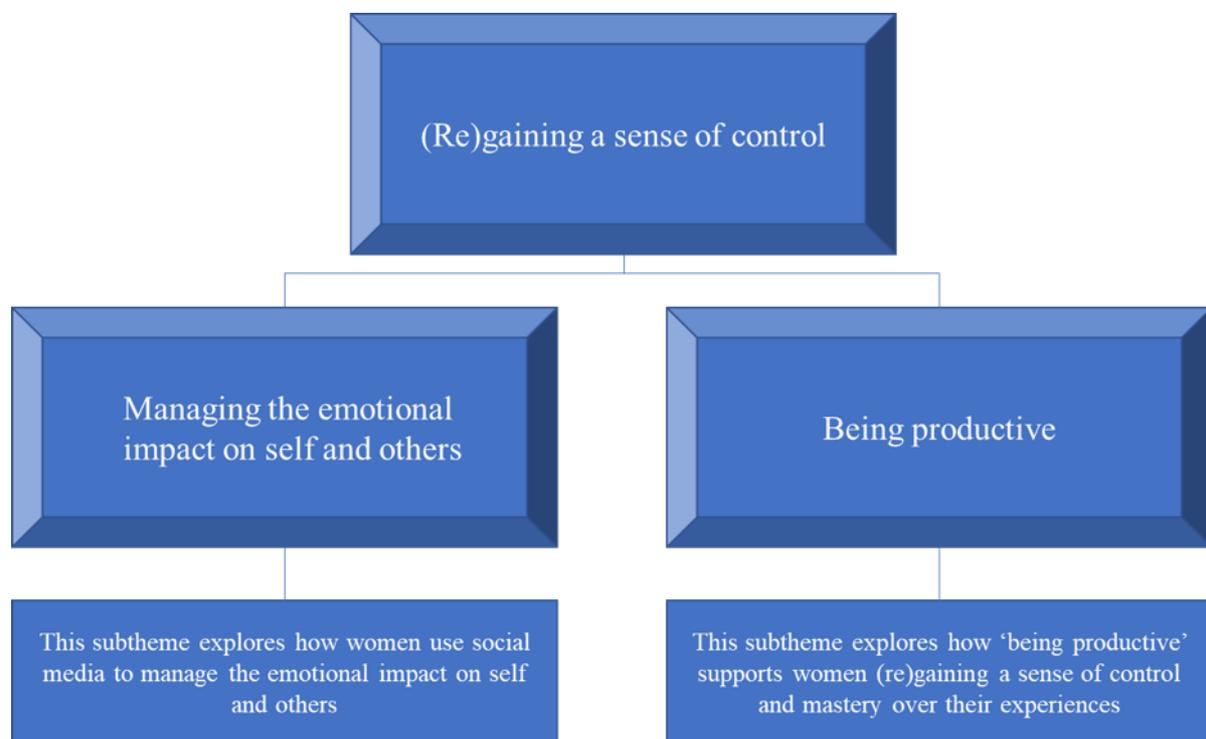


Figure 9-1 (Re)gaining a sense of control -Thematic map

9.1 Subtheme 1: Managing the emotional impact on self and others



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'I think it's a lot more difficult for them [her family] because they hear 'cancer' and all that and..., whereas for me, I'm in control so I feel quite OK about it. If I don't, I don't. It's kind of scary thinking about the future probably really, although I have got an OK, a good outlook you know' (Sarah M).

Figure 9-2 Managing the emotional impact

9.1.1 Introduction

Women talked about controlling the emotional impact of their diagnosis on others by shielding them from aspects of their experiences of LwBBC. They used social media to control specific interactions with family or friends, in part by careful management of how they presented themselves. Women described social media as enabling conversations, which they felt they could not have, or did not want to have, with close family and friends. For women soon after diagnosis, social media mediated conversations with people who 'understood' but were not part of women's day to day lives. This enables women to compartmentalise aspects of their experiences providing a sense of control. However, social media was also reported as threatening, with women reporting anxiety through an absence of control in relation to content viewing and experience sharing. Women articulate the challenges access to 24-hour information about breast cancer brings, and the need to find ways to control access to other women's experiences and continual contact with 'support' groups; or particular types of content. Women adopt different strategies to combat this sense of threat.

9.1.2 Controlling interactions with family and friends

For some women a desire to control the impact of their diagnosis of breast cancer began immediately. Women's diagnostic narratives (Chou et al., 2011) described shock at the

moment of diagnosis: *'I completely broke down in shock. I was literally on the floor'* (Delly); *'in the sort of the shock of those few seconds'* (Jayne); *'the shock of that was such a trauma'* (Kirsty); *'I kind of went into a state of shock'* (Mandy); *'a shock to us all basically'* (Michelle J); *'got the shock to discover I'd got cancer'* (Millie). As well as contending with 'the chaos' of diagnosis, women at all stages of LwBBC described anxiety about the impact of their cancer diagnosis on their families: *'you don't want to worry them do you?'* (Eleanor); *'I don't want them to worry about me'* (Sarah M); *'you don't want to worry them'* (Nicola); *'I'm more worried about the effects of all of this on other people'* (Michelle M); *'it must have been a massive worry for them'* (Liz). The effect of breast cancer on family members is one of the most important concerns of women diagnosed with the disease (Figueiredo, Fries, & Ingram, 2004). Of specific concern was a desire to not burden loved ones:

'I didn't want to burden [my husband] anymore because he was frightened, he was really, really scared' (Photo-elicitation:Jayne)

'I don't like burdening family and friends, just want to say to them 'no, it is cool'. So you could compartmentalise, if you like...You could just have it as a section of your life that was there [on Facebook], you know. I would tell [my husband], because he would want to know, he would want to ask. But I guess it was protective, you know. I just thought I can't go to pieces' (Photo-production: Deborah)

Women continue to see themselves as carers of others and have to retain control *'I can't go to pieces'* (Deborah). They do not position themselves as 'being cared for' by others. Use of 'burden' is reminiscent of women's use of 'mithering' (Chapter 7: section 7.1.2) to describe their measured use of health care professionals' time and support. The notions of being a 'burden' and 'mithering' are tied up with women's assessment of how much they can ask for, with a constant focus on limiting the impact of themselves and their disease on certain others. They relate to the gendered notion of selflessness (Atkins, 2016). Sulik (2007) argued that gender socialisation, which stresses the female role as one that is selfless and focused on caring for others, impacts on women's sense of their own entitlement to care. These notions of not burdening familial relationships concurs with women's use of the CHESS breast cancer online community (Shaw et al., 2000).

Women, diagnosed within the preceding 12 months, were anxious about managing Facebook relationships. Their diagnosis led to a careful assessment of what to share on their main Facebook page. Sarah M talked about the complexity of working out who *'to share'* with:

Cathy: Yeh ok, so, from what you've said I'm inferring that you only post in the Younger Breast Cancer network about how you're... experiences and how you're feeling ..?

Sarah M: Oh yeah, I wouldn't put that ...I would never put anything on Facebook to the, my norm...my friends and that. I would, didn't know, they wouldn't know ..a lot of people wouldn't know that I'm having chemo right now cos I just wouldn't, it's not something that I would share with... Because there's people on there, there's friends and family, but then there's friends that I'm not really close with so I wouldn't share that sort of stuff with' (Photo-elicitation: Sarah M).

Sarah feels her experiences are inappropriate to post on her main Facebook page: *'I wouldn't put that. I would never put anything on Facebook to the, my norm...my friends and that'*. I offer an inference – that she shares aspects of her experiences of breast cancer only on YBCN – which Sarah takes up *'oh yeah'*. Rather than going on to say what she shares on YBCN, she remains focused on her 'normal' Facebook page, trying to find a form of words to explain her use in relation to LwBBC. She indicates a desire to distance herself from weak ties on her normal Facebook page *'there's friends that I'm not really close with so I wouldn't share that sort of stuff'*. This raises issues of complexity whereby existing weak tie relationships are rejected as potential sources of support. Yet, at other points in the interview, Sarah talks about sharing a photo *'with her headscarf on'* and posting an image of herself just before surgery on her 'normal' Facebook page:

'I put those pictures on and its just like a little guide [Coppafeel!⁹¹ awareness information] and then that's me before I went down [to theatre] and it got shared 220 times' (Photo-elicitation: Sarah M).

Here, Sarah M broadcasts a photograph and breast awareness information. She states the post was shared *'220 times'* emphasizing audience and others interest in her experience. There is therefore some ambiguity in Sarah's account. She talked about sharing a photo of herself on her normal Facebook page prior to surgery with breast cancer awareness information attached. Yet, she also states she has not posted anything about having chemotherapy – *'people wouldn't know I'm having chemo right now'*. In line with women's experiences of 'hiding' discussed in Chapter 8: section 8.2.2. Sarah M controls which aspects of her life and experiences she shares. This supports Coll-Planas & Visa's (2016) contention that women try

91 Coppafeel! is a breast cancer awareness charity promoting early detection of breast cancer to women under 30.

to hide the side effects of treatment. Rasmussen et al., (2010) offer an interpretation as to why women choose to restrict the sharing of experiences. They report that

'cancer as a disease is hidden, both by the individual, and by society, and consequently it cannot be addressed when meeting others' (p.158)

Kirsty also talks about the complexity of sharing publicly on Facebook aspects of LwBBC with 'friends'. She talked about why she was not currently using her 'normal' Facebook account in the same way as she did pre-diagnosis:

'I've not been using my normal Facebook account as much since I had cancer. Because, oh I don't really know, it's a bit complex really. I do use it. I haven't been doing as much so that's part of the reason, so I'm not as busy. I don't really have much to say I suppose on my normal account. And I don't really use it for chit chat and things. I don't really just put random stuff on like 'oh woke up this morning and blah blah', I don't really do that. It's more just like events and things that I'll be doing. So, I've not been doing as much and then I didn't want a lot of people...obviously a lot of my friends on Facebook are people that I've known for years, school friends and I didn't necessarily want to air my cancer journey with them all the time. I don't want them to think that...whenever I put anything on, so if I put only like three or four posts on, a couple of them about cancer, people are so nice and there are immediately comments and likes and this and that. And I don't want them to think that I'm asking for sympathy and I want them to do that. I don't actually want them to do that really. It's nice, you do feel supported but if my friend was putting, I'd feel like I had to really otherwise it would look a bit bad. So, I don't want people to feel they have to. And there are some people I just don't really want them to know really. I don't really want them to know that much about me really in that way' (Photo-production: Kirsty).

Kirsty provided multiple reasons for why her Facebook had changed. It was related to 'not doing as much'; 'not wanting to air my cancer journey'; not wanting 'them to think that' they need to provide 'comments and likes' and concluding with not wanting 'some people' to 'know'. This suggests significant identity work (Chapter 8) being undertaken. Prior to diagnosis, Kirsty had used Facebook extensively:

'I use it for all kinds of things to maintain friendships and to keep in touch with people all over the country, all over the world really. I use it as a Messenger add on. I use that all the time and obviously use the Young Breast Cancer Network and other breast cancer related groups. I use it as event planning, friends. All kinds. I use it for storing photographs and things like that. Like a chronological sort of record of, I like looking back over my whole Facebook

because you get an insight into what all of like the important times I suppose over the last six years. Most of the positive things. I don't really upload a load of negative stuff. But I do use it to record events and then share photos with family and people there' (Photo-production: Kirsty).

This type of use is conceptualised as “event society” (Murthy, 2012; Therborn, 2000) or “the society of experience” (Huysen, 2000, p.25) whereby identity is constructed as event based, focused around a “stream of transient or trivial events” (Bouvier, 2015, p.157). Kirsty describes a change to her ‘normal’ use by moving away, may be temporarily, from “event society”. She is agentic in navigating aspects of her changing identity in closed Facebook spaces with people she has had no previous connection, developing new social identities.

In contrast, when Wendy described broadcast updates to her own Facebook page she aimed to control individual responses by giving ‘*very matter of fact*’ event updates:

'I took my little iPad to [name of hospital]. Because I knew I was having chemo, or after, I would post 'first out of six chemos'. 'Last chemo – nailed it'. That kind of thing. Erm, I do put it as very matter of fact. I did not say anything like 'chemo is crap'. 'I feel awful'. And I would never post anything like erm, 'I'm really down today' or anything like that. It was always very upbeat. I didn't want anyone to pity me'. (Photo-production: Wendy).

Here, Wendy uses ‘*matter of fact*’ posts because ‘*I didn't want anyone to pity me*’. Wendy seeks connectedness with others through broadcasting status updates yet, is careful to construct a positive cancer identity on Facebook. She engages and seeks to control the online performance (Goffman, 1959) aware that her ‘act’ is monitored by an audience (Hogan, 2010). She establishes communicative boundaries – by influencing the affective responses gained and controlling the communication process through Facebook - to maintain a sense of control over the emotionality of being treated for breast cancer. Wendy used photographs to express controlling the narrative (Figure 9-3). For instance, she talked about being unprepared for losing her nails (Figure 9-3: Image 19):



Image: Wendy 19



Image: Wendy 28

Figure 9-3 'Being happy'

© Wendy Northway /28.04.16/ University of Salford / Cathy Ure

'Nobody ever says to you are you going to lose your nails. It's something that I didn't realise. Anecdotal evidence says that if you put dark colours on "...", if you put dark colours on then that reduces the possibility that you might lose your nails. So, mine were black all the way through; and I lost all my nails. "...". But they started coming away from the nail beds and two thumbnails they were awful because they split across there and stuff. And I was so worried about them tearing off. And I didn't know what to do about that. That was actually one area where there was very little advice. "...". I painted the nails that I had left. I painted those, and I posted nice pictures and so everything was nice and jolly wasn't it!' (Photo-production: Wendy).

She uses the image to raise the issue of lack of awareness – *'nobody ever says to you'*. She suggests silence around a potential side effect of chemotherapy – loss of nails and an inability to prepare herself for this potential development. She describes the anxiety felt *'I was so worried about them'*. She caricatures the troubled relationship between herself and uncontrollable changes to her body by posting *'nice pictures'*. She recognises the pretence. She highlights the irony of a photograph posted on Facebook *'so everything was nice, and jolly wasn't it'*. The visual imagery acts as a metaphor for painting over the realities of LwBBC. This is re-emphasised by the inclusion of Image 28 (Figure 9-3) which she uses to express feelings of conflict:

'Everything is fantastic. Everything is good. Stay positive. I am trying to come to terms with that at the moment. Was that actually a good bit of advice? Where does that advice come from?' (Photo-production: Wendy).

Through her photographs, Wendy gives voice to the complexity of managing her own emotions during treatment. The inclusion of the explanation alongside the image, provides greater context for the posting of ‘nice and jolly’ images. The sharing of her reflection on whether that was an appropriate coping strategy suggests Wendy is working through her experience as she seeks to (re) gain a sense of control.

Sarah J sought control through careful selection of social media to communicate with friends. She describes navigating her need to maintain her privacy while also seeking out emotional support (Chapter 7: section 7.3). She prefers to broadcast aspects of her life - ‘*things that I’m doing or places that I have been*’ - on Twitter to ‘*either people I don’t know or my closer friends*’ rather than using Facebook. She is concerned about being judged and talks about how this concern restricts what she posts:

‘I don’t want people judging me and you know knowing about what I am doing and going – like I do to other people (laughs)’ (Photo-elicitation: Sarah J).

While Sarah J asserts an intent to maintain privacy, her social media use audit identified eleven platforms in active use. Sarah uses different social media platforms to achieve different communicative purposes. Using Twitter and WhatsApp as her main communication platforms provides a greater sense of being able to control her social identity; while lurking on Facebook also provides benefits (‘*I can spy on them [her ‘friends’]*’).

Even though women describe compartmentalising their cancer experiences online (to be discussed in section 9.1.4), some women also described the challenges of ‘*crossovers*’ between their ‘group life’ and their ‘*normal, everyday*’ Facebook life. Kirsty described use of her own Facebook page and the closed YBCN group as running ‘*in parallel really*’:

‘And there’s no way of, they can’t log into my... the YBCN girls can’t see my normal Facebook because I have my privacy settings set to full. All they can see is my exterior profile unless they are my friend. A couple of them I have added as friends, so they can see my full Facebook, but generally you can’t. So, it kind of runs in parallel really’ (Photo-production: Kirsty).

This was a sentiment echoed by Sarah M – ‘*I want to keep it separate*’. Sarah M brought forward the notion of dissonance created by ‘*crossovers*’:

Sarah: ‘No, I think (pause) I’ve found that, that there’s been a little bit of a crossover. A couple of people have, erm from the group have

requested to be friends and that's a little bit awkward and I have, I have accepted three, three of them but I'm going to be deleting them in the future (laughs).

Cathy: Tell me about that then.

Sarah: Erm, well one of them is in my chemo buddies – Laura (pseudonym) and I've spoke to her a little bit on it so I don't feel so bad about that. But the two others, that I don't even, I don't, I've never talked to them and it just feels a bit weird like it's a crossover, think I'd keep it very separate. Erm, so I've accepted them because I feel like rude not to whereas in real life I don't know. If I didn't know them that well I just wouldn't. Like there's people at Uni that I wouldn't accept. But I will, I will delete them 'cos it just feels a bit intrusive' (Photo-elicitation: Sarah M).

Sarah suggests feeling encumbered by an unspoken etiquette to accept individuals from a closed Facebook group, who are also LwBBC, despite not having had contact with them previously. She describes a sense of it *'being rude not to'* yet also states that this would not be her normal approach *'in real life'*. This entanglement of whether Facebook represents and reflects *'real life'* was a sentiment echoed by Denise D too, *'it's not real'*. Sarah's response raises interesting questions about the difference between rejecting a request from someone already known *'like people at Uni'* and considering rejecting someone not known - *'I've never talked to them'* - from a closed group. She suggests her agency in how to respond varies. She questions why not accepting friend requests from women in YBCN is *'rude'* when not accepting friend requests from people at University is normalised as acceptable Facebook behaviour. It suggests either a notion of greater identification with *'similar others'* (Chapter 8: section 8.1) or potentially, concern about own relationality within YBCN should *'friend'* requests be rejected. This is particularly interesting given Sarah's feeling that she wanted to keep it *'very separate'*. Understanding in more depth how women experience *'crossover'* may illuminate new understanding about social media use, social norms and social support mechanisms along the cancer continuum. Delphi also develops the theme of friendships *'in the real world'*:

'There are very few of them that I would feel I would get along with necessarily in a real way in the real world. And my own Facebook thing, I've got very few of the women from the group on there. Whereas, lots of people, every time someone's added [to YBCN], they'll add them to their Facebook and you know, I'm not that person' (Photo-production: Delphi).

Delphi's comment, *'I've got very few women from the group on there'* suggests some crossover between YBCN and her main Facebook account. She brings forward the notion of similarity and difference (Chapter 8: section 8.1.2) in relation to how women 'manage' their online identities. She differentiates herself from *'lots of people'* adding YBCN members to *'their Facebook'*, *'every time someone's added'*. This may explain the requests Sarah M received from closed group members she had had no communication with. There is a tension described when women in a closed Facebook group seek to shift an absence of relationship from a closed Facebook group onto the wider public Facebook platform. Sarah M demonstrated having to navigate how she felt about an activity which may present itself as a social norm given its prevalence - *'every time someone's added'*; indicating that she will *'delete them because it just feels a bit intrusive'*. Some women therefore articulate that the ability to have a sense of control over 'social' boundaries is a critical aspect of their Facebook use when LwBBC. Women feel benefit from being able to compartmentalise aspects of their experiences and controlling other people's access to facets of their life that they do not wish to broadcast.

As Sarah M wrestled with managing the emotional impact of 'new' uninvited relationships, Sarah J reported feeling ill-prepared in how to tell her friends about her diagnosis. She described regaining a sense of control by using Facebook Messenger:

'Messenger's the easiest especially when I was first diagnosed. Erm, I really struggled to tell people. I didn't mind talking about it in general but just that first...How do you start that conversation? Like, you know, I was going round my friend's house, and they just thought I was going round their house for tea, and it's like how do I start it? Do I pretend everything's fine and then tell them or? So, every time I had to tell someone I'd erm spend the whole day thinking how? What am I going to say? How am I going to word it? What's going to happen? And I was just like 'I'm sick of this like I'm the one with cancer, it's not fair that I have to spend my day worrying about how I am going to tell someone else, so then half my friends I decided to just send them a message to tell them' (Photo-elicitation: Sarah J).

Sarah uses Facebook Messenger to disseminate difficult news to both inform others and release the emotional energy required to deal with sharing her news. Sarah speaks candidly about the conflict she experiences in working out how to tell people and her feeling of pretence. Her voice is conflicted *'how do I tell people'*; *'what am I going to say'*; *'how am I going to word it'*; *'what's going to happen'*. She articulates concern for her relationship to

others created by the pressure of telling other people face to face 'how do I say it'; 'I really struggled'. Her voice shifts and articulates a sense of injustice: 'it's not fair'; 'I'm sick of this'; 'I'm the one with cancer'. Through using Facebook Messenger, she reduces her own anxiety in telling people; informs people to suit her own temporal needs; provides individuals the space and time to think before responding (Chapter 7; section 7.1.4) and reclaims control of the initial 'cancer diagnosis' dialogue. Denise also describes using Messenger to inform friends. Similar to Wendy's use of 'matter of fact' posts, she framed her 'diagnosis' Messenger posts in a way which gave her some control over the type of response received subsequently:

'so, what I did I told them it's a small lump; I've caught it in time; the prognosis is good; it's really good; I'm really lucky. You know everyone's been fantastic. The National Health is unbelievable - and it was - and so people were kind of "aw that's I'm so pleased for you. I'm glad it's been caught in time"' (Photo-elicitation: Denise D).

Denise describes her use of Facebook to meet her specific communication needs. She chooses the platform (Facebook); feature (Messenger – targeted communication) and strategy (framing her 'diagnosis' message positively) to control the type of responses she wants to receive as support - 'I'm so pleased for you. I'm glad it's been caught in time'. Through adopting this strategy Denise takes control of the 'diagnosis narrative' and anticipated responses through being agentic 'I've caught it in time; the prognosis is good; it's really good. I'm really lucky'.

Both the examples provided by Denise D and Wendy describe a discriminating approach to deciding what to post online. They indicate a need to manage the message. Other women explained their concern about using social media and their own capacity to cope with others' responses more explicitly. For instance, some women selected to use social media only after treatment ended. Liz described how challenging she found chemotherapy. She gained some sense of control through not posting on her social media channels about having breast cancer until her treatment was almost complete:

'I didn't really use Facebook in the, the start of my diagnosis it was only when I was starting to get to the end of the treatment on my penultimate Herceptin [...] I just didn't want to put it out there I just didn't want to put it out there' (Photo-elicitation: Liz).

Liz conveys a need for privacy and suggests a concern about potential loss of control of her breast cancer experiences by putting *'it out there'*. In comparison to Denise D's account of using Facebook Messenger to frame a particular message to gain the right support for her, Liz stated:

'I didn't want people asking me about it particularly because I was so mixed up in my own head about it' (Photo-elicitation: Liz).

This may point to opportunities for health care professionals, or peer led groups, to offer support to women in developing strategies for framing the 'diagnosis narrative' or 'treatment narrative' that can be utilised through social media channels.

9.1.3 Controlling own access to other women's experiences

As well as choosing when to 'go public', women also demonstrated selectivity or careful consumption over the type of content to access. For instance, both Kirsty and Wendy talked about careful consumption of YouTube content related to women's experiences of LwBBC. Decisions on whether to watch content were made in relation to *'the atmosphere'* conveyed at the outset of videos. Women protected themselves from viewing material that was related to *'desperation'* (Kirsty) or were *'very upsetting'* (Wendy).

'you don't know what you're going to find, that's the other thing as well, is I suppose with like a film you don't really want to see, I don't know, you don't want to see too much. So, if I click on something and I don't like the immediate atmosphere of it I'll just click it off. I don't want to see people's really, you know desperation' (Photo-production: Kirsty).

This shows women as discriminating information consumers; balancing information gathering with a developing sense of what works for them and need to control access to content that may be experienced as potential threat. This is in line with women's approaches to information searching in relation to breast screening (Galpin et al., 2017). This sense of information threat is experienced at all stages of LwBBC. Lizzie, some ten years past treatment, talked about her decision to stop going on line after her treatment had ended:

'I went through the treatment and I went back on these forums, these fora, or whatever you want to call them, I started feeling that they were adding to my anxiety because the last thing I remember reading on one of those was 'right, so I've had all this treatment' - which was the same as my treatment - 'and now I've got cancer of the sternum because my sternum was irradiated so does anyone know

what to do about cancer of the sternum?', and I thought I don't think I want to think about that and that's when I stopped looking' (Photo-production: Lizzie).

Here Lizzie describes anxiety caused by reading about other women's experiences post treatment online. She adopts an avoidance strategy to protect herself from ongoing information threat and removed the internet and online forums as a potential source of information regarding her breast cancer. Lizzie gained a sense of control through focusing on her own experience and evidence based information:

'I tend to go for evidence based information now and I actively avoid patient forums. In some ways I feel a bit bad about that because I might have something that I could offer somebody else. I might be able to help somebody else but I find them infuriatingly inaccurate and they tend to promote you know the stuff on the grapevine. Popular, popularising myths and things and it just gets me down so I don't look at them' (Photo-production: Lizzie)

Other women talk about joining groups, leaving groups and re-joining groups as their own sense of mastery grows:

'I have re-joined it again now but I had to come off it at that time because I just found some of the ladies put quite a lot of negative things on there. And now when I see it on like on the young one, the young site, I just ignore it now. Because some people are probably more negative anyway regarding breast cancer. So I can just take myself away from that now' (Photo-production; Michelle J)

Women at all stages of LwBBC describe adjusting their approaches to social media use in order to control their access to other women's experiences, as they move away from the time of their initial diagnosis and treatment. Within these conversations, women state *'I've got to protect myself'* (Denise G). Mandy talked about how ongoing use *'would knock me back'*; and feeling *'quite frustrated'* (Delphi) on the behalf of women recently diagnosed and how this was *'impacting seeing what people were going through'* (Delphi). Consequently, women were selective in what they chose to get involved or stay involved with. For instance, Deborah as a moderator on the YBCN closed Facebook page sought to minimise her exposure to reading other women's posts:

'But I really don't like reading back through all the posts and I still won't do it' (Deborah)

'So I still offer time, but I try to distance myself from the actual posts' (Deborah).

These comments begin to develop an idea of how women continue to contribute within breast cancer communities while also developing strategies to protect their psychological wellbeing. Mandy described her changing use of social media:

'I did that very much so in the beginning, very much so during treatment and for a few years afterwards, less so now because I don't want to be part of those groups, because again you get close to people and you lose people' (Photo-elicitation: Mandy).

Mandy describes the challenges of using social media to gain support from unknown others and becoming emotionally connected and invested (section 8.3.4). Some women experience the loss of friends made through social media as damaging to their personal well-being and consequently, become increasingly selective as to where they source support from on an ongoing basis. Harkin et al., (2017) proposed death anxiety in health populations as detrimental to psychosocial well-being. However, women focused more on the impact of the continual exposure to bereavements as impacting their sense of well-being rather than consideration of a self that 'does not exist'. Denise G, some ten years post diagnosis and an active user of Facebook, purposefully does not use Facebook to support other women LwBBC. She describes this decision as protecting herself from the exhaustion of being immersed in that environment:

'I don't want to spend the time reading things and to read about people's problems. I can read a little bit about it but if I did that all the time, it drains my energy erm and I think that's; I've got to protect myself' (Photo-elicitation: Denise G)

Careful selection of how to and what to participate in provides a sense of control. Social media use supports a level of fluidity to move in and out of 'social' environments. There were no barriers described in re-engaging with platform use or in specific breast cancer groups as women's use shifted and changed. This has significance for women who may experience several diagnoses of breast cancer across the life course or may seek support at different times when LwBBC. Interestingly, how membership continues of groups structured around age at diagnosis was not an issue raised within these interviews. Reluctance to leave groups because of age considerations may result in women remaining strangely tethered and unable to 'move on'.

9.1.4 Compartmentalisation and ‘moving on’

Women also talked about the notion of compartmentalising their breast cancer experiences to manage the emotional impact of their diagnosis:

‘I’m good at, I’m very good at I think in my head I have these little erm I call them boxes erm and when you’re challenged or when you’ve got to get on with something but other stuffs happening, I am very good I think at saying “ok you’re going in; the doors shut and you’re coming out when I’m ready” and I’ll get on with things’ (Photo-elicitation: Denise D)

The intrusion of breast cancer into private family space was warranted by Deborah as prompting her initial use of social media. Deborah talked candidly, just a few minutes into our conversation, about the emotional trauma of telling her parents she had breast cancer:

‘But telling my parents was horrid, you know. Just to watch their faces go. And the worse thing of all of it was just feeling – and you couldn’t explain this to people and I guess that is where I started with social media, was I couldn’t bear talking about it to people I loved. Because there is just something about knowing, planting this little seed of darkness and nastiness in them, which I know you are not doing deliberately, but I found that unbearable’ (Photo-production: Deborah).

‘I think perhaps social media has given a platform to greater understanding of just how much it’s affecting younger people. And control, as well. I think it gives you – (clicks on to next photo using laptop) and that is just the same thing there, an actual page. But yes...

Cathy: Control you were going to say?

Deborah: Control of things you can’t control as well, isn’t it, in some ways? To feel as though you can – is control the right word? Well, I think when things feel out of control emotionally and stuff and you feel trapped with something, it can help just compartmentalise it’ (Photo-production: Deborah).

Both Sarah M and Jojo talked about the differences in the way they were able to talk on social media to other women, in comparison to their own families:

‘I think you can say more to the group, or on Facebo ...to the Breast Care group than you would to your best friend because if I’m having a problem like for instance if I tell my family that I am suffering I’ve got this; I’ve got that. They suffer as well. They feel for me. They are brilliant, but I don’t want them to, so I can share my problems with a

*group of people who, I don't know, who will also understand'.
(Photo-elicitation: Jojo).*

Sarah M indicated she felt she could talk more honestly about her experiences because she was not invested in relationships within the Facebook group:

'through social media I think you can be a little bit more honest because (pause) you've not got as much invested in their feelings. If you know, what I mean and their going through it so you can't shock or scare them or make them feel.... There's no guilt in telling somebody on social media that yeah you do feel like shit, do you know what I mean, cos there not going to come rushing round to your house, so there's that distance so I think you can definitely feel you can be more honest' (Photo-elicitation: Sarah M).

Sarah M describes there being 'no guilt' because other women LwBBC cannot be shocked or scared and warrants her ability to control anticipated reactions from her friends and family (stopping them from 'rushing round to your house') as beneficial. This links with Denise's use of language to frame specific responses from friends and family – both seek to control or limit their emotional investment. Sarah supports Jojo's 'you can say more to the group' with 'I think you can be more honest' with those she is not 'invested in'. Wendy expressed a sense of being able to be vulnerable with other women LwBBC

'I felt that I could actually open up and allow myself to, to be frightened with them' (Photo-production: Wendy)

The way in which women talk about compartmentalising experiences, and not broadcasting them or sharing them with family, suggests a type of self-silencing. Compartmentalising experiences is related to not burdening others (section 9.1.2). Social media provides an alternative space to manage their own emotional responses to the diagnosis:

'sometimes you don't want to talk to your family members about your fears and everything, because they've got their own and you don't want to worry them and you know that sometimes you just want to get things out there and say it out loud and it almost kind of...it's cathartic isn't it. And then once you've said it out loud, you can kind of move on from it. But if you say it out loud to your family and they might start panicking and they might start running' (Photo-production: Nicola)

Nicola contrasts her self-silencing about 'your fears and everything' when with her family, with her need to 'say it out loud'. She transposes the idea of vocalising through speech her concerns, to vocalising through Facebook posts her concerns which enable her 'to move on'. The ability to express her emotions in a space, regardless of whether anyone will respond,

enables her *'to move on'*. Within this discussion, Nicola separates her audiences, using closed Facebook groups (YBCN; BBB's) to *'say it out loud'* to prevent her family from *'panicking'* and *'running'*. This need to feel a sense of control through being able to protect close ties brings to the fore an interesting dynamic. Immediately post diagnosis, women seeking support through social media describe its benefits in relation to gaining control. This is achieved through creating distance to process information and their own emotional responses through sharing with women who understand, but who they *'don't know'* (Jojo). Both Sarah M and Wendy questioned whether this compartmentalisation was related to *'trying to be brave and strong for everybody else'* (Wendy). For some women, the 24/7 connectivity of Facebook supports that compartmentalisation. Deborah and Jayne, (both 1-5 years post diagnosis), reflected on how using social media enabled them to fulfil expected identity roles during the day – manager, employee, mother – enabling them to *'normalise'* daily activity and then seek a sense of control through talking to others online after the family had gone to bed

'I could go on at night at midnight and there would be people on and there would be people to talk to' (Photo-elicitation: Jayne)

As seen in Chapter 7: section 7.3, many women LwBBC who seek out support through social media, experience their emotional lives becoming entangled with the lives of the women they meet and share with there. In seeking to manage the emotional impact on themselves and control the emotional impact on family, women perhaps inadvertently develop strong emotional bonds to other women LwBBC. Women use social media to choose, to control, who to be vulnerable and frightened with.

Women gain a sense of control by using social media spaces to vent frustration, anger and their sense of loss, with others that understand. Deborah talked about her own grief following her mother's death and whether to share an image of flowers laid next to her mother's ashes on Mother's Day on social media (Figure 9-4 Image 5). She described how she was able to share the experience of her own mother's decline with women who also operated as EDNA's (moderators) on the YBCN Facebook page and how she recognised a need to protect other women LwBBC from her own experiences. This indicates *'social'* microsystems of *'sisterhood'* (section 7.3.3) participants within the wider YBCN network; a discerning approach to supporting self, and to managing potential emotional impact on others simultaneously:

'I relied on the other Edna's, the collective name for the people that do the admin. Kind of relied on them, I didn't want to post it in the main group because I just thought, you know, there is people there who – you have got to be mindful, got to be mindful there is people there who are very new in the diagnosis, not like myself, out the other side, going to hear that and it is going to be absolutely terrifying. So of course we know each other quite well as a small group, now and the other members who have lost relatives as well. Because it is kind of a concentrated, corrupt genetic gene pool (laughs)' (Deborah),



Image: Deborah 1



Image: Deborah 4



Image: Deborah 5

Figure 9-4: Mother's Day imagery

© Deborah / 11.03.16 / University of Salford / Cathy Ure

Deborah draws on the Edna's joint experiences of being *'part of a corrupt genetic gene pool'* and having *'lost relatives as well'* as empathetic support she could *'rely on'*. While she is *'mindful'* to restrict the impact of her experience on other members of YBCN, her use extends the notion of protecting others beyond YBCN members to her own family, as she draws on specific support to help manage her grief and loss. She demonstrates the inter-relatedness between finding relevant, timely and appropriate support (Chapter 7) and gaining a sense of control through compartmentalising aspects of her experiences. This is further exemplified through Deborah's inclusion of images 1 and 4 in Figure 9-4 to describe how social media discussions about Mother's Day can have psychosocial implications for women who are unable to have children due to the side effects of breast cancer treatment.

'I think they use it similarly to the way I did, in that the 'public facing front' and their 'show face' is they're really happy for their friends, and knowing that their friends have the right to be happy on Mother's Day. And then that bit of them just wanting to scream 'I can't have kids' and they'd gone on the page and it was somewhere where they

could just sit and just go 'I hate it' but they wouldn't dream of in front of their friends or their family. Saying 'shut up, I hate it'. (Photo-elicitation: Deborah)

She brings to the fore how social media posts act as unwelcome reminders and emphasise women's absence of control over aspects of their future and their bodies. She also employs the notion of Goffman's (1959) facework to explore how women wrestle back a sense of control through posting their responses to imagery of motherhood circulated on social media on Mother's Day. Croson & Keim-Malpass (2016), through secondary analysis of blog data, examined the grief processes women experience when cancer treatment creates infertility. They found that aspiring mothers and young mothers experience denial, depression and acceptance in relation to the challenges to identity (Chapter 8) that potential loss of fertility, and uncertainty regarding future life course, brings. Deborah uses women's experiences of infertility to describe how women hide or silence their grief from loved ones that is created by unanticipated changes to the life course (Chapter 8; section 8.0). Intimacy in closed Facebook spaces enables women to articulate and navigate their emotional loss in ways that they *'wouldn't dream of in front of their friends or their family'*.

Women also describe using social media in different ways to compartmentalise aspects of the experiences. This is often described as *'moving on'*. This was illustrated by women in one of two ways; either through *'moving on'* within Facebook groups away from threads which focused on treatment, to threads focusing on life post treatment; or by recognising a need to leave the group altogether. Both signal advances across the cancer continuum and evidence of adaptation and change for women participating. For instance, Delphi recalled how she and *'another girl on the group petitioned'* to join:

'the Moving On group the day after [surgery]'. That's what we did because we were like that's the end, we're not having any more treatment bar Tamoxifen which doesn't count' (Photo-production: Delphi).

Here, Delphi describes agency in determining her readiness to *'move on'* to a different type of support within a safe closed environment post-surgery. Delphi described women remaining in the *'moving on'* group despite being diagnosed with secondary breast cancer and knowing they would never *'move on'* from breast cancer. Delphi's tells how individual interpretation of *'moving on'* created complexity within the closed group she was part of:

'we have had a number of women who have joined the moving on group who have then been diagnosed with secondaries. And that's a bit of a predicament because they can't move on now, so what do we do? Do they stay in the Moving On group?' (Photo-production: Delphi)

Delphi voices a question for the group – *'what do we do?'* - suggesting group responsibility to determine how to be with women whose breast cancer 'social' identities no longer 'fit' with the identified purpose of a particular social space. She commented:

'we've had a couple who have gone through the remainder of their lives in there, the moving on group, which has been good for them because they've stayed with their original cohort which was excellent. Also, Evie (pseudonym) was adamant that she was moving on, even though she had a horrific amount of secondaries. She was absolutely adamant that she was still moving on with it. So, it's good. It's your choice' (Photo-production: Delphi).

Delphi celebrates the agency of the individual and the support structure of YBCN that enables women their 'choice' in how they use the wider YBCN group. She sees positive benefit in individuals deciding for themselves the appropriate time to move on and the tragedy that for some 'moving on' is about the finality of life. Psychosocial support was available to Evie through her ability to exercise choice and stay with her *'original cohort'*. This demonstrates the challenges for women in navigating one another's differences in interpretation of what 'moving on' means but also signals understanding of the need for women to feel in control of who they access for support.

Deborah positioned moving on as a time when she felt she *'had given back as much as I had taken'*

'I was about to leave. Because I think I had reached a point where I felt it was holding me, you know. I had this kind of guilt of leaving. I wanted to make sure I had given back as much as I had taken'. (Photo-production: Deborah).

'I think there is a case of natural attrition, you know, people move on. I am not far off now. I feel as though I have given back as much as I have taken. You know, I have, I will reach a point where I need to say I need to draw a line under this now' (Photo-production: Deborah).

Nicola reflects on how her changing social media signals she is moving on. She uses her changing Twitter profile as evidence of these changes.

'I follow a lot of people with regards to running. I think over time it's kind of, and it's the same with Facebook, everything has all kind of changed gradually, it's more into slightly less breast cancer stuff and now it's getting more running stuff. So, it's quite nice to see that transition. It will always be there, the breast cancer stuff, it will always be there because it never completely goes away' (Photo-production: Nicola).

Nicola talks about breast cancer as a subject by referring to *'breast cancer stuff'*. Nicola describes how her social media use is changing by being less about breast cancer and more about running, She shows active engagement in participating in a new community of 'friends' by engaging in new activities post treatment. Notably, she refers to her continuing engagement with breast cancer content on social media being related to *'stuff'* rather than a community of people. She states that LwBBC *'will always be there'* because *'it never goes away'*. While this sentiment appears to be expressed in relation to the experiences of LwBBC, it may also be reflective of Nicola's view of social media, and their dominance as communicative technologies, which will *'never completely'* go away. This may reflect a recognition that lives captured through social media gain a permanence. The inference is that despite her focusing increasingly on new activities, she will never be able to 'move on' because her digital footprint (which includes her breast cancer experiences) can never be erased. Therefore, she will not be able to truly forget or move on from it. It points to the complexity of an apparent agency in using social media to manage the emotional demands breast cancer entails but potential loss of agency through posting aspects of themselves in digital spaces when at their most vulnerable.

Lizzie also talks about making active choices to 'move on'. Opportunities to join new groups related to different personal interests was also described as a positive benefit and important next step. Lizzie, LwBBC for ten years, described recently joining a new group on Facebook:

I've joined this Welsh Terriers Group they know nothing about me. All they know is that I have got a dog and we talk about dogs and it's a bit like the choir thing [] the choir the dog is a release from everything' (Photo-production: Lizzie)

Lizzie brought forward the importance of the Welsh Terriers Group through photographs taken for this project (Figure 9-5; Images: Lizzie 3).

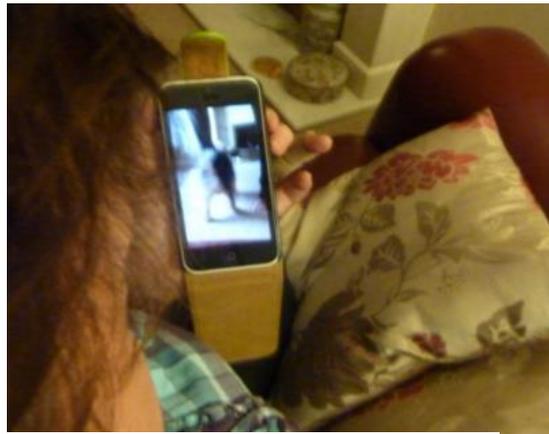


Image: Lizzie 3

Figure 9-5 Moving on

© Lizzie / 18.11.15 / University of Salford / Cathy Ure

The ability to join a Facebook group where members ‘*know nothing about me*’, provides Lizzie with psychosocial support – ‘*a release from everything*’ through sharing a common interest which has nothing to do with LwBBC. ‘Moving on’ in social media terms therefore is constructed by women as self-determined (Nicola, Lizzie); socially determined (Deborah, Mandy) and physiologically determined (Delphi).

9.1.5 Managing notifications

Women using Facebook as part of their day to day lives pre-diagnosis, reported a feeling of being overwhelmed by the quantity of content posted in breast cancer groups which they joined post diagnosis. Both Sarah M and Sarah J described how their experiences of using Facebook changed once they had become members of YBCN:

‘but if like you’re scrolling through [picks up phone] now if I scroll through I’ll see my friend’s cat or whatever and stuff like that and I might not even be thinking about breast cancer, yet then something comes up from there [YBCN] and then you’re just brought back to it and I just don’t want that constant reminder of it’ (Photo-elicitation: Sarah M).

Sarah M conveys a sense of ‘normal’ posts on Facebook through ‘*my friend’s cat*’ positioning her smartphone and Facebook use as a device and platform for entertainment and to pass time. This is in keeping with the uses and gratifications of smartphone use (Wang, Wang, Gaskin & Wang, 2015; Elhai, Levine, Dvorak & Hall, 2017) and Facebook use

(Papacharissi & Mendelson, 2011). By picking up her phone and scrolling through her Facebook feed, Sarah M demonstrated ‘the Martini effect’⁹² (Quinn & Oldmeadow, 2013). She describes content coming in to her feed posted on the YBCN as an intrusion, a ‘*constant reminder*’ and ‘*being brought back to it*’. Sarah is agentic in explaining ‘*I don’t want that constant reminder of it*’ suggesting a preference for compartmentalising aspects of her experiences of LwBBC so that they do not intrude on all aspects of her daily life. Sarah J also describes a changing experience of Facebook use:

‘One of the things with it is erm when you first register on it or become a member, the posts come up as if you’re ‘friends’ and it’s quite an active group so a lot of people are posting all day and it really annoyed me to be reminded every time I went on Facebook that I had breast cancer’ (Photo-elicitation: Sarah J).

Sarah J describes receiving push notifications⁹³ and suggests an absence of control - of being ‘*reminded everytime I went on Facebook that I had breast cancer*’. This is because push notifications control the flow of information (Kim, Kim & Hang, 2016). Sarah alludes to a shift in her experience of Facebook ‘*friends*’ – ‘*the posts come up as if you’re friends*’, disrupting her previous experience of ‘Facebook friends’. She alludes to the quantity of content posted ‘*a lot of people are posting all day*’ and to experiencing a sense of intrusion ‘*it really annoyed me to be reminded every time I went on Facebook that I had breast cancer*’. The use of Facebook here, suggests dissonance between women’s desire to compartmentalise aspects of their lived experiences to protect strong ties and the unanticipated consequences experienced when not being able to compartmentalise aspects of their own experience, after joining active groups on Facebook. Sarah M also described accessing YBCN before considering the type of content she may be gaining access to:

‘Yeah because they, they, they obviously post when somebody’s died and I don’t think I’d really thought about that that much and then there’s, and also erm a couple of people posted about secondaries and stuff and I hadn’t really thought that much about that’ (Photo-elicitation: Sarah M).

Sarah M reflects on how the instant accessibility to other women LwBBC through Facebook has brought aspects of breast cancer in to her daily life – ‘*somebody’s died*’; ‘*people posted*

⁹² The ‘Martini Effect’ refers to social connection – anytime, anyplace, anywhere (Quinn & Oldmeadow, 2013).

⁹³ Push notifications act like frequent alarms telling the user they have new information available to them, whether they want it or not (Kim et al., 2016)

about secondaries' – which were unanticipated. Women move into active experiential communities when they are uncertain and looking for support. Both Sarah M and Sarah J talked about the impact of gaining information they were not prepared for and described gaining a sense of control over information flow by changing their notifications on Facebook:

'so, I've turned off the notifications now I don't. You got a notification if someone posted and it showed on my wall which I didn't want to see it all the time I felt like it was just ther..even if I was sat waiting for something and flicked through Facebook it was just there all the time and it..I didn't like that' (Photo-elicitation: Sarah M)

Sarah describes flicking through Facebook as a taken for granted activity to pass time and gain connection. She alludes to the dissonance experienced of being permanently connected but losing control of the content she is connected to. She and others, chose to turn off the notifications rather than to leave YBCN, suggesting a benefit experienced from access to and participation in the YBCN community. Sarah stated that after turning off her notifications, she probably used YBCN as often as she did when responding to alerts, however she now felt in control by specifically going looking for it:

'So, I have to specifically go looking for it and I still look at it as probably as much as getting a notification, but I feel like now I have the choice to be reminded rather than having to see it twenty times a day' (Photo-elicitation: Sarah J).

Similarly, Michelle J alludes to the challenges of *'seeing things'* on Facebook when she was in treatment that she found unsettling. She gained a sense of control by switching off the notifications but her ability to *'still have a snoop'* indicates that it was not the content per se that was unsettling, rather the lack of control experienced through notifications *'coming up'* on a Facebook wall and how these were experienced:

'I had to at one time take myself off it. I changed the notifications, so I didn't get any coming up on my Facebook wall, but I could still have a snoop if I wanted to. But it stopped all the information coming up. Because I was seeing things. Now I'm fine if something pops up because I've come out of treatment' (Photo-production: Michelle J).

For some women, the timing of accessing certain discussions was experienced as unsettling. As identified in Chapter 7: section 7.2.1, women tended to have very limited previous knowledge of breast cancer before their diagnosis. As women's personal knowledge of treatment grew and as they experienced a sense of growing mastery in relation to their own

experiences of LwBBC, women's approaches to engaging in social media conversations changed too:

'I'm not scared now. I can read it now you know and there are some helpful elements to it' (Photo-production: Michelle M)

[YBCN] 'doesn't scare me at all now. I know what people are talking about and I know the full sort of range of stages and there's different groups as well' (Photo-production: Kirsty).

These responses indicate that initial use of social media in relation to breast cancer might be detrimental to women's sense of wellbeing through constant access to a wide range of information and experience. But the responses also indicate women's adjustment to that information rather than rejection of it. Using the technology to manage notifications provides one way in which women gain a sense of control over that information.

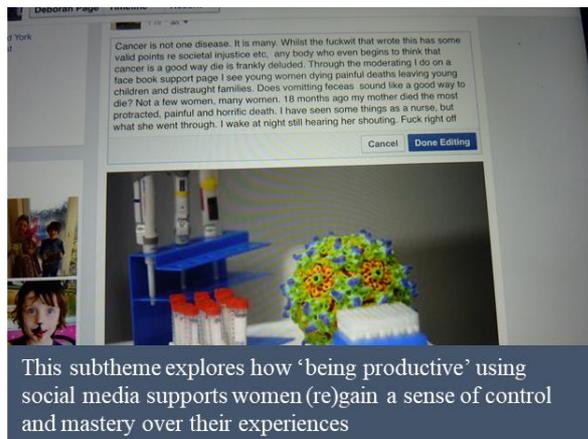
9.1.6 Summary: Theme Three – Subtheme One: Managing the emotional impact on self and others

Women's use of social media platforms indicates use as dynamic and flexible as women seek to control the emotional impact on themselves and on their family and friends. Women carefully manage how they present themselves online. They are agentic in determining which platforms best support their preferred communicative approaches. WhatsApp provides women a sense of intimacy, privacy and connectedness. For women who are not members of closed Facebook groups but are Facebook users, broadcast communications are controlled to achieve responses that are manageable. In closed groups, women described social media use as enabling conversations, which they felt they could not have, or did not want to have, with close family and friends. For women soon after diagnosis, social media use mediated conversations with people who 'understood' but were not part of women's day to day lives. This enables women to compartmentalise aspects of their experiences providing a sense of control. However, social media use was also reported as threatening, with women reporting anxiety through an absence of control in relation to content viewing and experience sharing. Women articulate the challenges brought by access to 24-hour information about breast cancer, and the need to find ways to control access to other women's experiences and continual contact with 'support' groups; or particular types of content. Women adopt different strategies to combat this sense of threat. Women made use of messaging services

when initially diagnosed to inform others. This was seen as protective to psychosocial health through removing uncertainty around sharing the ‘diagnostic narrative’ and afforded a sense of control through framing experience to influence the type of response required. Women describe initial use of social media platforms as related to having conversations with others who ‘know’, and with whom they are not invested. This enables them to process worries, concerns and to gain information without putting additional ‘burden’ on loved ones. As discussed in the introduction to this chapter, there is a sense that women continue to extend their socially embedded ‘caring’ role to protect loved ones post cancer diagnosis.

Women also identify the need to control their own access to other women’s experiences available through social media platforms. Issues in terms of the quantity and topic focus of content available were raised. Women described strategies to master controlling content so that it did not impinge negatively on their psychological health. This included prompt closing of content identified as having the wrong ‘atmosphere’ but also included flexible strategies of joining and leaving groups, and conversations, to reduce negative impact on their sense of well-being. Women demonstrate themselves as discriminating consumers of social media content, focused on building knowledge in line with their own capacities to process the information available. Any sense of information threat is met with a change of strategy including avoidance and adaptation. One way in which women managed to control the emotional impact of LwBBC was by seeking to compartmentalise this aspect of their life. In closed Facebook groups, women articulated the ability to be *‘more honest’*, to be able to say things they wouldn’t *‘dream of’* to their family and friends and to find an expressive outlet *‘to scream’*. Benefit is most experienced when women control their access to Facebook community posts rather than the community being present in their lives by default through push notifications.

9.2 Subtheme 2: Being productive



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'I'm going to go and see him about this new chemotherapy' "... " which she'd Tweeted about ...so she asked him and he said: 'yes, go on that if you want.' So, that's quite amazing isn't it? That patients are actually being ... are driving this change with ... they're actually saying what they want' (Jo).

Figure 9-6 Content creation, counter narratives and being productive

9.2.1 Introduction

Most women had very limited experience of breast cancer prior to their own diagnosis (Chapter 7: section 7.1.2). Women who used Facebook groups and Twitter to learn from others and then share their own personal experiences demonstrated increasing mastery over their own experience. In this subtheme, 'being productive' explores the productive work women get involved in using social media when LwBBC. Women (re)gain a sense of control over aspects of their lives through crafting out new roles which grow out of their different responses to LwBBC. 'Being productive' is considered in relation to: i) creating the breast cancer community landscape; ii) gaining a sense of purpose by becoming an experiential expert; iii) advocating for self and others; and iv) voicing counter-narratives.

9.2.2 Creating the breast cancer community landscape

Women's accounts provided many examples of women using social media to define and shape aspects of the breast cancer community landscape. They are using the 'participatory web' (Beer, 2009; Blank & Reisdorf, 2012) to set up or participate in new Facebook breast cancer communities (YBCN; BBB's) and cancer communities (Jan's Cupcakes; Osborne Trust); to establish Twitter chats (#bccww); and breast cancer related websites (abcdiagnosis) (Figure 9-7). This supports Bender, Jimenez-Marroquin, Ferris, Katz & Jadad's (2012) perspective that women LwBBC are taking a significant role in creating internet-based health resources. By establishing new communities, women can better control their social lives.

They create “new forms of social relations and sociality” (Miller, 2016, p.134) by using different features of platforms to “exploit degrees of intimacy and distance” (p.134). Conversation is guided by ‘grassroots’ experiences rather than addressing organisational objectives. For instance, Jo describes launching her own website (abcdiagnosis), six years post primary diagnosis⁹⁴ aimed to provide information about breast reconstruction following mastectomy and to support women in making an ‘informed choice’

‘I just thought, ‘That’s what I need to do’. So I started working on writing information up and in 2012...was it?...three years ago now...so what are we in now, 2015? Yeah, so in 2012 I created and launched - on the sixth anniversary of my diagnosis, which is the 15th of February - I created the website’ (Photo-production: Jo)



Image: Jo 25

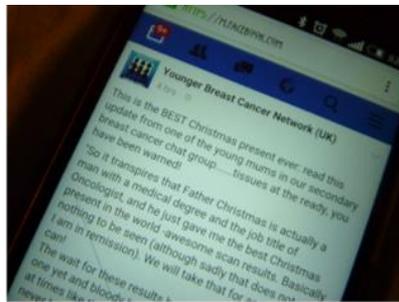


Image: Delphi 9



Image: Deborah 8



Image: Michelle M6



Image: Deborah 12

Figure 9-7 Peer led cancer communities created by women LwBBC

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The inclusion of peer-led, user generated breast cancer communities (Figure 9-7), as photo-study material, indicates their salience to women’s experiences. One explanation for the

⁹⁴ Prior to Jo’s secondary diagnosis.

development of new social media sites is that they afford a sense of control to those that establish them. Deborah spoke with a founder of The Osborne Trust website (Figure 9-7, Image Deborah 8):

'I did chat to one of these ladies, who I met at some event somewhere. And she was saying, you know, I might not be able to control my illness but I can try and fight back against the impact. I am not big on the fight rhetoric thing, but it does give me a sense of I am kind of fighting back in some way, even if I am not attacking the illness, I am fighting back at the impact it is having and hopefully doing that for other people's children as well, because that is what I was thinking of there' (Photo-elicitation: Deborah).

For some, establishing a social media presence within the breast cancer landscape equates to making 'an impact' and enables navigation around the sense of having 'no control' over their illness. Potentially, those who establish new spaces for connection may experience additional benefit, from filling gaps in service provision, through gaining a sense of control or mastery (Thoits, 2011) over aspects of the breast cancer landscape. For instance, where existing communities do not meet personal needs, women demonstrate self-efficacy by developing new ones. Jo⁹⁵ set up the Twitter chat #bccww (Breast cancer chat worldwide) as an alternative to #bcm⁹⁶, because of the challenges of synchronous global communication:

'I wanted to replicate bcm in the UK, but because of the time difference over there, you can't...unless you're up at two o'clock in the morning - which occasionally I am but don't want to be Tweeting at that time and getting into an hour long conversation - we started bccww, which is good because it's a nine o'clock, nine 'til ten at night, and anybody can really join in the world at a reasonable time, Yeah' (Photo-production: Jo)

The public nature of Twitter enables 'good practice' to be identified and copied - *'I wanted to replicate bcm'*. Issues related to global communication were raised in a recent meta-synthesis of cancer survivorship interventions (Coffey et al., 2016). The researchers reported engagement in interventions by UK testicular cancer patients as being limited when 'cancer experiences stories' were experienced as 'too American'. Notably, women within the current study engaged in social media conversations rooted predominantly in UK based groups. Only

⁹⁵ In conjunction with four other women LwBBC, 'met' through Twitter use

⁹⁶ Breast Cancer Social Media – a Twitter chat held weekly on Monday nights at 9PM Eastern Time, 6PM Pacific Time. (#BCSM - Healthcare Social Media Analytics and Transcripts, 2018)

Jo, Liz and Delphi talked about linking with breast cancer advocates in the US⁹⁷. While social media use enables women to learn about global developments in the breast cancer field, women have different preferences in terms of global versus local knowledge. Sharing knowledge of localised norms, including the relevance of healthcare system experiences, may therefore be a contributory factor in supporting women's sense of mastery over their experiences.

Jo's self-efficacy in establishing new, alternative, more localised, yet global, tweet chats raises interesting questions about being 'publicly private' (Papacharisi, 2009) in relation to LwBBC. Determining which platform(s) to use to share knowledge and expertise enables women to shape the type of 'experiential expert' they wish to be. Those sharing using the hashtag BCCWW do so knowing their conversations are available for all to listen to and engage in. Use of the hashtag (#bccww) enables 'searchable talk' that is, "online discourse where the primary function appears to be affiliation via 'findability'" (Zappavigna, 2011, p.789). Women sharing their experiences to meet psychosocial needs in a closed Facebook group do so within a bounded, safe environment. For instance, YBCN was established in response to limited appropriate and relevant support (Chapter 7) for women under 45. While YBCN has a public facing Twitter account, membership of the closed Facebook group comes following screening questions designed to protect the overall group. The organisation demonstrates its expertise at understanding the needs of women under the age of 45 LwBBC by providing space to protect identity where needed (Chapter 8). As Deborah described in 'Managing the emotional impact on self and others' (p.227) women meet backstage (Goffman, 1959), 'behind closed doors', in 'closed' groups to navigate the experience of carrying out 'facework' with close ties in safe online spaces. Women therefore utilise closed peer led groups to develop understanding and expertise from other experiences of LwBBC as well as their own by expressing and testing out responses to situations. Women LwBBC who use both platforms can determine how 'publicly private' they wish to be on any given topic; they can scale their sociability (Miller, 2016) to share knowledge and expertise which fits their own needs in relation to privacy. In comparison to participating in organisationally led online communities, women's movement across platforms – use of Facebook and Twitter for example -enables mastery over what is shared with whom, when and where. Women can

⁹⁷ This will be discussed further, later in this subtheme in relation to women advocating for themselves.

become experts within small homogenous groups or seek a global platform to influence and advocate for change.

9.2.3 Gaining a sense of purpose by being an experiential expert

The establishment of new communities of connection convey to women the notion that they are ‘experts in their own lives’ (Clark-Ibanez, 2004) able to develop a voice both for themselves and others. Increasing mastery, juxtaposes the experience of loss of control over body, health and life course at the time of diagnosis:

‘you can’t get your arms around it to start with. And I think that was the first thing I realized when I started Googling things. I’m just going around in circles here. I can’t find what I want. There isn’t anything that says, ‘this is Liz Morton’s diagnosis and this is the outcome’, cos that’s really what I was looking for. It’s all going to be ok’ (Photo-elicitation: Liz)

Liz describes searching for control by ‘Googling’ in the immediate aftermath of diagnosis; describing her diagnosis as something ‘you can’t get your arms around’. Women described reading information posts as opportunities to validate their experiences. Through adding reflections on information posted by organisations, such as the BBC (Figure 9-8: Image Delphi 11), women added to the flow of information. The opportunity to ‘add to’ existing posts and reposting them in specific communities demonstrates both a personalisation of content but also a sense of being part of and having access to a wider community.

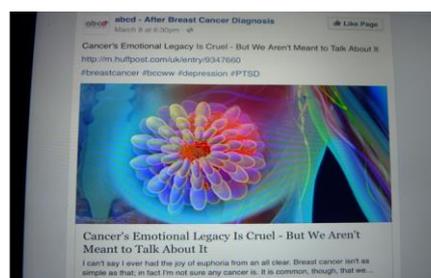


Image: Deborah 12



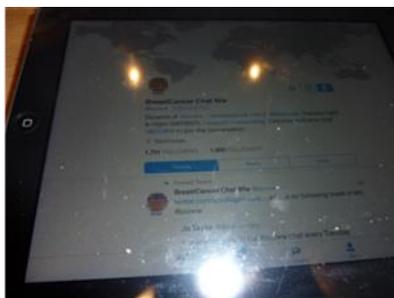
Image: Delphi 11

Figure 9-8 Being able to share experiential expertise

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The image created by Liz of random searching and of seeking to gain control through finding out *'this is the outcome'* is contrasted by Jo providing insight and answers, based on her experience, using #bccww and her abcdiagnosis website. This tailoring of information flow is reflecting in Figure 9-8: Image: Deborah 12. An article originating from The Huffington Post is additionally framed when forwarded with the addition of hashtags (#breastcancer #bccww #depression #PTSD). This informational work by @abcdiagnosis serves to link the singular post with a wider 'discursive field' (Tembeck, 2016).

Jo's photographs widen the above example of 'patient experts' curating and sharing information (Figure 9-9). Through presenting images 4, 33 and 25 together Jo demonstrates active engagement and information sharing in the #bccww community, while in treatment in hospital and at home. She captures the 'object' and platform (Twitter) used to curate and share her patient expertise, exemplifying the significance of digital technologies developing 'reach' and in enabling women to take up participatory, informed patient advocacy and expert roles (de Bronkhart, 2015). Her interview and images convey a sense of an 'expert patient' who attains a sense of purpose through advocacy and involvement in the wider 'living with and beyond cancer' field.



Jo: Image 33



Jo: Image 4



Jo: Image 25

Figure 9-9 Demonstrating patient expertise - curating information

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Women were agentic by finding avenues through which they were able to share their experiences of LwBBC with others. Kirsty reflected on her current sense of self being dominated by breast cancer and a sense of wanting to contribute in relation to her current day to day 'expertise':

'I just wanted to do something. I relate it to cancer because that's what I do at the moment. That's what I've got to offer, but I just want

*to do something, to get out of the house and contribute to something.
Take part in something I suppose' (Photo-production: Kirsty).*

She voiced a need to 'contribute', 'to do something' and 'to take part' to gain a sense of deciding her own timetable and activity, rather than it being dominated by the treatment process and being in 'the house'. Contributing to breast cancer related projects enables a sense of regaining control; of beginning to write a new script. For instance, contributing to research has become an area of activity where women feel they are of value. Jayne identified a series of roles existing within the breast cancer community.

'whilst I can't commit myself to being an admin in YBCN; I don't think I can commit myself to blogging for the benefit of other people on a regular basis; and I'm not the sort of person who goes out and asks for money erm or part of the pink brigade. My way of being involved, where I feel that I am being of value from my experience, is through the Facebook thing and being involved in research' (Photo-elicitation: Jayne)

The sense of a need to be 'involved'; to have her opinions sought out 'through the Facebook thing' and to feel that she is 'being of value' underlines the challenge a cancer diagnosis has to women's sense of self. Jayne lists a series of potential role opportunities/challenges – 'an admin in YBCN'; 'blogging for the benefit of other people'; asking 'for money'; being part of 'the pink brigade'; 'research'; 'through the Facebook thing'. There is a sense that some of these notions would be experienced as extremely challenging and would impact on Jayne's psychosocial health. Through the list of options, she suggests are available, she positions Facebook as enabling a sense of 'mattering'⁹⁸ to others through being a reliable contributor within the YBCN group and through 'research'. Her consideration of where her skills were best made use of gives rise to the view that women may feel they have to 'work' voluntarily – that they have to 'give back' - within and for the breast cancer community post diagnosis. This may impact on women's ongoing relationships with and immersion in online social support groups.

Sharing their experiences with women subsequently diagnosed was a significant factor in some women's use of social media platforms. Sustaining these communicative spaces

⁹⁸ Mattering relates to an individual's significance to other people (Thoits, 2011). Thoits argues it is conceptually close to the notion of gaining purpose and meaning in life from relationships. Previous research indicates a sense of mattering as having positive effects on health and psychological wellbeing (Berkman, Glass, Brissette & Seeman, 2000; House, Landis & Umberson, 1988; Uchino 2004; Umberson and Montez, 2010).

through regular active contribution was experienced by women differently. The positive benefits of sharing personal experience stories has previously been reported in the literature relating to effective self-management (Coffey et al.,2016; Thompson et al., 2014) Sharing personal experience however can also be experienced as *'addictive'* and *'draining'* (Jayne).

'I went through such a stage of almost being quite addicted to going on everyday whilst I was off work to support those other people and it became quite draining' (Photo-elicitation: Jayne).

Rather than providing a sense of control or suggesting a sense of regaining control, Jayne suggests a lack of control - a need – an addiction – to being involved in the YBCN Facebook community *'everyday'*. Significantly, she uses a time frame in relation to this experience *'whilst I was off work'* suggesting a need to share experience may have been related to reducing feelings of isolation (Bottomley, 1998; Harkin, 2016) or to avert boredom due to having more limited demands. The notion of cancer survivors who actively participate in online communities becoming drawn further into using online communities was identified by Harkin et al., (2017). This indicates that immersion of self in new *'social'* worlds is therefore a common experience as individuals embark on a process of knowledge growth and reconnection with themselves. Jayne states how sharing her expertise to support others in a closed Facebook group unwittingly created a less favourable outcome – *'it became quite draining'* - in terms of her own psychological well-being.

9.2.4 Advocating for own and other's health

A number of women, more recently diagnosed, stated that they had begun to advocate for themselves by informing their breast care nurses of their need *'to know'*. The fear of recurrence (Chapter 8: section 8.3.4) combined with *'the shock'* of primary diagnosis leads some women to advocate for immediate knowledge regarding any changes to their health status:

'I said I can feel this pain and you're telling me it's nothing, but just what if. You know. I mean I'd rather know and then we can see what other path we need to go down. Because for me, it's all about if you find something soon, we can get it treated, even if they say, God forbid, you can't treat it, but you know, I know where I stand. And I never thought in life I would ever even feel like that, think like that, because you never would ever have to. But now I do, I want to know

if anything did change, I'd like to know exactly what's happening.'
(Photo-production: Michelle J)

'the shock of that was such a trauma I don't want to have to do that again, so I'd rather know' (Photo-production: Kirsty)

While women newly diagnosed indicate a growing advocacy when in conversation with breast care nurses, women with complex health issues (Jo – secondary breast cancer; Delphi – multiple diagnoses of cancer; Jojo – Multiple Sclerosis and breast cancer) provided examples of using social media to build a knowledge base which enabled them to advocate for themselves. They moved use beyond informational support (Chapter 7: section 7.2) to influencing decision making in relation to treatment and care. Jojo describes how knowledge sharing on Facebook has changed her healthcare conversations with her GP:

Jojo: I learn to write things down and then I can go to the GP and say 'look I think this because', I wouldn't say 'because some of the ladies on the Facebook group have had it'. I'd say I think it's this because I've had a pain here; an ache there. So, wow.

Cathy: So it's changed that interaction between you and your Doctor. Is that fair?

Jojo: Yes, yeah. It's er oh gosh. It's good. Its brilliant."..." , I don't know what I would do without Facebook or without the group'
(Photo-elicitation: Jojo)

Jojo describes adopting a strategy '*I learn to write things down*' of knowledge shared within the Facebook group, which she feels, is pertinent to her own experiences. She acknowledges potential clinical resistance to information gained from Facebook – '*I wouldn't say ...*' , focusing the clinical encounter on '*the pain*' or '*the ache*' from her own informed perspective. Jojo gives voice to a sense of empowerment she experiences from being able to advocate for herself – '*wow*'. '*It's good. It's brilliant*'. Interestingly, Jojo conflates the benefit of participation in '*the group*' with Facebook use, positioning them as interconnected.

Both Jo and Delphi described how their active involvement in developing their own knowledge and being at the '*forefront*' (Jo) of developments in breast cancer treatments

enabled them to advocate for changes to their treatment regimes. Jo talked about using Google Alerts⁹⁹ to ensure timely receipt of developments in the field:

'I've been able to then go to my Oncologist and say, 'Look at this, this is what they're doing over in America, when are we getting it here?' Or "this is the treatment now available, when can I have it?'. Well, maybe not 'when can I have it', but I was able to talk to my Oncologist because of something that came out from an alert, [...] that happened with Tamoxifen, [...] the Perjeta as well, I was aware of, and then he was able to get me onto that...it wasn't available through the normal route, NHS route, through the Cancer Drugs Fund, so we applied for it' (Photo-production: Jo)

Where oncologists are active on Twitter, Twitter was identified as providing a platform which opened up communication between women and their oncologists. Jo shared an example of someone new to Twitter:

'She wasn't very open to Twitter and said, 'I don't know how to use it', started Tweeting things to me and then copying [oncologist's name] into all these Tweets [laughter]. But all to do with new treatments and things like that...' (Photo-production: Jo)

Twitter is described as removing barriers, as enabling connection between patients and oncologists. Jo describes both a reticence and growing self-efficacy as confidence grows in using Twitter – *'wasn't very open'; 'started Tweeting things to me'; 'then copying [] into all these Tweets'*. While Jo seems to suggest the approach may be slightly unconventional, she conditions and supports her Twitter friend by warranting the content as purposeful *'all to do with new treatments and things like that'*. The narrative continues and demonstrates Jo's own admiration for another's self-advocacy achieved through using Twitter:

'and then she said, 'I'm going to go and see him about this new chemotherapy', "..."], which she'd Tweeted about...so she asked him, and he said 'yes, go on that if you want'. So that's quite amazing isn't it? That patients are actually being...are driving this change with...they're actually saying what they want because they've read up from Google or wherever, they've read an article...a very serious article with the right information in and everything, not just some random person talking about this, and actually made that decision

⁹⁹ Google Alerts provides notifications of any new content posted on the internet to users, in relation to subject areas of their choice.

themselves and then they've said 'yes, you can actually go on that if you want' (Photo-production: Jo)

Jo warrants joint decision making as being driven by being an informed health consumer having 'read up'. 'the right information', in 'a very serious article' and cites the provenance of the source as significant and 'not just some random person'. She describes a changing clinical relationship where patients are 'actually saying what they want' and are 'driving this change' to move towards a situation where they 'actually made that decision themselves'. Twitter is identified as the mediator enabling agency and self-efficacy. This is in line with the work by Lee, Gray and Lewis (2010) which identified that breast, prostate and colon cancer patients' Internet use (n=1293) leads them to prefer a more active role in medical decision making.

Other women reported a positive sense of well-being from being empowered through understanding developments in the field and being agentic in using this knowledge to support positive, collaborative interactions with oncologists. In contrast to many women reducing the role of their healthcare professionals within the interviews (sections 7.1.2 and 7.1.3), Delphi talked enthusiastically about her relationships with her breast surgeon and oncologist. Delphi describes discussing information she has researched through social media with her oncologist. In so doing, she demonstrates a partnership-based approach to decision making around her care and an acceptance of patient sourced information by her oncologist. Delphi's account outlines a discussion about moving on to a drug (G-CSF) to raise her platelets and avoid risk of neutropenia¹⁰⁰ after discovering her 'Mum's friend' has also experienced neutropenia following chemotherapy:

'and then I'd talk to my oncologist and ask whether or not, a) it could be funded on the NHS, if it was under NICE here, because my mum's friend's in California and obviously...yeah. And also whether or not he would be able to justify it, given that it's not a regular thing. And my oncologist was incredibly responsive and receptive to my feedback. I was never...I was never sort of, 'No, we're not doing that'' (Photo-production: Delphi).

Delphi voices a set of informed questions she posed 'could it be funded on the NHS', 'is 'it under NICE', can he 'justify it' acknowledging the cultural and healthcare system differences

¹⁰⁰ Neutropenia is the term used when the bone marrow fails to make enough of a specific group of granulocytes (white blood cells) called neutrophils. This impacts on the body's ability to fight infection. (NHS, 2017).

in drug availability between the US and UK. In so doing, she positions herself as an informed health consumer negotiating access to treatment, supported by her claim that she ‘was never’ disempowered by conversations about her care. This focus on building a partnership-based approach to her care at more senior levels is likely rooted in her childhood experiences of treatment for leukaemia, which often required *‘extreme medical intervention to keep me alive’*, although I did not specifically ask whether this was the case. She stated:

‘I was getting all of this information, verifying it and then I would speak to my oncologist and I breezed through. And I think a large part of that was because I didn’t try and struggle on with things that didn’t suit me thinking.....this is how it’s supposed to be’ (Photo-production: Delphi).

Delphi signals changes to her own treatment and care by taking control and not *‘struggling on’*. She resists *‘this is how it’s supposed to be’* advocating to improve her experience of treatment. Knowledge of other’s women’s experiences was warranted by Jayne as influencing her own self-care:

‘when I chased up last time the erm mammogram didn’t come back clear so I then had to go back and have a biop...another biopsy on this other side and they put a little marker in but I felt that if I hadn’t chased it it could have been longer and potentially that could have been...I’ve seen it in the group when they haven’t chased up because they’ve been fine and then it’s been something else or something bigger that can’t be sorted’ (Photo-elicitation: Jayne)

Jayne voices concern over a delayed response to receiving her annual mammogram result. She identifies other women’s experiences *‘in the group’* of finding *‘something else’* or *‘something bigger’* as motivating greater self-care and chasing up her screening results. She takes control arguing *‘it would be my fault for not having chased it’* (Jayne). This links to her sense of managing the emotional impact on others (section 9.1) as Jayne warrants the need to chase the results as they could *‘impact on me kids and me husband and whose going to look after all of them?’* Jayne retains a sense of control by ensuring effective management of her ongoing screening programme. Deborah as a healthcare professional and moderator of YBCN is immersed in the lives of women LwBBC. She too expresses a reliance on the annual mammogram to give her confidence that she remains well. However, her ‘lack of

trust' in her body and in healthcare professionals¹⁰¹ has resulted in her ignoring lumps and bumps that might appear between annual mammograms:

'And I have gone through a stage and it is probably not big or clever now but I don't check my boobs anymore now because there is always something and it drives you potty, I'm like you know, you might as well just give me a chair up at the breast clinic if that's how it's going to be. They haven't got time for that. I haven't got time for it. I'm just going to have to rely on the fact that they will be found at the annual check-up' (Photo-production: Deborah).

Individual experience at time of diagnosis may therefore result in avoidance strategies in the longer term regardless of women's immersion in other women's experiences. Women determine what strategies work best for them in terms of supporting their own psychosocial health.

It is interesting that there were no accounts of direct connection with healthcare professionals using social media independently brought forward by participants. US based nursing academics, Given and Given (2017), assert that healthcare professionals in the US have been slow to move towards personalised communication for patients, despite being a hybrid system of private and public funding largely delivered privately (Department for Professional Employees, 2016). They contend that patients experience symptoms and side effects at home away from the clinical encounter where there is an absence of clinical communication to support self-care management. They argue that two-way, real time communication in relation to symptom management is required to improve the cancer experience of patients. Women's need for supportive conversations move beyond symptom management to include navigating ongoing effects that impact on everyday living. Filling this wider self-managed care gap therefore may potentially lead to some clinical benefits (e.g. reducing presentation at Accident and Emergency Departments) if a channel of connectedness between healthcare professionals and women LwBBC developed using social media. Due to concerns about accessing support from breast care teams, this study indicates women are filling this self-management care gap through appropriating social media sites to crowdsource experiential knowledge. At the same time, it is unknown whether use of informal social media peer support networks exacerbates issues within the clinical setting, through poor decision-making

¹⁰¹ Prior to diagnosis, those she met along the diagnostic pathway *'just kept saying it is nothing, it is fine'*.

on the part of the individual LwBBC, which later increase demand on clinical services. Understanding UK oncologists' and breast care nurse's perceptions of the use of social media platforms to support self-managed care 24/7 is an area for further research inquiry.

9.2.5 Voicing counter-narratives

Encouraging self-management and self-care within the wider breast cancer community was identified as a particular focus for Jo, living with secondary breast cancer. Through an extensive portfolio of photographs, Jo sought to communicate what secondary breast cancer entails and how *'your life doesn't stop when you have something like this'*. She describes her proposed use of the radiography photographs (section 7.1.3.) in a forthcoming blog to tell

'the story of what I'm going through, and this is another side to that people don't see, and this is what secondary breast cancer is. It's not in the breast, it's somewhere else. So I think that's what I always try and get over to people. What I'm trying to fight against, people's understanding' (Photo-production: Jo)

This lack of awareness of secondary breast cancer was supported in other women's accounts also:

'I didn't even know what secondary breast cancer was. Like Dad's wife erm you know it went to her brain but even then I didn't know, I just thought she had cancer of the brain I didn't make the connection it was breast cancer in a secondary site' (Photo-elicitation: Liz)

All the women participating in YBCN spoke about secondary breast cancer, referencing a separate group within YBCN specifically for women with secondary breast cancer. This simple, structural separation of different experiences (to help support the emotional impact of LwBBC for women newly diagnosed) works to raise wider awareness and develops notions of different areas of experiential expertise when LwBBC. In relation to her own experience of living with secondary breast cancer, Jo counters the 'fight' narrative typically employed in relation to cancer (Breast Cancer Care, 2016; Garrison, 2007; Semino et al., 2015; Twombly, 2004). She shifts focus from fighting the disease, to fighting people's ignorance in relation to the disease. Jo's living of her experience of secondary breast cancer on social media creates a counter narrative through which she seeks to educate her followers and challenge public understanding of secondary breast cancer. She is agentic in using Twitter and Facebook to encourage greater self-efficacy in other women LwBBC. She actively promotes daily

physical activity on Twitter. Through posting regular photographs of Nordic walking, cycling or running she challenges perceptions of living with an incurable illness, while displaying agency and self-efficacy in maintaining as healthy a body as possible. The significance of this activity for her psychosocial health was represented in her photographs and her interview (Figure 9-10).

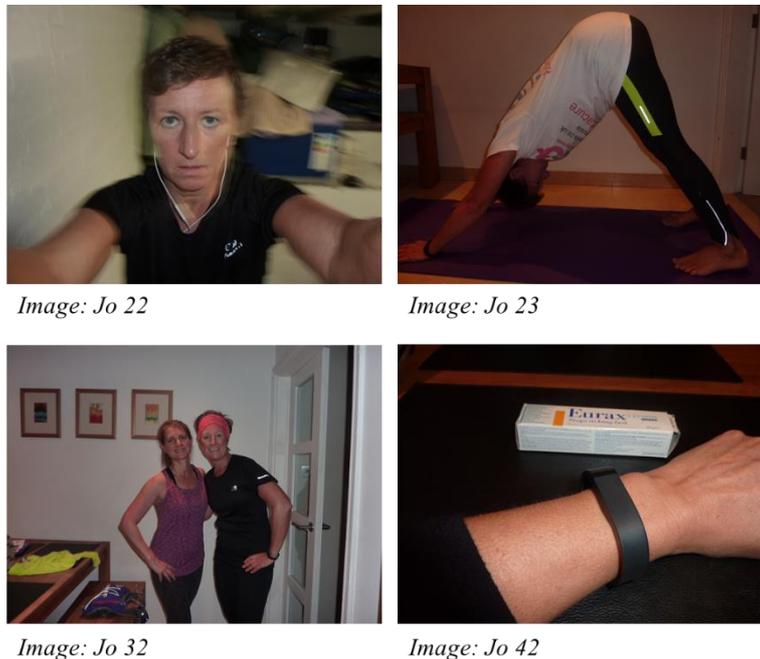


Figure 9-10 Gaining a sense of control and sharing 'exercise' expertise

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'I want to keep as fit and as healthy for as long as possible, and that's why I do it, and that's why I want to say to people, 'Please try, please do it because it will keep you in good stead for the future'. Because I think...what's come out from some of these conferences that I've been to is that Consultants and Oncologists will say 'no' if you can't take it. If your body can't take it, And I think if you're physically fit and active and healthy in all other respects, it will give you a better chance of getting something that maybe if you were overweight, couldn't handle it mentally and physically.[...] I find it's important, and I just wish people would take it more on board' (Photo-production: Jo).

Jo navigates being both well and unwell through seeking to influence her ability to take up treatments as her disease progresses. She encourages other women LwBBC to engage in physical activity to give themselves 'a better chance'. She invokes her patient expert role, through making known she attends conferences, and invokes the

power of the professionals - 'consultants and oncologists' - to back up her own perspective that physical activity provides opportunities to gain some kind of control. This perspective is reflected by the positive benefits shown in the literature. The patient-reported outcomes for women LwBBC 1-5 years after diagnosis, identify that those participating in more days of physical activity reported better functional and Quality of Life outcomes (Brenner, Neilson, Courneya, & Friedenreich, 2014; Glaser et al., 2013; Ibrahim & Al-Homaidh (2010).

Deborah also uses Facebook to privately and publicly reject a cancer narrative circulating in the mainstream press and on social media. Deborah includes a photograph (Figure 9-11) that evidences the closed Facebook group as an environment in which counter-narratives can be expressed.

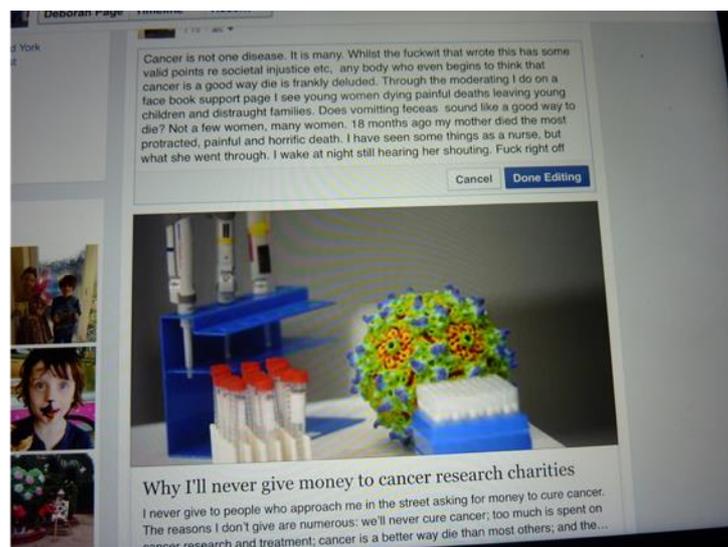


Image: Deborah 10

Figure 9-11: Counter-narratives as a form of expertise

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Deborah's response, posted in a Facebook post, to a British Medical Journal (BMJ) blogpost and Telegraph article written by a doctor and former BMJ editor. (Smith, 2016) creates a 'scene' (Goffman, 1959). She asks: 'does vomiting faeces sound like a good way to die?' and shares deeply personal aspects of her own experience of her mother's 'protracted, painful and horrific death' from cancer. She utilises her multiple identities and roles to position herself as someone who can speak as an experiential expert. She draws on her experiences as

a moderator 'of a Facebook support page'; as a healthcare professional 'cancer is not one disease. It is many'; 'I have seen some things as a nurse'; and as a daughter '18 months ago, my mother died the most protracted, painful and horrific death' before concluding with the dissonance of 'Fuck right off'. Deborah responded in such a way 'as to destroy or seriously threaten the polite appearance of consensus' (Goffman, 1959, p.205). It is an act taken knowing dissonance "is likely to result" (Goffman, 1959, p.205). She counters this 'new narrative' presented by Smith. The post suggests the external expression of the individual psychosocial challenges Deborah experiences –'I wake at night still hearing her shouting' gives women both the opportunity to reply – to share their reality - and to give voice to the grief subsumed by managing the emotional impact of cancer (section 9.1). This shows women using social media to post counter-narratives as they seek to regain a sense of control over the emotional impact some 'cancer narratives' create. It demonstrates that in seeking to 'regain' a sense of control, aspects of women's experiences emerge from their previously compartmentalised spaces to give voice to the personal impact of cancer. It demonstrates the fluidity of expression and how women adopt multiple strategies to manage the emotional impact on self and others while seeking to regain control. In some circumstances, this relates to seeking to influence and gain control of the narrative and a sense of place within that narrative.

9.2.6 Summary: Theme Three – Subtheme Two: Being productive

Women are confronted by the 'shock' of their breast cancer diagnosis with the need to 'get their arms around' what their diagnosis means for them. Women develop a range of coping strategies through social media use as they develop greater knowledge of their own cancer and begin to become experts in their own breast cancer lives. One way women are taking control is through taking a significant role in creating social media based health resources. These are often borne out of the lack of service provision and is shown in the proliferation of 'niche' sites (Bender et al., 2013) including Facebook groups for younger women with breast cancer; and to support children of parents affected by cancer (The Osborne Trust). Where existing support does not adequately meet needs due to time zone differences, women have sought to replicate ideas that have proven successful (#bcsm and #bccww) (Attai et al., 2012). This enables women to benefit from 'globalised local' knowledge and learning.

Women experience positive benefits from sharing their personal experiences with women more recently diagnosed.

Providing support can lead to women becoming increasingly immersed in their new 'social' worlds which can be draining. For women who are isolated or have limited social support, the extent of involvement or time spent communicating online might benefit from discussion during annual check-ups. Another way in which women develop a sense of mastery is through sharing their experiences with others for research purposes. This was a consistent message across the timeline of women LwBBC. Involvement provided a sense of purpose, of contributing; of mattering. It enables women to feel that their experience contributes to something larger than themselves. However, it may also be the case that the 'give back' narrative may also control or influence how women feel about how they live their lives after a breast cancer diagnosis. This may benefit from further exploration as some women may feel 'tied' to a 'give back' narrative.

Some accounts indicate that women with complex health needs experience knowledge growth from social media use and position it as supportive in gaining positive outcomes. Engaging with oncologists on social media platforms and through sharing new evidence was seen to support women in making decisions about their own healthcare. Social media platforms were actively used to educate and inform. Women shared their own experiences seeking to empower others living with cancer or wider chronic conditions to maximise their chances of being able to benefit from treatments or surgical procedures through a focused approach to healthy, active living. At the same time, social media enables women to challenge cancer narratives which circulate in the mainstream press and online. This countering of narratives or 'right to reply' provides emotional release and learning across wider communities. Women LwBBC use social media to take opportunities to reduce a sense of being disempowered by reframing the conversation. Women can, therefore, develop social media identities which enable them to regain a sense of control through immersion in, shaping of, and sharing of expertise with others at the level which serves own individual needs.

Chapter 10: Discussion

10.0 Overview

The overall aim of this research was to: (i) explore how women LwBBC use social media; (ii) explore how women use social media as communicative resources in relation to LwBBC; and (iii) make sense of how women use social media to support their psychosocial health. The approach taken to achieve these aims focused on eliciting in depth experiential accounts at different stages along the cancer continuum using visual methods. This research responds to the call by Falisi et al., (2017) to explore naturally occurring groups on social media in order to increase understanding of the function they serve; the call by Meng et al., (2016) to engage in research to explore social support on diverse social media sites by taking a holistic approach to use; and the call by Brabham (2015) for social media researchers to “actually talk to social media users” (p.2). This final chapter has been divided into six sections. The first section reflects on several findings in this thesis in more depth. The second section reflects on theoretical considerations and how these supported answering the research questions. The third section focuses on methodological discussions. The fourth section highlights specific issues of interest to individuals with a substantive interest in cancer care. The fifth section explores the limitations of this study. Finally, the sixth section offers some thoughts related to future areas of research.

10.1 Reflecting on findings from this thesis

In this section, I reflect on a number of important findings from this study rather than seeking to give a comprehensive review of all findings. Previous work has shown that cancer survivors tend to use several different online health communities rather than one (Harkin, 2016). This thesis study extends that understanding to the social media environment specifically, for women LwBBC. All women used social media in their daily lives. YouTube (n=21), Facebook (n=19), Wikipedia (n=18) and WhatsApp (n=16) were the four most commonly used social media platforms for ‘everyday’ use. Women’s use of social media in relation to LwBBC differs to their ‘everyday use’. In relation to LwBBC, the five most commonly used platforms were Facebook (n=17), YouTube (n=15), WhatsApp (n=8), Twitter (n = 7) and Wikipedia (n = 7). Over 70% of participants used Facebook and YouTube

in relation to LwBBC. The number of platforms used ranged from 0-12. There is therefore considerable variability in engagement. Women LwBBC experience different benefits from different platforms and from different groups on the same platform. A single platform approach to understanding social media use by women LwBBC can only reflect women's experiences of use when LwBBC in a partial way. That said, it is acknowledged that this investigation too can only ever be partial as women's use of platforms, and the platforms themselves change, given the dynamic nature of the social media environment. This is aptly reflected in the current fake news, data harvesting crisis besieging Facebook that threatens to undermine the trust of Facebook users (Drenick, 2018).

The overarching themes found through this exploration is that women experience psychosocial benefits from social media use through gaining timely, relevant and appropriate support. Women also show how social media provides psychosocial benefits through enabling the navigation of complex feelings related to identity and biographical disruption and through providing opportunities to (re)gain a sense of control. This thesis provides an insight into women's searching strategies when LwBBC for the first time and demonstrates these as complex with women focused on satisfying multiple needs including timeliness (immediacy), relatability (women like me), and authenticity (experiential experts). However, the findings of this study do not imply that social media is being used to replace the advice and support from healthcare professionals but is used in addition to these. That said, it is acknowledged that the growing number of people in the UK living with and beyond cancer creates challenges in relation to how the NHS and support organisations can appropriately support the psychosocial health needs a cancer diagnosis brings (Foster et al., 2018). Indeed, in recognition of this challenge, the James Lind Alliance (JLA) is currently conducting a prioritisation survey with clinicians, patients and carers to identify the ten priorities for research relating to Living with and Beyond Cancer, the consequences of cancer and its treatment (during and in the months and years after it has ended) (JLA, 2018). From an initial fifty-four questions posed, developed from previous research to identify 'unanswered questions', ten priority areas will be selected for further research attention. This suggests that there are considerable demands for work across all cancers to understand the ongoing psychosocial implications of diagnosis and treatment and only a minority can be attended to. While this prioritisation exercise actively engages patients in determining next steps, research

shows patients themselves are reticent to raise psychosocial health concerns at a more local level with their HCPs. For instance, recent work shows those living with head and neck cancers are reluctant to raise concerns about fear of recurrence with their oncologists (Ozakinci, Swash, Humphris, Rogers & Hulbert-Williams, 2017). Patients fear seeming ungrateful and do not wish to endanger a relationship they hold in high esteem. Furthermore, the patients in the Ozakinci et al. study did not consider psychosocial issues to be the responsibility of their consultants. For some, it is conceivable that connection through social media goes some way to fill these gaps in support.

Interestingly, the findings provide no evidence currently of women using selfies to link with their consultants or breast care nurses for advice over physical changes to the body. Women's everyday use of smartphones with built in cameras opens the way for 'selfie' consultations to address issues arising post-surgery or post-chemotherapy. 'Selfie teledermatology' is a growing area of interest in the practice of dermatology (Hogan, Cullen, Patel & Raipara & Aires, 2015). Potentially, 'selfie consultations' in oncology may empower women to share visual images relating to scar healing; bruising and possible sites of infection. Use may have the potential to reduce time taken to resolve concerns arising post-surgery/chemotherapy; provide confidence to patients in managing their own body post-treatment; and reduce costs through non-urgent attendance at clinic or Accident & Emergency departments. 'Selfie consultations' could feature within a web-based reporting system of symptom monitoring during routine cancer care using patient reported outcomes.

In relation to the issue of sharing concerns with clinicians, Wendy made contact by email after receiving the Participant Feedback report (Appendix 26). She commented:

'I felt quite saddened that a common theme is that we do not wish to mither the medical profession. I am guilty of that, but I had hoped that I was in the minority as after all, they are the experts! (Photo-production: Wendy).

Wendy describes the finding as 'ringing true' (Ziebland & McPherson, 2006); verifying its trust-worthiness (Birt, Scott, Cavers, Campbell & Walter, 2016; Doyle, 2007). Rather than 'mithering' the healthcare profession, some women create their own social media resources. Women are actively involved in digital labour in relation to meeting some or all of their psychosocial needs. Digital labour in a social media context relates to the unpaid creation of

content and information online (Fuchs, 2014). In so doing, women articulate a perspective that they are reducing potential demand on secondary health service provision. This seems to support The Health Foundation's (2011) review of the self-management evidence. They reported that self-management programmes may reduce visits to health services by up to 80%. However, the evidence should be treated with some caution. The six research studies used in The Health Foundation report to support this perspective were old studies, published between 1989 and 1999, that related to arthritis (n=4); chronic pain (n=1) and asthma (n=1) only. Currently there is no understanding of how many women LwBBC use peer led, naturally occurring, groups on social media in the UK or the wider contribution women's digital labour in relation to LwBBC makes. However, given the recent Facebook controversy, it might be prudent for healthcare commissioners to gain greater understanding of the role social media are playing in supporting aspects of people's psychosocial health needs. They may wish to consider the impact that the changing use of social media could have on the accessibility and availability of naturally occurring peer led support; together with potential implications for changing demand on existing services should the 'culture of connectivity' (van Dijck, 2013) be redefined.

Within this study, women appear to experience a sense of empowerment or a sense of regaining control by choosing to access groups, or set up new groups, that are 'alternatives' to the status quo – i.e. to established support structures that are organisationally driven; such as cancer charity forums. Women create and utilise niche sites to fill a gap in the services provision they experienced. However, their use of these sites is not without complexity as women travel further away from diagnosis. The evidence within this thesis shows that women in the 1-5 years post diagnosis become faced with decisions as to whether to and when to move on. This raises interesting questions relating to what women 'moving on' means from a digital labour perspective. Women remaining in the group are important resources for women more recently diagnosed. They move from receiving support to providing support (Preece & Shneiderman, 2009; Wang, Kraut & Levine, 2016).

Interestingly, Wang, Kraut & Levine (2016), using machine learning methods, identified that exposure to more emotional support within breastcancer.org discussion boards predicted people stayed in a group longer and resulted in lower dropout rates. In contrast, exposure to more informational support predicted leaving the group sooner. It may therefore be the case

that when women are engaged in environments where they feel they can access high levels of emotional support they remain attached and take longer to 'move on'. Arguably, healthcare providers may be interested in women remaining involved in peer-led support groups. Arguably, through their digital labour they are delivering services at no cost to the NHS or UK tax payer. Furthermore, research suggests emotional support from women with more experience of LwBBC contribute more to improvements in quality of life and reduced levels of depression in newly diagnosed women, than emotional support from newly diagnosed women (Moon, Chih, Shah, Yoo & Gustafson, 2017). These may be reasons to encourage women to remain engaged and 'give back'. Exploring whether the outcomes are similar in open, naturally occurring support groups however, would be a useful next step.

Galston (1999) argued that if exiting an online community "represents a true loss of social, psychological, or practical benefits, a group member will exert effort to stay and contribute" (cited in Williams, 2006, p.611). The practicality of participation in some niche social media groups may be having an impact on women's reluctance to move on. For instance, what happens if women are members of a younger women's group and fear a cancer recurrence but if they leave may then be "too old" to re-join? Ahmed, Fergus & McCarthy (2015) noted that younger women (<50) demonstrate the poorest psychosocial adjustment during and after treatment but that their needs are often overlooked by healthcare providers. Remaining attached to an existing support structure may therefore be considered beneficial. How do women weigh up the benefits of lurking or occasionally being able to touch base with women that joined a group at a similar time but are not 'friends' outside of the group? These concerns lead to wider questions about the social media breast cancer community. How important to women is a group that is 'secret' compared to being 'closed'? How sustainable are peer-led groups, and does it matter if the peer led breast cancer community is in a state of constant flux? Does a state of constant flux support the status quo? For instance, within the last few years, Flat Friends UK moved from being a peer led group to a charitable organisation. This necessitates a change in the underpinning ethos of the 'alternative space' originally created. Indeed, do 'alternative' groups inevitably become part and parcel of the status quo as they grow and develop a set of acceptable practices for how women communicate on line with one another? Do differences in group autonomy change women's

emotional connectedness with the group itself? Wendy commented after reading the participant feedback:

'I also found it interesting that women migrate across and between groups to find one which suits - again that is something I found, and I felt rather disloyal about it at times. As time has progressed, my observation is that these groups fold and new one's form' (Photo-production: Wendy)

Researchers are trying to understand why online health communities thrive or fail (e.g. Zaagar & Paul, 2012) although this question has not, to my knowledge, been extended to naturally occurring groups on social media.

There is a conundrum in how women engaged in niche social media groups advocate for themselves and others. From a research perspective, there seems obvious benefit to be gained by different groups working together on targeted issues. During this study period, #bccww began an awareness campaign on Twitter during breast cancer awareness month (BCAM), using the hashtag #breastcancerrealitycheck. This offered women a counter-narrative to the pink ribbon culture (Ehrenreich, 2001; Nielson, 2014; Sulik, 2011) - an embedded aspect of BCAM – by sharing the realities of women's experiences of LwBBC. This idea was taken up by YBCN who adopted a different hashtag, #breastcancerrealities. These two hashtags have been running separately for at least the past two years, missing opportunities for engagement and reach created by becoming one voice in relation to the 'realities' of breast cancer once a year. This small example suggests that a continual focus on own group identity may miss wider opportunities to gain presence, inform the breast cancer awareness debate; and to advocate for all women LwBBC.

10.2 Theoretical reflections:

An objective at the outset of this study, was to produce findings that were understandable and accessible to a range of different stakeholder groups. At the same time, it is important to articulate the complex relationships women described about their use of social media. The thematic findings represent key aspects of women's experiences of use. However, the complex ways in which women use social media to support psychosocial health is inaccurately portrayed if we consider the thematic findings as stand-alone, independent

themes/subthemes. They are interconnected, intertwined and sometimes it is difficult to cleanly distinguish where one subtheme ends, and another begins. This is not a fault of the analysis but rather a signal that factors which influence psychosocial health are themselves interconnected and intertwined. One way to demonstrate this interconnectedness is to consider the thematic findings in relation to Deci and Ryan's self-determination theory (2008). Self-determination theory (SDT) posits that "there is a set of universal psychological needs that must be satisfied for effective functioning and psychological health" (Deci & Ryan, 2008, p.183). Deci and Ryan argue that satisfying the need for autonomy, competence, and relatedness predicts psychological well-being. These universal psychological needs are relevant across cultures globally (Deci & Ryan, 2008) and have been extensively used in healthcare, particularly in health promotion settings (Ng et al., 2012). Autonomy refers to an individual's perception that she has choices and control in her life. Competence refers to the feeling of control and mastery over one's environment. It is similar to self-efficacy—the perceptions that one has the relevant skills to accomplish goals (Bandura, 1997). Relatedness is a sense of belonging; of feeling cared for by others and understood (Hull et al., 2016; Ng et al., 2012, Ryan & Deci, 2000). Ferguson, Gutberg, Schattke, Paulin and Jost (2015) contend that due to the user-generated underpinnings of social media, social media operate as autonomous-supportive contexts. Figure 10-1 provides a potential explanatory model of mediated psychosocial support that satisfies women's basic needs for autonomy, competence and relatedness across the cancer continuum. Using this model, it is possible to see how gaining psychosocial support through social media satisfies basic human needs and the intertwined way these needs are satisfied. For instance, in reviewing Figure 10-1 and reflecting on autonomy, women have described social media as enabling the management of: the physical impact of change; their changing informational needs; the emotional challenges they and their family face; and the day to day negotiation of LwBBC. This autonomy is entangled in women's competence and confidence in their capacity to do something about their situations. For instance, seeking information using Google, providing information, and exchanging information with others to construct knowledge through social media enables women to find ways to supplement the gaps in support they experience. Furthermore, women gain resources and support to navigate the day to day challenges through a sense of connectedness with women 'like me'. Some women utilise their social media self-efficacy to be productive, gain a sense of purpose and of mattering (Thoits, 2011).

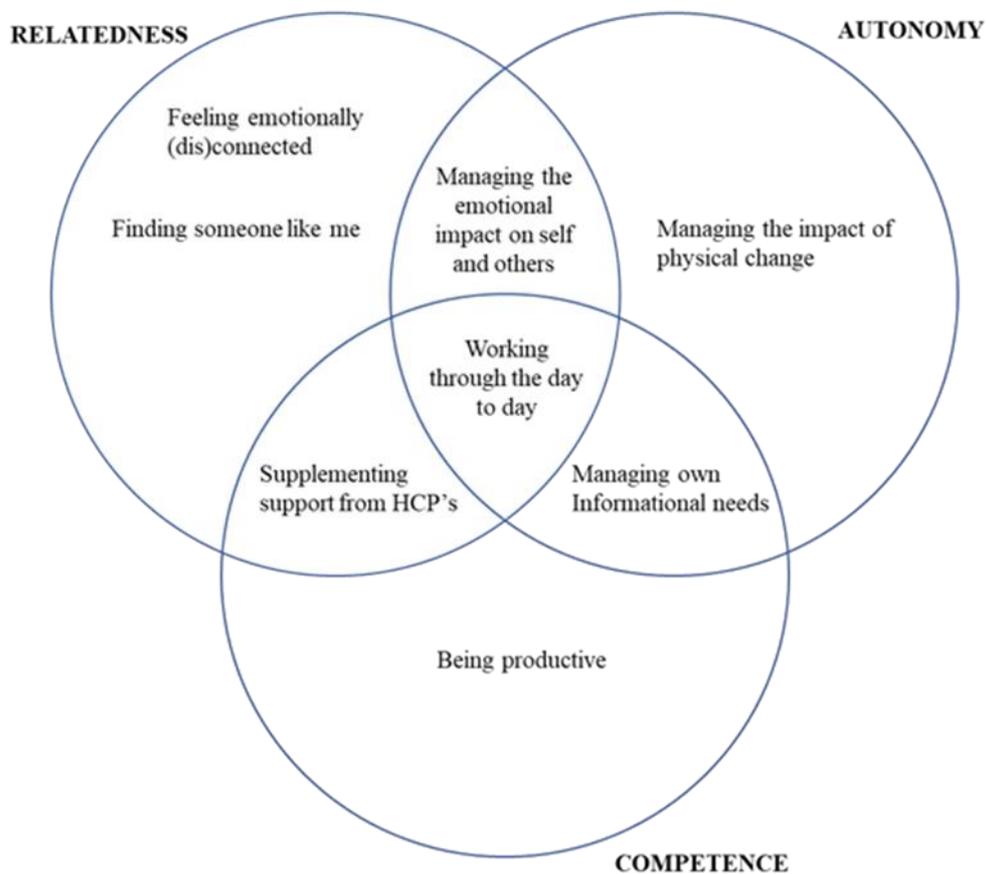


Figure 10-1 How social media mediates psychosocial health: A potential explanatory model

The significance of the interconnectedness of social media as a space in which women satisfy the needs of autonomy, competence and relatedness seem to echo the findings of Zhang (2015) and Hull et al., (2016). Hull et al. sought to find out whether, and how, autonomy, competence, and relatedness mediate the relationship between engagement with an interactive cancer communication system (CHESS) and quality-of-life outcomes. They found deeply intersected and mutually reinforcing relationships between the SDT components. This knowledge changed their understanding of how a cancer communication system affected quality of life outcomes. Previously, CHESS researchers had assumed that the SDT constructs affected quality-of-life outcomes discretely (Hawkins et al., 2010). Conveying to

healthcare professionals the basic human needs women's use of social media seeks to satisfy may enable fruitful discussion and support for social media use by women LwBBC.

10.2.1 Reflections on functional social support and social media use

When analysing visual and verbal data relating to social support, it became evident that emotional and informational support are often entangled or intertwined, rather than discrete and separate. These findings indicate that the provision and receipt of social support is more nuanced when mediated through social media than is currently reflected in the literature. This is a significant observation given the proliferation of research exploring emotional and informational support as discrete constructs in social media studies. However, such complex entanglements have perhaps remained hidden due to a dearth of qualitative literature exploring social media and social support. In a review of all studies published between 2004 and 2015 that explored social support on SNS (n=88), only 12.5% (n=11) were qualitative (Meng et al., 2016). It is perhaps surprising given the explosive growth of social media since 2004 that more qualitative scholarly work in this area has not been completed. It is therefore timely to identify whether the existing conceptualisation of discrete social support constructs adequately reflect the expression and receipt of social support on social media in a health context. Interestingly, the challenges of distinguishing whether online posts offer informational or emotional support, or both, has recently determined the research approach taken by Deetjen and Powell (2016). Using machine learning approaches to carry out a content analysis of posts made to the Dailystrength.org website, the authors removed all posts from their sample if they could not classify with a probability of at least 75% that they were either informational or emotional. While this acknowledges the entangled nature of informational and emotional support on social media across a range of health conditions, only 2275 posts from an initial 40612 posts were excluded (5.6%). That said, posts were analysed using specific words as signifiers of emotional and informational content and did not include emoticons or use of other text features as communicative features. Given emotional support is recognised as significantly more important for women in breast cancer groups than it is for men in prostate cancer groups (Blank et al., 2010; Deetjen & Powell, 2016), it is plausible women entangle the constructs of informational and emotional support on social media as a taken for granted cultural practice. This needs exploring further but potentially it has implications for organisations involved in providing support to women LwBBC.

10.2.2 Reflections on structural social support and social media use

When women join web-based health communities, they typically interact with new weak ties developing additional bridging capital. In comparison, using social media such as Facebook and Twitter requires women LwBBC to consider interactions with strong (bonding capital) and weak ties (bridging capital) simultaneously. It is of note that within this study, many women spoke in limited ways about close tie relationships particularly with their partners. This was even the case when partners' roles in providing social support was addressed directly in the photo-elicitation study. Partners were only captured directly in the photographs of two participants. This reticence to talk about this close relationship may reflect women's desire to protect others (section 9.1) when in conversation in a research context. But it may also reflect a tendency for women to share more about some aspects of their experiences of LwBBC with selected weak ties. It is clear that women experience complexity in managing relationships with strong and weak ties and that Granovetter's (1973) original conceptualizations of tie strength do not cleanly map onto modern relationships mediated through SNS (Rozzell et al., 2014). For instance, some women describe not wanting to publicly 'out' their experiences on their normal Facebook page – typically a combination of someone they have never met and their close family members (boyd & Ellison, 2007). In addition, for women who participate in secret groups, they can be resistant to blurring the boundaries they perceive between their 'normal' Facebook lives and their secret breast cancer Facebook life. Given Facebook's mission to "give people the power to build community and bring the world closer together" (Constine, 2017), women describe challenges with whether to integrate ties from one aspect of life with their pre-cancer life (original Facebook). De Meo, Ferrara, Fiumara, and Provett, (2012) offer a different explanation of strong and weak ties mediated on SNS. Using network theory, they contest that strong ties are those connecting users in the same community, while weak ties are the edges linking individuals belonging to different communities. Given Granovetter's original definition of strength of ties as influenced by time spent, intimacy gained, emotional intensity and level of reciprocity, it is evident that some women engaged in social media spaces form new ties that are more akin to strong tie relationships. These may however be time limited and transient. Understanding how women compartmentalise online relationships with other women LwBBC is of significance from a psychosocial health perspective. This compartmentalisation

may reflect an underlying concern for some related to health-related stigma (Wright & Rains, 2013), hence the reluctance to move across perceived 'boundaries' within Facebook. These findings suggest it may be the applicability of the social media space which acts as a signifier of relationship rather than the relationship per se. They add nuance to Miller's (2016) 'Goldilocks Strategy' whereby platforms such as Facebook allow people to keep connections at exactly the right distance – "neither too hot nor too cold, but just right" (p.5).

Weak ties were distinguished by Granovetter (1973) as having "low levels of trust, relational intimacy, and support" (cited in Rozzell et al., 2014). Weak ties as providers of bridging capital who provide informational support but not emotional support (Krämer et al., 2014) is clearly not the experience women LwBBC convey. The way women talked about their 'weak tie' relationships - developed through closed Facebook groups or on Twitter - problematise this definition. Descriptions of digital mourning for members of the group who had passed away provides one example of women experiencing a sense of intimacy and relatedness, different to that achieved with traditional strong ties. The notion of tie strength in relation to emotional connectedness and psychosocial health needs may need to take greater account of subjectivities; relatedness; engagement 'space'; length of relationship; and anticipation of relationship longevity. In doing so, this would build on Lasén's (2014) perspective that social media are not applications that we use, but spaces we inhabit and spaces that inhabit us; and therefore, are places of experience and subjectivity (cited in Serrano-Puche, 2016). This notion of spaces we inhabit and inhabit us is extended when considering women typically accessed social media platforms via smartphones and tablets. Digital devices including smartphones have affective atmospheres (Lupton, 2017). This means users gain a sense of emotional attachment to the technology (Fullwood, Quinn, Kaye & Redding, 2017). Understanding more about the role of feeling, intimacy and immediacy created by the technology itself would extend current understanding of women's use of social media further. Notably, most women were using social media as part and parcel of their everyday lives prior to their cancer diagnosis. They already inhabited spaces on Facebook and Twitter for example. Opportunities for healthcare professionals to support women's psychosocial health through communication channels which are part of women's everyday lives and to which they have an existing emotional connection, seems an obvious route to explore in future work.

This notion of the applicability of the spaces we inhabit is demonstrated in how public or private women chose to be in their communication practices related to LwBBC. Women describe their use of different platforms and aspects of those platforms as a portfolio of communication options enabling them to amplify voice and broadcast to a wide audience or seek personalised, intimate care often simultaneously. The dynamic and flexible nature with which women employ multiple platforms suggests use as less static than the literature currently suggests and demonstrates multiple strategies taken to seeking control.

Figure 10-2 demonstrates how women LwBBC scale their sociality (Miller, 2016). Rather than using social media as discrete platforms, women demonstrate user agency within a polymedia setting (Chambers, 2017). Women select which platform or which communication feature of a platform best suits their needs. They have control as to whether they seek one to one contact (Facebook Messenger; Twitter direct messaging; WhatsApp) through targeting messaging, shown in Figure 10-2 as ‘private conversation’.

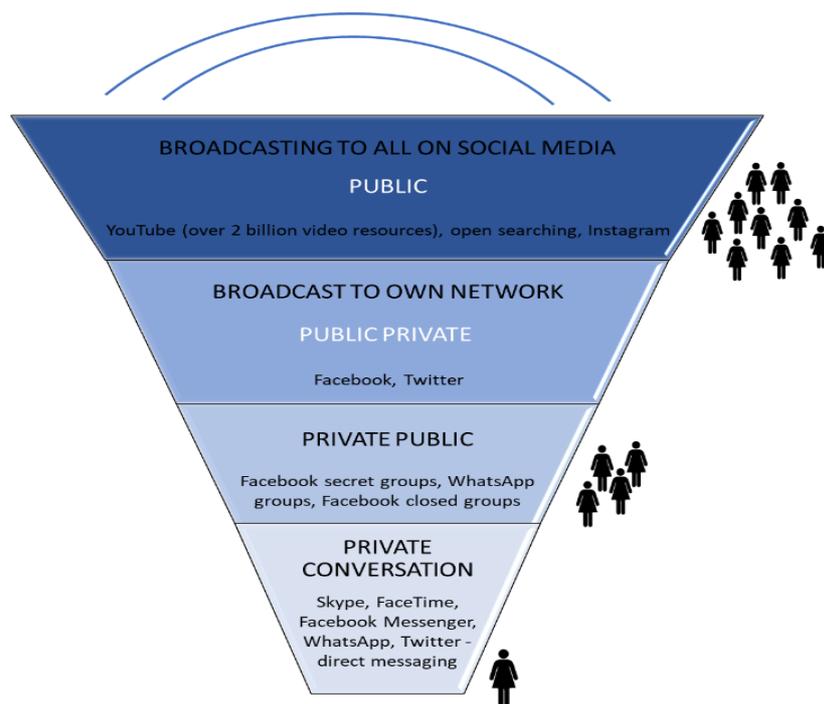


Figure 10-2 Controlling the conversation - using multiple platforms to support psychosocial health

Using social media, in comparison to say online health communities, women have greater choice over the degree of privacy or size of group they may wish to communicate or interact with (Miller, 2015). Within this small sample, women show that Facebook Messenger and WhatsApp are particularly useful within the first 12 months post diagnosis.

With both Facebook Messenger and WhatsApp having over 1.3 billion users each, social media analysts contend that social interaction is moving away from the public domain into private spaces (Hutchinson, 2017). It is not possible to generalise to wider use from this study, however women's preferences for closed, more intimate spaces may not reflect a need to manage their breast cancer experiences out of the public gaze but may reflect a general trend in preferences for social media use. With the advent of more intimate settings such as WhatsApp to share personal experiences of LwBBC, Miller (2016) advocates groups on this platform as more 'genuine' than those identified within the 'individual networks' of Facebook. Taking this premise, the intimacy of WhatsApp, supporting up to 30 'trusted members' (Chambers, 2017) in any group, may become a new proxy for strong ties/bonding capital; and individual networks on the large broadcast networks of Facebook and Twitter as a proxy for weak ties/bridging capital.

10.3 Methodological reflections

The epistemological and analytic perspective taken has treated the interview and visual data as providing honest, "transparent" (realist) accounts by women of how they use social media. However, the interview and visual data collected are explored from a relativist perspective and examine the meaning women give to their use and the relationship this has to their psychosocial health. These two approaches are used in a complimentary way to provide a wider perspective on how women use social media in relation to LwBBC. While a more discursive analytic approach was used (voice centred relational methodology) to bring forward how women spoke about themselves in relation to others, this was used to help 'hear' women's voices rather than considering discourses as "action-orientated" (Breakwell et al. 2012) and identifying what women accomplished through their talk (Goodman, 2017). It seems fitting that in a study designed to give voice to women's experiences, so many women did not want anonymity in relation to their participation. For women who utilise social media extensively, this may reflect the connectivity culture they are part of, where

anonymity is not an option (Conrad, et al., 2016) and a taken for granted aspect of modern life. Most of these women certainly reject the notion of anonymity as being an important factor in enabling the sharing of health experiences online (Blank et al, 2010; Chen, 2012; Klemm et al., 2003), albeit these are complicated by the spaces in which experiences are shared.

In keeping with the experiences of Del Busso (2011) and Harrison (2002), photo-production as a method gave women greater control over the conversation as women were able to direct my attention to those aspects of their experiences they determined significant. Using photography shifted the power relationship from myself as the researcher to enable women to tell their story as they saw fit. I am keenly aware that the contexts shared visually, and the narratives explored through detailed examination of photographs using this method were driven by the women. They controlled the interview space through determining which aspects of their experiences they were happy and prepared to visually share both with me as the researcher, but also potentially with an unknown wider audience through dissemination. For some women, this resulted in a very close focus on use of the internet and social media specifically. While for others, social media use was visually depicted alongside other aspects of women's daily lives. I found the use of photo-production methods to be empowering not only for those participating but also for myself. As a researcher, I experienced a sense of gaining significantly greater insight into women's lives through the 'glimpses' (Silver, 2013) into a different world that a photograph brings, when explaining and sharing experiences. I felt more immersed in women's personal experiences because photographs, when combined with women's narratives, provided wider access to the life lived and created a real sense of intimacy as we worked together to understand the role of social media in women's lives when LwBBC.

Prior to the participant feedback report being shared, I contacted each of the photo-production participants, who had waived their anonymity, to check permissions to use photographs were still in place. Given consent to reproduce photographs has been provided at the time of interview, this was not strictly necessary. From an ethical perspective, however, I was conscious that while I was engaged with material provided at a certain time in women's lives, these women had moved on. I was aware that I did not know the health status of women and felt that assuming the 'right' to use photographs was inappropriate given the

collaborative nature of this type of study and the focus of the research. All women remained happy for their photographs to be used and after receipt of the participant feedback, no comments were raised about onward use of the photographs. This suggests the processes of pre-briefing; the shared interaction around the photographs within the interview; and conversations around copyright gave women a sense of control through determining what is made public. The permissions for use by women suggests the act of taking photographs involves self-awareness that is intertwined with a public gaze (Mountian et al., 2011). Within interviews, it may have been of value to understand 'missing' images. Photographs that were planned but not taken; lost photographs; and photographs noticeable by their absence (Frith, 2011). This may point to increasing understanding about how women negotiate boundaries between the public and the private when LwBBC. Similarly, women's photographs were taken using a camera and sim card provided by the University. With the exception of Kirsty, none of the women, to my knowledge, retained a copy of the photographs taken. This raises interesting questions about the significance of these photographs for women, in that it suggests they were not of significance. However, this inference also assumes that women did not also take a photograph of the same image on their smartphones or own camera as a personal record.

While participants have given consent for use of their photographs and have signed copyright release forms, there remains an ethical dilemma (Guillemin & Gillam, 2004) in relation to the inclusion of photographs depicting children and the issue of informed consent. While making children 'visible' through photography was an important element for two women in using their photographic 'voices' to describe the ongoing effects of living with and beyond breast cancer, I am aware that this thesis will be published online and open access. It felt important to ensure children were given the opportunity to express their own voice regarding the inclusion of these photographs. On reflection, I decided to seek additional consent for the inclusion of photographs in the final thesis that included children under the age of 18. I re-established contact with the two women who had included photographs of their children. Both parents and children included in photographs were asked to provide written consent that the photographs which include children can be included in the thesis and in onward dissemination materials (published articles, presentations etc.) (Appendix 25). A copy of the relevant photograph(s) were provided. In seeking to be ethically responsible, this approach

provides an additional level of consent and is mindful of the requirements set out by the Children’s Commissioner for digital rights to provide children with a level of control over their digital life (Children’s Commissioner.gov.uk, 2017).

The use of visual methods to elicit conversation to explore how women use social media when LwBBC provided a significant quantity of rich data. Figure 10-3 provides an overview of whose voices are quoted in each of the subthemes across Chapters 7-9. It demonstrates which type of interview using the two visual methodologies– photo-elicitation or photo-production – elicited the quotes used within the analysis chapters. Through visualising whose voices have been heard, it is possible to reflect on the contribution the photo-elicitation and photo-production methods made to this thesis as single and combined methods. It should be noted, however, that not all quotes relating to particular sub-themes were utilised. As Braun and Clarke (2006) point out, in seeking to reflect women’s voices, these are invariably framed by the researcher. Fine (2002) argues, that taking a ‘giving voice’ approach “involves carving out unacknowledged pieces of narrative evidence that we select, edit, and deploy to border our arguments” (cited in Braun & Clarke, 2006, p.7). Inevitably, therefore, through the crafting of the analytical story, some women’s supportive evidence informs the development of themes and subthemes but do not appear in the final edit.

Figure 10-3 visually demonstrates that each theme has contributions from both visual methods and from women at each of the different stages of the cancer continuum. The combination of the two visual methods can be seen to be complementary in that they supported and widened overall understanding of how women use social media when LwBBC and in relation to addressing psychosocial needs. For instance, the inclusion of images of healthcare professionals (Figure 7-3, p.111) in the photo-elicitation interviews brought the clinical relationship to the fore at all stages of the cancer continuum. Without this visual prompt, it is possible that concerns to limit contact with HCPs would not have been vocalised and demonstrates the role of photo-elicitation as “conduits to narratives” (Fleury, Keller, & Perez, 2009, p. 678).

		Photo elicitation Under 12 months				Photo-production Under 12 months			Photo-elicitation 1-5 years			Photo-production 1-5 years				Photo-elicitation Over 5 years				Photo-production Over 5 years		
		Sarah M	Sheena	Sarah J	Denise D	Michelle J	Michelle M	Kirsty	Liz	Jayne	Jojo	Delphi	Deborah	Nicola	Wendy	Mandy	Millie	Delly	Eleanor	Denise	Lizzie	Jo
		Theme One: Finding timely, relevant and appropriate support	1. Supplementing support from healthcare professionals																			
	(i) Women seek to limit demands on healthcare professionals																					
	(ii) Photography limits the significance of support from healthcare professionals																					
	(iii) Social media offers immediate support																					
	(iv) Social media supports shared decision making																					
	2. Managing own informational needs																					
	(i) The need to Google																					
	(ii) Gaining the appropriate level of information at the right time																					
	(iii) Using social media to learn from experiential experts																					
	3. Feeling emotionally (dis)connected																					
	(i) Using social media to navigate feeling disconnected from strong ties																					
	(ii) Social media supports intimate, emotional connection with strong and weak ties																					
	(iii) Facebook features and feeling emotionally connected																					
Theme Two: Navigating disrupted identities	1. Finding someone like me																					
	(i) Who do women search for?																					
	(ii) Managing the challenges of 'being similar yet different'																					
	2. Working through the impact of physical change																					
	(i) Hiding changes																					
	(ii) Using social media to explore changes to physical appearance																					
	(iii) Using the selfie																					
	3. Working through the day to day																					
	(i) 'Normal' interactions disrupted by cancer																					
(ii) The impact of treatment																						
(iii) Navigating mortality, loss and grief																						
Theme Three: (Re)gaining a sense of control	1. Managing the emotional impact on self and others																					
	(i) Controlling interactions with family and friends																					
	(ii) Controlling own access to other women's experiences																					
	(iii) Caomartmentalisation and 'moving on'																					
	(iv) Managing notifications																					
	2. Being productive																					
	(i) Creating the breast cancer community landscape																					
	(ii) Gaining a sense of purpose by being an experiential expert																					
(iii) Advocating for own and others' health																						
(iv) Voicing counter-narratives																						

Figure 10-3 Visualising voices across themes, subthemes, visual method and time since diagnosis

Through photo-production, the psychosocial issues created by challenges to physical identity for women within 12 months of diagnosis were made evident; as was the ongoing impact of negotiating the day to day in this group and the 1-5-year group. These may have remained largely hidden from view utilising photo-elicitation methods in isolation or a semi-structured interview without visual methods. This supports previous research that has shown that photo-production interviews can produce richer, more detailed, and more precise information than that generated by word-only interviews (Capello, 2005; Frith & Harcourt, 2007).

A tentative observation is that there appear to be more quoted contributions from women who are members of closed Facebook groups and women's quoted contributions are fewer overall in those diagnosed more than five years previously. However, for women diagnosed more than five years previously quoted contributions are greater for those experiencing ongoing issues post treatment; those experiencing recurrence and living with secondary breast cancer. This suggests social media as an important presence for those unable to 'move on'. Only one of the women in the over five years group, were members of closed Facebook groups although many used Facebook in relation to LwBBC with their existing networks. Fewer quotes from this group overall may be related to two participants in this group deciding not to use social media in relation to LwBBC specifically, although they did use social media more generally. Women were not screened in advance of participation to ensure they were active social media users in relation to LwBBC as this research was interested in exploring how women used social media in relation to breast cancer as part of their everyday lives. Non-use therefore demonstrates social media as not considered useful or applicable to some women in relation to LwBBC.

During the data collection and analysis processes, I reflected on my positionality and whether I was positioned by my participants as an 'insider' or 'outsider' (Bengry, 2018; Berger, 2015; Corbin Dwyer & Buckle, 2009). Bengry (2018) comments that the status of 'insider' or 'outsider' is nuanced and shifting rather than fixed or related to "absolute notions of identity and status" (p. 101). At the outset of this study, I held some concerns about being viewed as an 'outsider' having not experienced breast cancer directly myself although I had friends who had. On reflection, by positioning myself as a woman not LwBBC, I was inadvertently failing to identify those aspects of my experience which provided 'insider' status. These became clearer to me as I developed rapport with participants during interviews. I came to recognise that the binary distinction of being either an 'insider' or an 'outsider' was a false one and that

I occupied ‘the space between’ (Corbin Dwyer & Buckle, 2009). I shared some similar life experiences to the women participating in the study which bridged aspects of our relationship and supported conversation. These included: being female; using social media; having children; being an ‘academic’; being in the WoMMeN group; having worked in a chemotherapy unit; being a colleague; being a friend of a friend. For different women, some of these experiences moved me further towards having ‘insider’ status as our focus together was on the use of social media in the context of LwBBC. This was reflected in the language used within interviews, whereby women utilised technical medical terminology to describe aspects of their experiences. While this may be interpreted as women demonstrating their own technical understanding and knowledge of their cancer, it may also be indicative of an assumption that I was familiar with, and understood, those experiences too.

I do not know how the data elicited would have been different if I had previously been diagnosed with breast cancer. Or, if I had been diagnosed with breast cancer and used social media to support my understanding of that experience. Potentially, in these circumstances I may have explored differently aspects of social media use or been interested in how particular topics were addressed or not addressed by women online. However, as Fay (1996) concludes, an area of research can gain much from exploration from ‘the space between’. These include articulating a clearer conceptualisation of experiences by not being enmeshed by personal experience. As has been seen, women also describe their experiences of social media use and LwBBC as “full of overlapping, confusing, ambivalent, mixed, and sometimes contradictory goals, motives, desires, thoughts, and feelings” (Corbin Dwyer & Buckle, 2009, p. 59), by being more distant it may be the case that it is easier to explore this complexity.

10.4 Implications for those with a substantive interest in cancer care

Internet and social media use are embedded activities in many people’s lives. It would be beneficial for women if healthcare professionals acknowledged women’s use of these tools for everyday information searching and by extension, health information, when women become aware that they may or do have breast cancer. Seeking to restrict people’s use of the Internet using the ‘don’t Google’ discourse without providing alternative information seeking strategies is counterproductive given women’s need to gain some sense of control. Positive strategies for information seeking online should be discussed instead. This could be

contextualised by HCPs gauging the support network of women at the point of diagnosis, and again at key moments along the cancer continuum. This can include gaining an understanding of whether social media forms part of women's regular activities. This will then enable healthcare professionals to direct women to appropriate or potential sources of support, including social media groups.

Alternatively, women can be encouraged at the time of diagnosis or any time subsequently to create a Patient CV. #patientcv¹⁰² is a one-page patient owned skill set document that conveys to clinical teams the person the other side of the illness. It is designed to show doctors that patients are active in their own care and includes insight into their professional life; which social media platforms they use; what type of offline support they have; and any health tracker apps already used. This type of approach has been heralded recently on social media by e-patients and healthcare professionals as a new approach to 'patienting' – the activity of being a patient (The Medical Futurist, 2018), that should be core to any healthcare plan.

Women's testimonies indicate visual input regarding treatment, surgical and self-care procedures are wanted. Women use YouTube in multifaceted ways, including to learn from other's experiences and sharing their own experiences. The visual need to understand from other's experiences appears to be particularly beneficial when there is a strong sense of relatedness. There is significant opportunity for women to post and share videos for the benefit of the breast cancer community/healthcare professionals and vice versa to broaden awareness, understanding and to support effective ongoing self-management. The availability of visual input via a 'pathway to diagnosis flowchart' for women waiting for diagnostic results prior to initial diagnosis may also be useful. Diagnostic teams carrying out triple diagnostic assessments could potentially signpost women to appropriate resources to enable online information searching that will support active coping strategies in a personalised way.

10.5 Limitations of the findings presented in this thesis

The small number of women that participated in this qualitative study may not be typical of all women's experiences of social media use when LwBBC. The women who took part in this study were self-selecting, choosing to respond to advertisements posted in social media

¹⁰² The brainchild of Lindsay Fallow (@betabetic) – who lives with multiple chronic conditions

groups; via cancer charity promotion; and through word of mouth. Research participants are often identified as being highly motivated and knowledgeable (e.g. Galpin et al., 2017). They may therefore represent a particularly motivated group of women LwBBC.

Another limitation is a risk that recruiting through social media for a study relating to social media use might result in elite bias (Myers & Newman, 2007). Myers and Newman state that elite bias “concerns overweighting data from articulate, well-informed, usually high-status informants” (p.5). Arguably, women who are creating, developing and investing in the breast cancer community landscape (Chapter 9; section 9.2.2.) through initiating weekly Twitter chats; establishing websites; and moderating closed Facebook groups, can be considered “stars” (Miles & Huberman, 1994) in the breast cancer social media landscape. As has been considered in section 9.2.2, their voices are particularly prevalent in relation to the need to gain a sense of control. From an axiological perspective, these women’s voices are as important to hear as women who have not created new communities and are not as embedded in the breast cancer social media landscape. Through listening to a wide range of voices, it is possible to explore and understand both the similar and divergent motivations for use; how these may be influenced by the trajectory of the life course and the cancer itself and attitudes to technology and social media. Rather than ‘stars’ being considered as a limitation in their participation in this study, their involvement extends our understanding of the benefits of social media as a set of tools with which to regain a sense of control.

A further limitation to take into account is that women were self-reporting their use of social media. There is therefore a risk of bias in how women reported use. Through utilising different approaches to understanding social media use within the interview (social media audit sheet; Venn diagram exploring examples of how social media was used specifically in relation to breast cancer using ‘platform cards’; and an exploration of social support and communication practices using photography in the photo-production study), women were asked to describe real examples of use. The use of the Venn diagram (Appendix 17) was particularly useful in asking women to think specifically about their use of social media in relation to LwBBC. The process of asking women to account for their use after they had identified earlier which platforms they used acted as a checking mechanism with verbal evidence of use in relation to LwBBC required.

A further limitation was that the sample was predominantly white. It is broadly accepted that in the UK, Black, Asian and Minority Ethnic groups are under-represented in medical

research contexts (Smart & Harrison, 2016). Indeed, Kerr, Ross, Jacques and Cunningham-Burley (2018) identified in their review of sociological analyses of patient experiences of cancer (reported between 2007-17), that the majority of the 101 articles they identified as concerned with living with and beyond cancer, focused on white Europeans. Understanding how and if women from different ethnicities use social media in the UK would add to our understanding of its use for these women too.

Another limitation which impacts on the conclusions drawn is the relatively young age of those participating in the study and their apparent educational status. In line with the debate outlined in section 3.1, many of the women participating appear to have had high levels of existing digital literacy prior to diagnosis due to their professional roles. Women more recently diagnosed describe extending their existing online information searching skills either pre-diagnosis or at diagnosis to meet specific needs. Many described extending existing digital competencies into the health arena to enhance their own knowledge of breast cancer per se and their own breast cancer specifically. Understanding whether these patterns of behaviour are similar with women with different educational experiences, different levels of digital expertise or who are identified as 'older' (Bostock & Steptoe, 2012), would be a useful next step.

In overall terms, most contributions reflected with quotes in the analysis were from women diagnosed in the preceding five years. More quotes were included from women in the photo-production study than the photo-elicitation study. It is likely this reflects the benefits women participating in the photo-production study had in determining what they wished to take photographs of to reflect their experiences. There was a noticeable difference in women's ability to engage in the visual materials used in the photo-elicitation interview. While the photographs were used as reference points (Frith & Harcourt, 2007), occasionally women talked about what they saw in the photograph literally rather than using the image as a general prompt to talk about their own specific relationships. In hindsight, it may have been useful to have asked women to also bring their own existing photographs to the interview to talk about their experiences of LwBBC and communicating their experiences to others.

10.6 Further research opportunities

One of the findings relates to women's cautious use of secondary healthcare resources. The extent to which perceived pressures on the NHS influence women's choices as to where they source support is not known. Similarly, it is unknown to what extent patient's decisions to access support from social media relieves demands on clinical service provision. These questions would benefit from further exploration as they may provide insight into alternative options for the provision of timely, relevant and appropriate interventions from a HCP perspective too. Furthermore, it is unknown whether use of social media exacerbates issues within the clinical setting, for instance through affecting attitudes to adherence to Tamoxifen or increased fear of recurrence for instance, which later increase demand on clinical services. Comparing how UK oncologists and breast care nurses perceive the impact of social media on clinical decision making with the perceptions of women LwBBC, at different stages of the cancer continuum, would help identify perceived gaps in communication and support.

Much work currently conflates social media use with online health community use. There is work to be done in understanding how women move in and out of different communities to understand whether use on traditional 'trusted' sites is shifting. For instance, many women participating in this study used the Breast Cancer Care forum early on after diagnosis but then moved away to Facebook groups or to set up alternative or 'underground' groups. It is important to understand how and if use is changing across the wider population. This will help inform key service providers about perceived changes needed either technologically or in terms of the provision of reliable support. This could be supported by further exploration of the benefits of multiple platform use in terms of relatedness, control and competence. Do women who actively move across platforms experience better health outcomes than those that use static online health communities? Given the ability to exercise control and gain greater sense of relatedness, this suggests that there may be greater benefits through a multiple platform approach.

Finally, there is limited understanding of whether the type of information and media content women consume is affected by the cognitive impairment that can be a side effect of chemotherapy. A diary study capturing women's information and content consumption at time of diagnosis, during treatment and at twelve months post diagnosis may shed light on

whether social media is an attractive resource due to the differing levels of attentional effort required.

'The report is really interesting and certainly resonates with me! I hope that service providers will find it insightful and create better resources and support because of it. It is a really good summary of what it was like navigating diagnosis, treatment and now recovery through social media' (Photo-production: Kirsty).

10.7 The original contributions of this thesis

To conclude, this thesis has developed new knowledge relating to four key areas of social media use by women LwBBC.

Firstly, this thesis extends current knowledge regarding women's use of social media to support their experiences of LwBBC. By taking a holistic approach to exploring social media platform use, rather than a single or dual platform approach, it answers the call by Meng et al., (2016) to develop a wider understanding of multi-platform use in relation to social support.

Secondly, this thesis provides the first exploration of women's accounts of social media use for functional and structural social support when LwBBC. Traditionally functional support such as informational and emotional support have been conceptualised as discrete concepts. However, women's use of social media demonstrates how some platforms enable significant entanglement of emotional and informational support thereby problematising this conceptualisation. Furthermore, women's use of social media problematises traditional conceptualisations of strong and weak ties as these do not cleanly map onto women's everyday online relationships mediated through different types of social media accounts.

Thirdly, this thesis provides new knowledge relating to women's use of naturally occurring groups and interactions on social media, rather than through established organisational groups or groups created to support an intervention. In so doing, it answers the call by Falisi et al., (2017) for research exploring naturally occurring groups on social media.

And finally, new knowledge is created through methodological development. Through exploring social media use using visual methods in combination with voice centred approaches, women are able to develop powerful testimonies, visually and vocally, to convey connection and dissonance in relation to their experiences of LwBBC.

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Appendices

Appendix 1: Charities' use of Twitter: exploring social support for women living with and beyond breast cancer

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 Check for updates

Charities' use of Twitter: exploring social support for women living with and beyond breast cancer

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ABSTRACT

Twitter is one social media platform that enables those experiencing breast cancer to access support from others. This study explores how cancer charities provide support to women living with and beyond breast cancer (LWBBC) through their Twitter feeds. Seven hundred and seventy-two tweets from seven purposively sampled cancer charities were used to explore Twitter posts made relating to social support. Two questions were posed: (1) what type of support is positioned by cancer charities on Twitter for women LWBBC and (2) what themes emerge from tweet content pertaining to support for women LWBBC? Using a peer-reviewed typology of 'social support' [Rui, J., Chen, Y., & Damiano, A. (2013). Health organizations providing and seeking social support: A twitter-based content analysis. *Cyberpsychology, Behavior, And Social Networking*, 16(9), 669–673. doi:10.1089/cyber.2012.0350], a deductive content analysis was utilised to identify informational, instrumental or emotional social support tweets ($n = 199$). Over half (56%) of tweets offered informational support; 27% provided or sought instrumental support and 18% related to emotional support. Interestingly, 74.3% ($n = 573$) of tweets were not related to providing or seeking social support. An inductive qualitative thematic analysis of the 199 tweets identified the focus (i.e., themes) of support. Three themes were identified: (1) raising awareness, (2) focusing on the future and (3) sharing stories. Cancer charities predominantly use Twitter to signpost women to informational resources and to seek instrumental support to meet charitable objectives. As the number of women LWBBC continues to increase, this study provides valuable insight into how charities represent themselves on Twitter in relation to the social support needs of women LWBBC.

ARTICLE HISTORY

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KEYWORDS

Breast cancer; tweets; social support; charities; living with and beyond; twitter

Introduction

The number of women living with and beyond breast cancer (LWBBC) in the United Kingdom (UK) is increasing due to earlier diagnosis, improvements in treatments and an ageing population (Maddams et al., 2009; Maddams, Utley, & Möller, 2012). For many, LWBBC is about managing chronic illness on an ongoing basis (Maher & Fenlon,

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Appendix 2: Types of interactions on key social media platforms ¹⁰³

Platform	Type of interaction	Interface driven interactions	Indicators re. social capital	Study authors	Participants
Facebook	Directed communication	Tagging			
		Commenting	Negatively related to BRISC ¹⁰⁴	Lee, Kim & Ahn (2014)	N=256; M _{age} = 20.9
		Liking	Positively related to BRISC	Lee, Kim & Ahn (2014)	N=256; M _{age} = 20.9
		Wall posting			
		Sending private messages			
		Exploring public ¹⁰⁵ and private ¹⁰⁶ use of all directed communication tools (tagging, commenting, liking, wall posting and sending private messages)	Positively predicts BRISC Public directed communications predicts BRISC	Burke, Marlow & Lento (2010); Burke, Kraut & Marlow (2011) Yoder & Stutzman (2011)	1. N=1193 adults; M _{age} =33.7. 2. N=415 adults; M _{age} = 33.7 N=557 students; M _{age} =19.9
	Consumption	Scrolling through news feed	Negatively predicts BRISC and BOS ¹⁰⁷ No effects found	Burke, Marlow & Lento (2010); Burke, Kraut & Marlow	N=1193 adults; M _{age} =33.7 N=415 adults; M _{age} = 33.7
	Broadcasting	Status updates	Updates that seek to mobilise help receive more response (social capital) than non-mobilisation posts	Lampe, Grey, Fiore & Ellison (2014).	N = 3877 status updates
		Sharing others content on own news feed			
		Frequency/use of wall posts	Positively related to BRISC	Lee, Kim & Ahn (2014)	N=256; M _{age} = 20.9
		Disclosure	PPositively related to BRISC	Vitak (2012)	N=364 students; M _{age} = 30.0
		Exploring use of all broadcasting interactions	Positively related to BRISC	Stutzman, Vitak, Ellison, Gray & Lampe (2012)	N=230 students; M _{age} = 21.2

¹⁰³ Developed from work completed by Autheunis et al., (2015)

¹⁰⁴ BRISC = Bridging Social Capital.

¹⁰⁵ Public activities include all communication activities visible to someone's friend network (Autheunis et al., 2015).

¹⁰⁶ Private activities include directed communication only visible to the one it is directed to, such as a private message (Autheunis et al., 2015).

¹⁰⁷ BOS¹⁰⁷ = Bonding Social Capital.

Appendix 3: Keyword search terms

Ovid, PsychInfo and Medline

# ▲	Searches	Results	Type
1	► (exp Breast Neoplasms/ or (breast adj3 cancer*).mp. or (breast adj3 neoplasm*).mp. or (breast adj3 carcinoma*).mp. or (breast adj3 tumour*).mp. or (breast adj3 tumor*).mp. or (breast adj3 DCIS).mp.) and "humans".mp. [mp=ti, ab, ot, nm, hw, kf, px, rx, ui, tc, id, tm]	272786	Advanced
2	► ("Internet" or "social media" or "Web 2.0" or "web-based" or "user generated" or "computer mediated communication" or "social network" or "online" or "on-line" or "online communit*" or "on-line communit*" or "online forum*" or "on-line forum*" or "virtual adj3 (world OR social worlds OR games worlds OR communit*)" or "content communities" or "Medicine 2.0" or "M-health" or "E-health" or "Phone app" or "mobile app" or "mobile application" or "mobile" or "smartphone" or "Twitter" or "tweet" or "Facebook" or "Blogs" or "Blogging" or "blog" or "weblog" or "microblog" or "micro-blog" or "You Tube" or "wikipedia" or "wiki" or "Wikis" or "instant messag*" or "text messag*" or "texting" or "text messaging").mp. [mp=ti, ab, ot, nm, hw, kf, px, rx, ui, tc, id, tm]	310768	Advanced
3	► 1 and 2	2069	Advanced

Appendix 4: Example appraisal of a survey study

Attai, D., Cowher, M., Al-Hamadani, M., Schoger, J., Staley, A., & Landercasper, J. (2015). Twitter Social Media is an Effective Tool for Breast Cancer Patient Education and Support: Patient-Reported Outcomes by Survey. *Journal of Medical Internet Research*, 17(7), e188. <http://dx.doi.org/10.2196/jmir.4721>

Appraisal questions	Yes	Can't tell	No
1. Did the study address a clearly focused question/issue <i>'To determine the effectiveness of social media as a tool for breast cancer patient education and decreasing anxiety'.</i>	x		
2. Is the research method (study design) appropriate for answering the research question? <i>Survey of '#bcsm tweet chat participants using 5 point Likert scales to identify whether participation increased understanding for different domains of care and treatment; level of anxiety pre/post Twitter engagement; safety and comfort of participation in #bcsm tweet chats and motivation re. future advocacy and volunteering.</i>	x		
3. Is the method of selection of the subjects (employees, teams, divisions, organisations) clearly described? <i>Survey completion (Survey Monkey) offered to #bcsm Twitter participants, the #bcsm blog and Facebook page over a ten day period in April 2014.</i>	x		
4. Could the way the sample be obtained introduce (selection) bias? <i>The authors identify issues with questionnaire completion that create bias issues. Responses overly balanced to a single demographic group (graduates – 53.9%) and lack of responses to all questions. The authors identify the survey is subject to recall bias. No control group of patients.</i>	x		
5. Was the sample of subjects representative with regard to the population to which the findings will be referred? <i>To a large extent. 69.4% of respondents had breast cancer; 92.7% female; 91.7% white; 53.9% graduates. However, the results suggest 30.5% of respondents did not have breast cancer. Of this 30.5%, 37% of were clinical health professionals or researchers who had not been treated for breast cancer; 37.3% were 'other' and 25% were caregivers, spouses of friends. 77% participated in the bcsm</i>	x		

<i>community outside of Twitter.</i>			
6. Was the sample size based on pre-study considerations of statistical power?			x
7. Was a satisfactory response rate achieved? <i>The number of unique individuals who posted using #bcsm was reported as 2094 (2011); 4303 (2012); 8248 (2013) and 14,186 (2014). Respondents = 206. This may indicate challenges when using a hashtag to denote a user as it is unlikely all those posting using the #bcsm were active on the tweet chat. This could have been explored further.</i>			x
8. Are the measurements (questionnaires) likely to be valid and reliable? <i>The authors identify that the survey did not under go formal reliability and validity testing.</i>		x	
9. Was the statistical significance assessed? <i>In part. Due to issues with bias identified by the authors, they limited analytical reporting to frequencies and percentages except for respondent-reported extreme or high anxiety before or after the #bcsm chats (used McNemar test)</i>	x		
10. Are confidence intervals given for the main results?			x
11. Could there be confounding factors that haven't been accounted for? <i>For instance, there is a claim that as a result of #bcsm, 28.4% of responders reported subsequent volunteering efforts without further exploration.</i>	x		
12. Can the results be applied to your organisation?			N/A

CeBMA Center for Evidence Based Management. Adapted from Crombie, The Pocket Guide to Critical Appraisal: the critical appraisal approach used by the Oxford Centre for Evidence Medicine, checklists of the Dutch Cochrane Centre, BMJ editor's checklists and the checklists

Appendix 5: Example appraisal of a qualitative study

Doh, H., & Pompper, D. (2015). Beyond the wounds: The SCAR Project as space for examining breast cancer and mastectomy experiences. *Social Semiotics*, 25(5), 597-613.
<http://dx.doi.org/10.1080/10350330.2015.1041792>

CASP question	Summary of study response
Is there a clear statement of the aims of the research?	Aims to examine how Facebook's SCAR (Surviving Cancer: Absolute Reality) is used. Good/extensive literature review exploring the ongoing invisible challenges for women after mastectomy or lumpectomy and the (inherent) renegotiation related to gender identity. Two research questions posed. These are clearly articulated.
Is a qualitative methodology appropriate?	Strong justification of methods provided. Narrative analysis of Facebook posts to the SCAR project page undertaken (between January 2010 & June 2013).
Was the research design appropriate to address the aims of the research?	The design was appropriate. The authors were interested in the reported benefits of autopathography and community building in the public sphere of Facebook. They used narrative analysis, employing a hermeneutic phenomenological approach, using each Facebook post as a unit of analysis.
Was the recruitment strategy appropriate to the aims of the research?	Secondary data collection so no recruitment strategy as such.
Was the data collected in a way that addressed the research issue?	The authors downloaded all posts, removing those that were not relevant to the research questions (exclusion criteria were provided). They identify the final data set of posts as 138. The number of posts seems low over a 3.5 year period however there is no discussion on size of the sample as a limitation. It may suggest women did not feel this project page an appropriate space to engage in autopathographic reflection. More transparency of total number of posts posted and who posted them would aid understanding of overall use of the page.
Has the relationship between researcher and participants been adequately considered?	As this was a study using secondary data collection and analysis, there was not relationship between the researchers and participants.
Have ethical issues been taken into consideration?	Ethical considerations were not addressed. It is not clear whether the SCAR Facebook project page is open, closed or secret and therefore whether it is publicly accessible. There is no discussion of ethical consent being sought to conduct the research. While the authors do anonymise posts quoted, there is no

	discussion as to whether individuals are identifiable through using Google to search for quotes.
Was the data analysis sufficiently rigorous?	The authors used word frequencies to identify key words used in posts as a starting point for hermeneutic phenomenological themes analyses using word relationships. They included a word tree map from Nvivo but did not explain how this contributed/was integrated into the process of data analysis. There was limited information about how final themes were arrived at. Supporting evidence for the findings was provided through quotes linked through brief commentary. Anomalies in the findings were discussed. The analysis and findings were assessed by two researchers.
Is there a clear statement of the findings?	Yes, these were clearly articulated. Additional discussion relating to how posts supported or did not support community building
How valuable is the research?	Useful exploration of narratives posted on Facebook specifically related to the ongoing psychosocial effects of surgery to women's breasts. It would have been interesting to have understood why the authors did not investigate narratives about mastectomy/lumpectomy more broadly in Facebook groups and why they chose the SCAR project to focus on.

Appendix 6: Ethical approval



Research, Innovation and Academic
Engagement Ethical Approval Panel

Research Centres Support Team
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27 August 2015

Dear Cathy,

RE: ETHICS APPLICATION HSCR 15-71 – Social Media use by women living with and beyond breast cancer in the UK: A mixed methods study

Based on the information you provided, I am pleased to inform you that application HSCR15-71 has been approved.

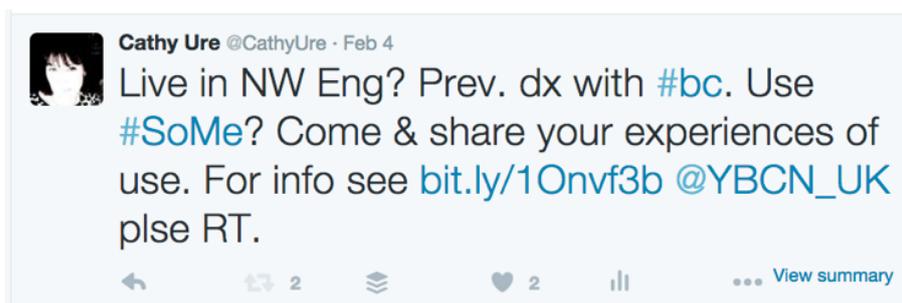
If there are any changes to the project and/ or its methodology, please inform the Panel as soon as possible by contacting Health-ResearchEthics@salford.ac.uk

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Sue McAndrew', on a light-colored background.

Sue McAndrew
Chair of the Research Ethics Panel

Appendix 8: Examples of tweets posted



Appendix 9: Participant information Sheet (photo-elicitation)



Participant Information Sheet – Semi-structured interview (Photo-elicitation study)

What role does social media play in the lives of women living with and beyond breast cancer?

Thank you for asking for more information about this research study. Before you decide whether to take part or not, it is important to understand why this research study is being carried out and what it will involve. Please read the information provided about the study, take your time to consider it and think about what it will entail for you. You are welcome to discuss the study with others if you wish. If you would like further information about the study or would like to clarify any aspects of your involvement in the research, please contact me using the contact details below.

What is the purpose of this study?

The central concern of this study is to understand what role social media use plays or does not play in the lives of women who are living with and beyond breast cancer. Previous research indicates that breast cancer is a phenomenon which has a significant ‘social’ presence online with over 100 million results searchable via Google (Quinn et al., 2013) and over 600 different Facebook groups (Bender et al. 2011) yet few studies have explored the role social media plays in the lived experiences of those living with and beyond breast cancer. With the number of women living with and beyond breast cancer in the UK set to rise substantially within the next fifteen years (Maddams et al. 2012), it is timely to explore how and why women use social media in relation to their breast cancer experiences.

Why have we contacted you?

We are inviting women over the age of 18, who have at some stage of their lives been diagnosed with breast cancer.

Do I have to take part?

It is entirely up to you whether to take part. Taking the time to read all of the information provided about the study will help you come to an informed decision. If you decide to participate, you will be asked to complete and sign a consent form – a copy of which I have attached so you can see what is involved. Remember, however that if at any time during the

study you decide you no longer wish to participate, you can withdraw or end your participation without needing to give a reason.

What do I have to do?

If you choose to take part, you will be invited to attend an interview. This is likely to be at The University of Salford, Frederick Road campus. It is anticipated that the interview will be informal and relaxed and a number of questions will be asked about how you use social media platforms. It is anticipated that the session will last for approximately 60 minutes. We would also like you to complete a brief questionnaire relating to your breast cancer diagnosis and social media use.

What are the possible disadvantages of taking part?

We recognise that each individual's experiences of living with and beyond breast cancer are different and talking about these experiences can be difficult at times. If you do decide to participate, you can withdraw at any time or you can choose not to answer questions that you feel are too personal for you.

What are the possible benefits of taking part?

This is the first study that we know of, in the UK, seeking to understand women's experiences of using social media platforms in relation to their experiences of living with and beyond breast cancer. As such it is an opportunity to talk about your own experiences, whether you use social media or not. I believe this study could provide new insight into ways in which women support their own psychological health post treatment. If this is the case, this information could help improve post treatment support for others.

Will my involvement in the study remain private/confidential?

All information that is collected, as part of this research study, will be kept strictly confidential. Names of individuals involved in the study will be kept on a password-protected computer, accessed only by the researcher. It would be my intention to not use your name in this study. However, should you wish to be named, then this can be accommodated with your written consent. I intend to transcribe all the information collected myself however, there is a small chance this work may be carried out by external transcribers. Should external transcription services be employed only those providing a confidential service will be utilised. Where participants have requested anonymity, data will be anonymised before being sent to the external transcription service.

What will happen to the results of the research study?

It is anticipated that the results of this study will be shared with health professionals and potentially breast cancer related organisations. Additionally, the study and its results will be presented at academic conferences and written up for inclusion in academic journals. We offer anonymity to all research participants. You will not be named or identified in any of the formal outputs unless you have specifically request to be named and provide that request in writing.

Who has reviewed this study?

This study has been reviewed and approved by The University of Salford, School of Health Sciences Ethics Committee (HSCR 15-71).

What happens now?

If you would like to share your experiences or would like more information about the study, contact Cathy Ure at c.m.ure@edu.salford.ac.uk

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers' supervisor who will do their best to answer your questions: **Dr. Adam Galpin:** t: 0161 2957146. Email: a.j.galpin@salford.ac.uk

If you remain unhappy and wish to complain formally you can do this through: Anish Kurien Research Centre's Manager, University of Salford, G.08, Joule House, Acton Square, Salford, M5 4WT. T: [0161 295 5276](tel:01612955276). Email a.kurien@salford.ac.uk Thank you for taking the time to read about this study and for thinking about participating.

Cathy Ure, PhD student. Email: c.m.ure@edu.salford.ac.uk

26-08-18version7

Appendix 10: Participant Information Sheet (photo-production)



Participant Information Sheet – Semi-structured interview (Photo-production study)

What role does social media play in the lives of women living with and beyond breast cancer?

Thank you for asking for more information about this research study. Before you decide whether to take part or not, it is important to understand why this research study is being carried out and what it will involve. Please read the information provided about the study, take your time to consider it and think about what it will entail for you. You are welcome to discuss the study with others if you wish. If you would like further information about the study or would like to clarify any aspects of your involvement in the research, please contact me using the contact details below.

What is the purpose of this study?

The central concern of this study is to understand what role social media use plays in the lives of women who are living with and beyond breast cancer. New evidence suggests the ‘health journey’ of women post diagnosis and treatment is both long term and complex (Macmillan Cancer Support, et al. 2014). Previous research indicates that breast cancer is a phenomena which has a significant ‘social’ presence online with over 100 million results searchable via Google (Quinn et al., 2013) and over 600 different Facebook groups (Bender et al. 2011) yet few studies have explored the role social media plays in the lived experiences of those living with and beyond breast cancer. With the number of breast cancer ‘survivors’ in the UK set to rise substantially within the next fifteen years (Maddams et al., 2012), it is timely to explore how and why women use social media in relation to their breast cancer experiences.

Why have we contacted you?

We are inviting women over the age of 18, who have at some stage of their lives been diagnosed with breast cancer.

Do I have to take part?

It is entirely up to you whether to take part. Taking the time to read all of the information provided about the study will help you come to an informed decision. If you decide to participate, you will be asked to complete and sign a consent form – a copy of which I have attached so you can see what is involved. Remember, however that if at any time during the study you decide you no longer wish to participate, you can withdraw or end your participation without needing to give a reason.

What do I have to do?

If you choose to take part, I will arrange a preliminary briefing session to outline specifically what is involved. I aim to hold interviews with women who are living with and beyond breast cancer to talk about their experiences of using technology and social media in relation to these experiences. To assist this discussion, I would like you to take a series of photographs which helps you tell your story of living with and beyond breast cancer over a 7-day period. During the briefing session, I will provide guidance and support, provide a camera and memory card for use and answer any questions you may have about taking photographs for this study. We will also agree a date to meet to discuss the photographs you have taken. It is anticipated that this semi-structured interview will last approximately one hour. Using photography is an innovative way of enabling you to talk about how and why you use, or don't use, social media platforms in relation to living with and beyond breast cancer. At the end of the session, we would also like you to complete a brief questionnaire relating to your breast diagnosis and social media use.

What are the possible disadvantages of taking part?

We recognise that each individuals' experiences of living with and beyond breast cancer are different and talking about these experiences can be difficult at times. Using photography as a technique to talk your experiences of living with and beyond breast cancer enables you to control the pictures you take and the story you tell. If however, at any point you feel uncomfortable about your participation in this study you are free to withdraw and any data collected, such as an interview transcript, will be destroyed.

What are the possible benefits of taking part?

This is the first study that we know of, in the UK, seeking to understand women's experiences of using technology and social media in relation to their experiences of living with and beyond breast cancer. As such it is an opportunity to talk about your own experiences. I believe this study could provide new insight into ways in which women support their own psychological health post treatment. If this is the case, this information could help improve post treatment support for others.

Will my involvement in the study remain private/confidential?

All information that is collected, as part of this research study, will be kept strictly confidential. Names of individuals involved in the study will be kept on a password-protected computer, accessed only by the researcher. It would be my intention to not use your name in this study however should you wish to be named, then this can be accommodated with your written consent. I intend to transcribe all the information collected myself however, there is a small chance this work may be carried out by external transcribers. Should external transcription services be employed only those providing a confidential service will be utilised. Where participants have requested anonymity, data will be anonymised before being sent to the external transcription service.

What will happen to the results of the research study?

It is anticipated that the results of this study will be shared with health professionals and potentially breast cancer related organisations. Additionally, the study and its results will be presented at academic conferences and written up for inclusion in academic journals. We offer anonymity to all research participants. You will not be named or identified in any of the formal outputs unless you specifically request to be named and provide that request in writing.

Who has reviewed this study? This study has been reviewed and approved by The University of Salford, School of Health Sciences Ethics Committee (HSCR 15-71).

What happens now? If you would like to share your experiences or would like more information about the study, contact Cathy Ure at c.m.ure@edu.salford.ac.uk.

What if there is a problem? If you have a concern about any aspect of this study, you should ask to speak to the researchers' supervisor who will do their best to answer your questions: **Dr. Adam Galpin: t: 0161 2957146. Email: a.j.galpin@salford.ac.uk**

If you remain unhappy and wish to complain formally you can do this through: Anish Kurien Research Centre's Manager, University of Salford, G.08, Joule House, Acton Square, Salford, M5 4WT. T: [0161 295 5276](tel:01612955276). Email a.kurien@salford.ac.uk

Thank you for taking the time to read about this study and for thinking about participating.

Cathy Ure, PhD student. Email: c.m.ure@edu.salford.ac.uk

26-08-18version7

Appendix 11: Approaching Facebook group moderators



Cathy Ure

13/02/2016 10:59

Hi, my name is Cathy Ure and I am a PhD researcher at the University of Salford. I'm researching the role of social media in the lives of women living with and beyond breast cancer. Details here <http://bit.ly/1Onvf3b> Would it be possible to make this study known to your community?

New evidence suggests the 'health journey' of women post diagnosis and treatment is both long term and complex (Macmillan Cancer Support, et al. 2014). Previous research indicates that breast cancer is a phenomenon which has a significant 'social' presence online with over 100 million results searchable via Google (Quinn et al., 2013) and over 600 different Facebook groups (Bender et al. 2011) yet few studies have explored the role social media plays in the lived experiences of those living with and beyond breast cancer. With the number of breast cancer 'survivors' in the UK is set to rise substantially within the next fifteen years (Maddams et al., 2012), it is timely to explore how and why women use social media in relation to their breast cancer experiences.

If any members of your community are interested in sharing their experiences, they can get involved in one of two ways. I am running one to one interviews or focus groups (if a group of (online) friends are happy to get together) and also a photo production study. This is where I would provide a camera and memory card and ask for photos to be taken over a seven-day period which captures how women communicate their experiences of breast cancer. We then meet and talk through the significance of the photographs taken and how they relate to that individual's lived experiences of breast cancer. This may involve the use of social media but it may be broader than that.

Follow the link <http://bit.ly/1Onvf3b> for more info. about both studies. If anyone is interested, they can email me at c.m.ure@edu.salford.ac.uk. Sessions will be held at the University of Salford. If individuals are particularly keen to be involved but live some distance away get in touch and we'll talk about what is possible. Could you let me know whether it is possible to let your community know about this research? Many thanks, Cathy.



- Salford Public Health

LIVING WITH OR BEYOND BREAST CANCER? A research study W...
hub.salford.ac.uk

Appendix 12: Facebook groups approached

Facebook Group	'About' – the group's description posted on Facebook	Where study advertised
Breast Cancer Now	We're Breast Cancer Now, the UK's largest breast cancer charity – and we're dedicated to funding research into this devastating disease.	Not advertised
Breast Cancer Buddies UK	This group is for anyone currently going through or had breast cancer treatment in the past.	Closed Facebook group
Cheshire Breast Cancer Now	Dedicated to saving lives by finding the causes of breast cancer, improving detection, diagnoses, treatment and services. Fund-raising and awareness-raising for Breast Cancer NOW	Not advertised
Flat Friends UK	Flat Friends supports women who have had or may face single or bilateral mastectomy without reconstruction	Closed Facebook group
Mummy's Star	Mummy's Star is the only charity in the UK and Ireland with the aim of supporting pregnancy through cancer and beyond.	Not Advertised
The Inflammatory Breast Cancer Group	The Inflammatory Breast Cancer Network UK is a registered charity in England and Wales (1177635). Our mission is to educate about Inflammatory Breast Cancer (IBC) and to promote and fund IBC research in the United Kingdom	Open Facebook group
The Word of Mouth Mammography e-Network Group	Word of Mouth Mammography e-Network. All you need to know about #breastscreening & #mammograms Join our network of researchers, professionals & #WoMMeN like you - ask us a question, go on	Closed Facebook group
UK breast cancer support group for survivors and sufferers	A support Community for those of us UK ladies suffering from breast cancer, and for the survivors, no negativity here 😊	Closed Facebook group
Younger Breast Cancer Network UK	Chat privately with other younger women from the UK/Ireland who've had a BC diagnosis & are 45 or under	Secret Facebook group

Appendix 13: Cancer support centres, charities and support groups approached

North West Cancer Support Centres	Contact details
Macmillan Information and Support Services	Beechwood Cancer Care Centre, Chelford Grove, Stockport, SK3 8LS 0161 47 0384 / 0161 477 8351
Bolton Macmillan Cancer Information and Support Service	Giles House, 43 Chorley New Road, Bolton, BL1 4QR 01204 669059
Macmillan Cancer Information and Support Centre (Central Manchester)	Main Out-Patients Department, Manchester Royal Infirmary, Oxford Road, M13 9WL. 0161 276 6868cancer.information@cmft.nhs.uk
The Christie Cancer Information Centre	The Christie NHS Foundation Trust, Wilmslow Road, Withington, M20 4BX 0161 446 8100
The Christie at Oldham, Macmillan Cancer Information and Support	The Royal Oldham Hospital Rochdale Road, OL1 2JH 0161 918 7745
The Christie at Salford, Cancer Information Centre	Salford Royal Hospital, Stott Lane, Salford. M6 8HD 0161 918 7804
Macmillan Cancer Information and Support Service (Crewe)	Macmillan Cancer Unit Mid Cheshire Hospitals NHS Foundation Trust, Leighton Hospital, CW1 4QJ. 01270 273603
Macmillan Cancer Information and Support Centre (Macclesfield Road)	East Cheshire NHS Trust, Victoria Road, Macclesfield, SK10 3BL. 01625 663128/9
Macmillan Cancer Information and Support Service – Pennine – Bury, North Manchester, Oldham, Rochdale	North Manchester General Hospital, Delaunays Road, Crumpsall, M8 5RB 0161 604 524macmillan.infocentre@pat.nhs.uk
Macmillan Cancer Information and Support Service (Salford)	Salford Royal Hospital, Stott Lane, M6 8HD 0161 206 1455/0161 918 7804
Macmillan Cancer Information and Support Service (South Manchester)	Wythenshawe Hospital, Southmoor Road M23 9LT 0161 291 4875
Trafford Macmillan Cancer Information and Support Service	Macmillan Wellbeing Centre, Moorside Road, Davyhulme, M41 5SN 0161 746 2081
Wigan Macmillan Cancer Information and Support Centre	The Christie at Wigan, Royal Albert Edward Infirmary, Wigan Lane, WN1 2NN 01942 822760.

Appendix 14: Letter to support groups



School of Health Sciences
Allerton Building,
University of Salford,
Salford,
Manchester,
M6 6PU.

Date

To whom it may concern

Dear

Re: Research into the role social media plays in the lives of women living with and beyond breast cancer.

I am a PhD researcher studying at the University of Salford, Manchester, with Dr Adam Galpin, Dr Anna Cooper and Dr Jenna Condie, researching the effects of social media use by women living with and beyond breast cancer.

I am writing to ask whether members of your support group would be interesting in taking part in this research. I would be delighted to attend a support group session to explain more about what this study entails to individuals who show an interest.

Understanding the health complexities of the breast cancer trajectory has only recently begun to attract real attention. Evidence is indicating that post treatment women are experiencing unmet emotional, physical and psychosocial needs. With the number of individuals in the UK living with and beyond breast cancer set to rise substantially within the next fifteen years, it is timely to explore women's social media use or non-use in relation to their breast cancer experiences. This is the first study that we know of, in the UK, seeking to understand women's experiences of using social media platforms in relation to their experiences of living with and beyond breast cancer. As such it is an opportunity for women living with and beyond breast cancer to talk about their own experiences.

Please find enclosed a poster which provides brief details which I would be very grateful if you would display. If you, or any members of your support group, are interested I can be contacted on xxxx xxxxxx or by email at c.m.ure@edu.salford.ac.uk to discuss how to get involved either as individuals or as a small group of friends.

Yours sincerely,

Cathy Ure

Supervised by Dr. Adam Galpin. Email A.J.Galpin@salford.ac.uk

Telephone: 0161 295 7146

Appendix 15: Photo-elicitation study consent form

Title of research study: What role does social media play in the lives of women living with and beyond breast cancer?

Name of researcher: Cathy Ure

1.	I confirm that I have read and understood the information sheet for the above study and what my contribution will be.	YES	NO
2.	I have been given the opportunity to ask questions via email contacts as provided below	YES	NO
3.	I understand that my participation is voluntary and that I can withdraw my consent at any time without giving any reason (see contact details below). However, I understand my contribution up to the point of withdrawal will remain part of the data.	YES	NO
4.	I give my consent to being audio recorded during the interview.	YES	NO
5.	I give my consent to being filmed during the interview	YES	NO
6.	I want my involvement in this interview to be anonymised.	YES	NO
7.	I want any quotes taken from the transcript from the interview to be credited to me; that is to say, I want to be named as(own name/pseudonym).	YES	NO
8.	I acknowledge that what is discussed in the interview should remain confidential	YES	NO

Name of participant.....

Signature of participant.....Date:

Email address of participant.....

Name and email address of researcher: Cathy Ure. Email: c.m.ure@edu.salford.ac.uk

Name and email address of my supervisor: Adam Galpin. Email: A.J.Galpin@salford.ac.uk

26-08-18version7

Appendix 16: Photo-production study consent form

Title of research study: What role does social media play in the lives of women living with and beyond breast cancer?

Name of researcher: Cathy Ure

1.	I confirm that I have read and understood the information sheet for the above study and what my contribution will be.	YES	NO
2.	I have been given the opportunity to ask questions via email contacts as provided below.	YES	NO
3.	I understand that my participation is voluntary and that I can withdraw my consent at any time without giving any reason (see contact details below).	YES	NO
4.	I give my consent to being audio recorded during the interview.	YES	NO
5..	I give my consent to being filmed during the interview.	YES	NO
6.	I understand that consent for using the visual materials taken for this study by myself will be discussed at the interview with the researcher, and that I have not given consent for use at this stage.	YES	NO
7.	I want my involvement in this study to be anonymised.	YES	NO
8.	I want any quotes taken from the transcript from my interview to be credited to me; that is to say, I want to be named as(own name/pseudonym)	YES	NO
9.	I acknowledge that what is discussed in the interview should remain confidential	YES	NO

Name of participant..... Email address of participant.....

Signature of participant.....Date:

Name and email address of researcher: Cathy Ure. Email: c.m.ure@edu.salford.ac.uk

Name and email address of my supervisor: Adam Galpin. Email: A.J.Galpin@salford.ac.uk

26-08-18version7

Appendix 17: Demographic questionnaire

The role of social media in the lives of women living with an beyond breast cancer

Firstly, thank you for participating in our study (HSCR 15-71). Your contribution is very important to us. We have a few questions about demographics, diagnosis and treatment. This information will add to the data we collect during the one to one interviews. This should take no longer than 5 minutes of your time.

1. Demographic Information

1. How did you hear about this study?

2. Are you currently:

- Employed Full Time
- Employed Part Time
- Unemployed
- Self employed
- Retired
- Student
- Not working through choice
- Unable to work due to health issues
- Prefer not to say

3. Are you:

- Single
- Co-habiting
- Married
- Separated
- Divorced
- Widowed
- Prefer not to say

○

4. Please describe your ethnicity:

- White British
- Black/African/Caribbean/Black British
- Asian/Asian British
- Mixed/Multiple ethnic groups
- Other ethnic group (please specify)

2. Diagnosis and treatment

5. How old were you when you were diagnosed?

6. When were you first diagnosed?

- Within the last 12 months
- Between 1 year and 5 years ago
- Between 5 years and 7 years ago
- More than 7 years ago
-

7. What type of breast cancer do you/did you have?

- I have primary breast cancer: breast cancer that has not spread beyond the breast or lymph nodes (lymph glands) under the arm (axilla)
- I have DCIS (ductal carcinoma in situ): an early type of breast cancer sometimes called pre-invasive, intra-ductal or non-invasive cancer
- I have a local recurrence: breast cancer that has come back in the chest/breast area or in the skin near the original site/scar
- I have locally advanced breast cancer /a regional recurrence: breast cancer that has come back and has spread to the tissues and lymph nodes around the chest, neck and

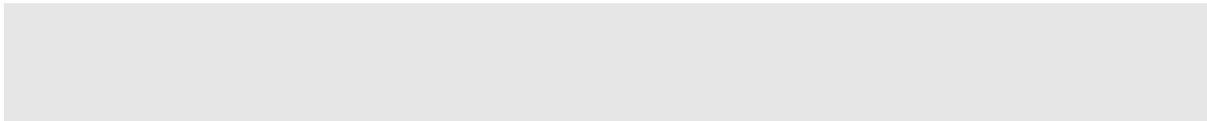
under the breastbone.

- I have secondary/metastatic breast cancer: cancer cells from the breast have spread to other parts of the body such as bones, lungs, liver or brain

8. Of these treatments, which have you received?

- Mastectomy
- Lumpectomy
- Chemotherapy
- Radiotherapy
- Tamoxifen
- Arimidex
- Herceptin

Please add any other treatments you have received.

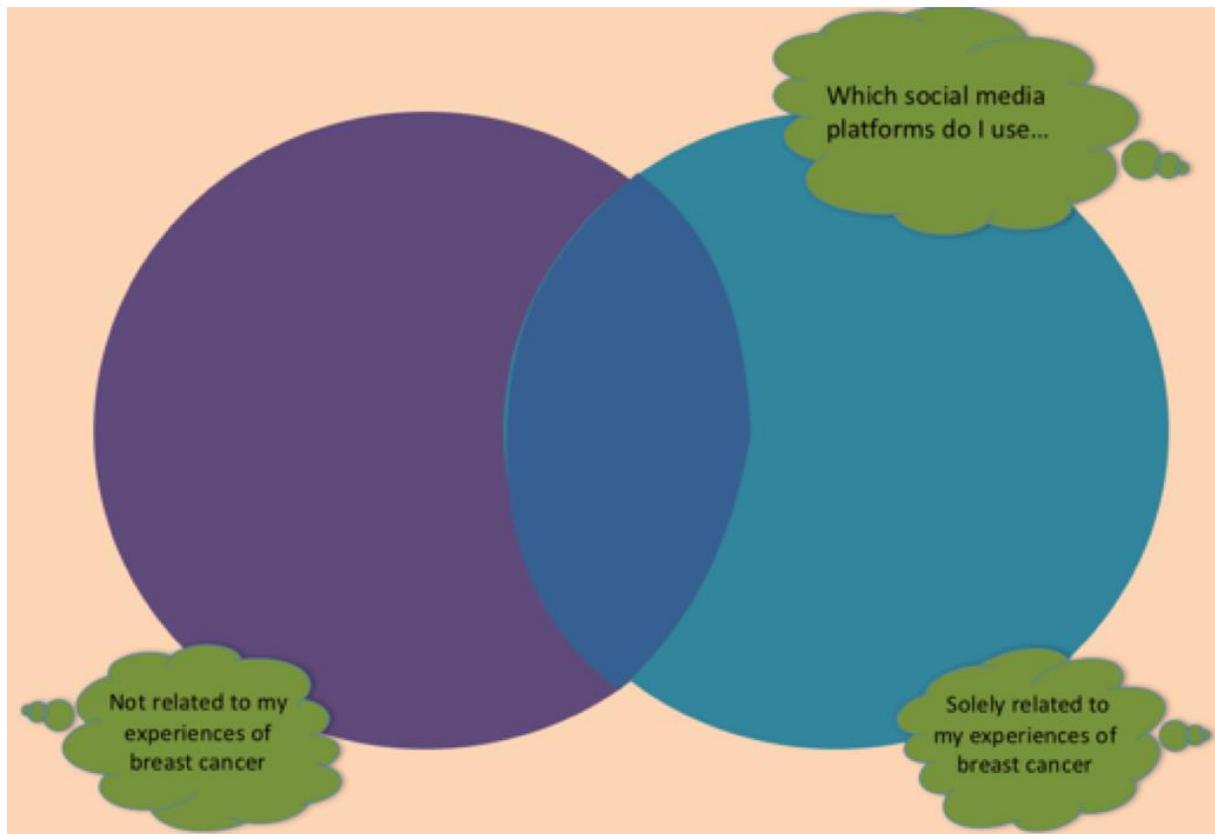


You have now finished the questionnaire. Thank you for taking the time to contribute to this study.

Appendix 18: Social media platform elicitation prompt

FACEBOOK				
GOOGLE+				
PERISCOPE				
LINKEDIN				
FRIENDSTER				
MY LIFE				
TWITTER				
HI5				
XING				
BLOGGER				
TUMBLR				
TYPEPAD				
WORDPRESS				
FLICKR				
GOOGLE				
FACE TIME				
ITUNES				
MYSPACE				
PICASA				
VIMEO				
YAHOO				
YOU TUBE				
DELICIOUS				
DIGG				
INSTAGRAM				
PINTEREST				
HOOTSUITE				
SCRIBD				
YELP				
TWEETDECK				
WIKIPEDIA				
SECONDLIFE				
SNAPCHAT				
WHATSAPP				
SKYPE				
VINE				
		I USE	I DON'T USE	DON'T KNOW ABOUT/ NOT HEARD OF

Appendix 19: Exploring social media use prompt



Appendix 21: Permissions for image use

Permissions have been given for use of all photographs within this report. Credits are indicated for each participant.

Participant	Images used credited as
Michelle	© Michelle / 29.02.16/ University of Salford / Cathy Ure
Deborah	© Deborah / 11.03.16 / University of Salford / Cathy Ure
Wendy	© Wendy Northway /28.04.16/ University of Salford / Cathy Ure
Nicola	© Nicola /19.03.16 / University of Salford/ Cathy Ure
Kirsty	© Kirsty /15.03.16/ University of Salford / Cathy Ure
Jo	© Jo Taylor - abcdiagnosis / 10.12.15 / University of Salford / Cathy Ure
Michelle	© Michelle Mullany / 03.03.16 / University of Salford / Cathy Ure
Lizzie	© Lizzie / 18.11.15 / University of Salford / Cathy Ure
Delphi Marmaduke	© Delphi Marmaduke / 05.01.16 / University of Salford / Cathy Ure

Appendix 22: Gleeson's (2011) Polytextual thematic analysis recipe

- 1 Look at the images over and over again, singly, in groups, serially and in as many different orders as possible. Note any potential themes that emerge, taking care to describe the features of the image that evoke that theme. These initial things might be called proto-themes to signal the tentative and fluid nature of the themes as they are beginning to take shape.
- 2 Feel the effects that the images have on you and describe these as fully as you can in your notes. Go back to these notes and add additional comments as you continue to analyse other images to see if you are experiencing the pictures in different ways as you start to 'get your eye in'.
- 3 Where the proto-theme appears to occur more than once, collect together all the material relevant to that theme. Pull the relevant pictures together and look again to see whether the proto-theme is distinct
- 4 Write a brief description (or definition) of the proto-theme.
- 5 Once a proto-theme has been identified in a picture you will need to go back to over all of the other images to see if it recognisable anywhere else.
- 6 Once again, pull together all of the material relevant to that proto-theme. Revise the description of the proto-theme if necessary, and bring together or descriptions of the elements from different images that best illustrate the theme. It is at this point that the proto-themes (i.e. the first attempts at themes, or primitive themes) may be elevated to the status of a theme. However, such a shift signals that the theme has been checked and considered many times. It does not mean that it is fixed in its final form.
- 7 Continue to work on identifying themes in the pictures until no further distinctive themes [that are relevant to the question (s) that you have brought to the analysis] emerge.
- 8 Look at the descriptions of all themes in relation to each other, and consider the extent to which they are distinct. If there is any lack of clarity, redefine the themes that you have identified. Write descriptions of themes that highlight the differences between themes. The object is to maximise differentiation in order to pull out distinctive features of the image.
- 9 Look at the themes to see if any cluster together in a way that suggests a higher order theme that connects them.
- 10 Define the higher order theme, and consider all themes in relation to it. As other higher order themes emerge consider each in relation to all other themes that have emerged.
- 11 It is at this stage that it is necessary to make a judgment about which of the themes that have emerged best address the research questions so that a limited number may be selected for writing up. It will be helpful to incorporate any supporting materials that contextualise the images being analysed.

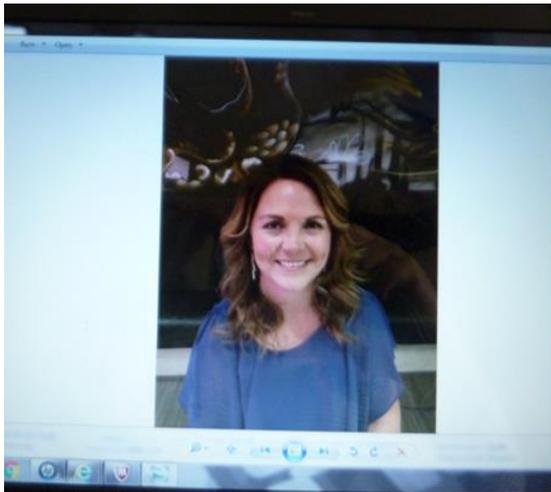
Appendix 23: ‘Track changes’ made to transcript following external transcription

And then two weeks later I've gone to the breast clinic and they literally told me on that day it's more likely it is breast cancer. I had the ultrasound biopsy, mammogram. I had to return, three days later on the Monday, where he then told me there was flaxocalcium in the left breast as well. So I'm probably looking at a mastectomy and a lumpectomy. So I had more procedures. I had a core biopsy on the left breast, another mammogram. I was told the right breast, the lump was triple negative breast cancer, so I wouldn't be able to have any medication and would definitely need chemo and radiotherapy. It took a few more days, yeah until the Friday to get the results back for the calcium. They all came back benign so they've put that breast to sleep. That's fine. We get calcium with age and things like that. So then he told me the grade. It was a grade three, so it is the most aggressive and he said it was probably just over 3cm. Four weeks later I then got the surgery. I thought it was quite a long wait really. The anxiety that I had over that four weeks, I don't think you could ever explain to anybody just going to bed at night just knowing I've got a cancerous lump inside my breast was awful. But the breast care nurse seemed to be really relaxed about it. Saying we know your type, how many days it is before the next cell change and it doesn't matter how much they tell you that, you are still panicking inside. And then on 1 July I had a lumpectomy. Came home the same day. I had a sentinel biopsy. They took out three lymph nodes. They came back clear again. And I recovered really well from that. I didn't return to work then because of the ward I work on, there's a lot of manual handling so I just stayed off from then. And then on 28 July I started chemotherapy and I had three lots of EC. That's...so it was once every three weeks as an outpatient, following nine lots of the Paclitaxel so weekly chemo. The week of chemo I just breezed through it. I had aches and pains, no sickness. That was it fine. The first three floored me for a week at a time. I couldn't really eat anything. I couldn't have a cup of tea. I was aching. I was sick. It was horrendous but I knew I needed, you've got to feel ill to get better. After the chemo, started the radiotherapy. So I had 19 sessions in total that included five boosters. I had a bad reaction to the radiotherapy. They said they'd not seen anything like it for around 15

Appendix 24: Composite table of social media use

Platforms	(a) Composite use (all use)	(b) Count of 'everyday' use but not related to LwBBC	© Count of use including use related to LwBBC	(d) Count of use solely related to LwBBC
YouTube	21	6	15	0
Facebook	19	2	17	0
Wikipedia	18	9	7	1
WhatsApp	16	8	8	0
iTunes	15	11	4	0
Skype	14	9	4	1
Pinterest	13	8	5	0
Facetime	11	8	3	0
Instagram	11	7	4	0
LinkedIn	11	10	1	0
Twitter	11	4	7	1
WordPress	10	2	3	5
Yahoo	9	4	4	0
Blogger	7	0	4	2
Google+	5	3	2	0
Flickr	4	3	1	0
Vimeo	4	1	1	0
Periscope	3	2	1	0
Snapchat	3	2	1	0
Hootsuite	2	1	1	0
Picasa	2	2	1	0
Tumblr	2	1	1	0
Vine	2	2	0	0
Delicious	1	1	0	0
Myspace	1	1	0	0
Tweet deck	1	1	0	0
Digg	0	0	0	0
Friendster	0	0	0	0
Hi5	0	0	0	0
My Life	0	0	0	0
Scribd	0	0	0	0
Second Life	0	0	0	0
TypePad	0	0	0	0
Xing	0	0	0	0
Yelp	0	0	0	0
Grand Total	237	108	116	10

Appendix 25: An example iPoem - Losing my hair



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So, this was my hair
 I hate my photos at the moment.
 I hate my hair.
 I don't like to look in mirrors.
 I almost forget what I look like
 When I look in a mirror I go 'ehh'
 This just does not feel like me
 I know I should be grateful.
 I'm not bald.
 I've kept, got my eyebrows and my eyelashes –
 The cold cap its working for me
 I still sort of feel like ...I wouldn't even say I felt like I had amazing hair before
 ...I didn't go around 'cos I'm worth it'
 The handfuls upon handfuls that have come out of my hair
 Got to day 20 and I was like 'this cold cap's brilliant',
 Yeah I'll be fine...
 I'm not going to lose any hair...
 I'm gonna be alright.
 And then I went and washed my hair
 I feel sick.
 I just couldn't believe it
 I just shouted'just come upstairs'...
 I didn't even dare look in the mirror.
 I just thoughtvirtually all my hair gone.even he was shocked
 I think, your hair and your boobsthe womanly bits about you
 You don't even really think about ityou're going to lose your hairyou
 might lose your boobs
 'I quite like my hair and my boobs actually'
 I know it will come back eventually
 I think it's just that feeling of will I ever like not look 'normal' but look like 'me' again
 if you know what I mean and feel like me again.
 I think that's what it is.
 I don't feel feminine with my hair at the moment, yeah,

Appendix 26: Participant feedback



University of
Salford
MANCHESTER

The Crescent,
Salford, M5 4WT,
United Kingdom

0161 295 5000
www.salford.ac.uk

Dear ...'

Living with and beyond breast cancer: Exploring women's use of social media to support psychosocial health.

Thank you so much for taking part in this research study. The information everyone provided was so rich that it has taken longer than I anticipated to analyse and pull together the key findings from all the interviews. I have now pulled together an overview of the findings for you and would value your comments. I have not included many photographs or quotes in this report for brevity's sake!

I have tried to identify the main topics (themes) that interviewees talked about. Please feel free to add/make suggestions or comments to any of the themes I have identified. The feedback is in a Word document so that you can add comments to it and send them back if you want to. If you want to email your comments, please email me at c.m.ure@edu.salford.ac.uk. If you want to post them, send to:

Cathy Ure, L817, School of Health Sciences, Allerton Building, School of Health Sciences, Frederick Road Campus, Salford. M6 6PU.

Alternatively, if you would prefer to talk, drop me an email and I'll arrange a time to give you a call.

As part of my thesis write up, I would like to include a 'pen portrait' of you. I have provided an example. I hope that this summary reflects the information shared between us when we met. If you would like to add to this or change any aspect of it, please feel free to amend and return. Just in terms of managing logistics relating to this request, I will assume an absence of response means you are comfortable with the pen portrait being included in its current format.

I would be grateful if you could get back to me in the next 10 days (date) with any comments about the findings or your 'pen portrait'.

If you have any queries, or would like more information about the findings please get in touch.

,

Cathy Ure

Postgraduate Research Student

School of Health Sciences

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University of Salford,

Salford.

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Living with and beyond breast cancer: Exploring women's use of social media to support psychosocial health

Background to the research

There has been considerable research on the use of online communities in a health context. In contrast, despite the extensive use of contemporary social media (Facebook, Twitter, YouTube etc.) in everyday life, use of these platforms by women living with and beyond cancer (LwBBC), remains underexplored. This study set out to ask women about their use across the cancer continuum.

Aims

The study aimed to explore a) how women LwBBC use social media b) how women use social media to communicate their experiences, and c) to make sense of how women use social media to support their psychosocial health.

The study

Twenty-one women participated in either a photo-elicitation or photo-production study. Both included a face-to-face interview. In the photo-production study, women provided 157 photographs related to their experiences of LwBBC.

Key Findings

While some women use contemporary social media platforms intermittently, for many social media use is integral to their lives. Contemporary platforms are considered an appropriate space to explore experiences when LwBBC. Often women describe use of multiple platforms simultaneously to meet different needs. Three key themes and eight subthemes were identified. The three themes were:

- finding relevant, timely and appropriate support;
- navigating disrupted identities; and
- (re)gaining a sense of control.

A summary of the each of these themes now follows. At the beginning of each subtheme, I have included an example photograph and a quote illustrative of the theme.

Theme One: Finding relevant, timely and appropriate support

Women talked about support gained through social media use in one of three ways. Through its use to: a) supplement the available support from healthcare professionals; b) help navigate information; and, c) navigate emotional (dis) connectedness. Some of the findings from each of these areas are provided in brief below:

If anything occurs to you, make a note and send it back. Be great to hear your thoughts.

Subtheme One: Supplementing support from healthcare professionals



'it's so fast-paced, that um, you know, it's all so clinical, it's like 'in assessment, get the chemo up, next person, in, out, in, out' that's how it is 135 patients a day we have' (Mandy).

This subtheme explores how women talk about their social media use in relation to the support of healthcare professionals.

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- Many women are using social media to supplement the level of informational support clinical teams offer.
- Collectively, women describe themselves as cautious users of secondary healthcare provisions and avoid 'mithering' services they experience as stretched.
- To supplement this support, women seek support in social media environments.
- Women experience benefits by removing reliance on clinical specialists as the source of all breast cancer knowledge.
- They source from experience-based experts – other women LwBBC.
- Women's accounts show Facebook groups and YouTube as the preferred sources of support to supplement information gained from health care professionals.
- They experience closed groups on Facebook as providing immediate, relevant responses that reassure and inform.

Subtheme Two: Navigating informational needs



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'Because there's that much information, you can't possibly take it all in at the appointment. And when they tell you, you're almost kind of shocked anyway. So, you don't digest any of it. Nothing is retained. Absolutely nothing is retained' (Nicola).

- Many women describe immediate social media use for information searching as a coping strategy.
- For some, information searching started after diagnostic testing and prior to formal diagnosis.
- Women report experiencing information overload in the clinical setting and use social media platforms to fill knowledge gaps through lack of information retention.
- Women often ignore clinical advice not to Google. Consequently, Googling and searching online for further information related to the diagnosis and treatment is common practice.
- Cancer charity websites, seen as legitimate and trustworthy, are often women's first port of call. The level of information provided however, is not of sufficient breadth or depth to satisfy all women's needs.
- Additionally, women experience charities' support as signposting or leaflet driven which do not align with how they search for or read information normally.
- Women supplement web information through active and passive consumption of 'experiential' knowledge principally using Facebook, YouTube and Twitter.
- Through moving across platforms and different groups on platforms, women describe gathering information at the appropriate time for them, determined by them. This supports women's ability to cope with the amount of information they encounter when newly diagnosed; and supports adjustment and informed anticipation of what the next stage in their cancer experience entails.

If anything occurs to you, make a note and send it back. Be great to hear your thoughts.

Subtheme Three: Feeling emotionally (dis)connected



This sub-theme explores women's experiences of (dis)connection; the use of social media to mediate relationships and explores the entanglement of women's lives when gaining emotional support from women who 'understand'.

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© Delphi Marmaduke / 05.01.16 / University of Salford / Cathy Ure
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'when I'm talking about things which I kind of wanted to talk about face to face, people feel a bit uncomfortable or people seem like they feel a bit uncomfortable like they don't know what to say or they're like you know, 'are you sure you want to talk about this' and I'm making jokes, but they just don't; they're not responding very well to it' (Sarah J)

- Feeling an emotional connection to other women LwBBC was a significant factor in using contemporary social media platforms.
- Some women used social media to gain proximity to others when experiencing disconnection from family and friends
- Some women showed how WhatsApp supported the continuation of relationships post diagnosis that had begun to feel (dis)connected or strained face to face.
- Some women 'tested' the availability of support available from friends and family post-diagnosis using social media.
- Connecting with other women who shared similar experiences and 'understood' was sometimes described as a 'lifesaver'. Women's accounts showed many positive experiences of targeted, composed communication (messaging; linking; tagging); one click communication (liking) and broadcast messaging (commenting) suggesting that all can support the development of a sense of belongingness.
- Using different platforms simultaneously enables women to scale how private or public they are about different aspects of their experiences. Platform functionality therefore enables women to create and reduce distance between themselves and others to suit their needs.

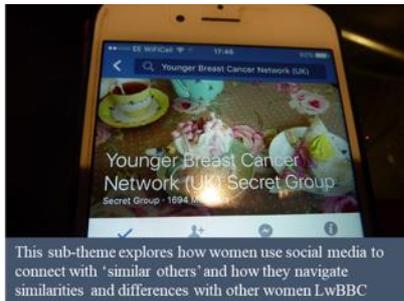
If anything occurs to you, make a note and send it back. Be great to hear your thoughts.

Theme Two: Navigating disrupted identities

Women talked about the notion of navigating disrupted identities in one of three ways: finding 'someone like me'; working through the impact of physical changes; and working through the 'day to day'.

If anything occurs to you, make a note and send it back. Be great to hear your thoughts.

Subtheme One: Finding 'someone like me'



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'I suppose I was looking for somebody like me. Somebody my age, somebody who had, was going through or had just recently been through what I was about to start. So that's what I was looking for really. Somebody similar to myself.' (Kirsty).

- In the immediate aftermath of a breast cancer diagnosis, many women use social media to find 'similar others'. The opportunity to see women who are in the 'same boat', 'look' similar and are experiencing similar treatments reduces uncertainty, enables adjustment and increases women's self-efficacy.
- The need to find 'similar others' can continue across the cancer continuum. Women move between and across groups as they seek out individuals who share aspects of a similar experience.
- When either women felt difference between themselves and others, in relation to age or sometimes in relation to treatment regimes, they sought out other women in other groups they more closely identified with.
- As social media breast cancer groups become more 'niche', women are increasingly able to find a supportive environment of likeminded women.
- Some women experience participation on Twitter and in Facebook groups as both positive and negative, sometimes simultaneously.
- When women move away from these discussions, because they feel their experiences are invalidated, the community they seek to be part of and contribute to is silencing them.

Subtheme Two: Working through the physical impact



This subtheme explores living with the physical impact of treatment and social media use to explore changes in appearance.

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'I think as well with my daughter sort of saying, 'you don't even look like my mum anymore', that's hard' (Michelle M).

- Use of visual social media can help women navigate their responses to their own changing bodies.
- This is set against women hiding from others how they feel about anticipated changes to the body.
- Navigating her own feelings about hair loss is complicated by navigating family member's sense of loss too.
- Being visibly different leads to people feeling 'they have to comment'. Women talked about stigma related to having no hair; not experiencing stigma related to having cancer.
- Some women struggle with the appropriateness of uploading photographs on to Facebook (own page and into closed groups) depicting the physical impact of treatment. Taking photographs is however found to be a positive navigational tool when adjusting to physical changes for some.
- Posting live updates was a popular method for gaining valued support when women shaved their heads after starting chemotherapy.
- WhatsApp enables 'intimacy' and live journaling with constant commentary from close friends. Through regular postings detailing every aspect of hair loss and regrowth for example, treatment and recovery becomes a 'live' online act recorded for prosperity.
- Women determine when, and if, to go public about hair loss. Women found this approach to be a positive one for forewarning others of a changed image that enabled others to adjust and support positively.
- Selfies posted across multiple platforms of women looking 'nice' and 'dire' were used to document the changes; reinforce individual's sense of self and communicate changes to others.

If anything occurs to you, make a note and send it back. Be great to hear your thoughts.

Subtheme Three: Negotiating the day to day



This sub-theme explores women's accounts of the day to day challenges of LwBBC - the ongoing effects and 'constant reminders'.

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'It can take me three quarters of an hour to an hour, but it was just absolutely manic when I was travelling there, and I was doing that for two weeks, every day there and back, there and back, there and back "... " you used to...when I had the first lot of radiotherapy eight years ago, you used to get a specific parking place, so that it was quick, because the treatment is quick, and now you don't. So I'm on bloody Level 12...I thought, 'Oh great!'" (Jo).

- Women at all stages of LwBBC describe having to work through aspects of their experience on a daily basis. They describe doing 'cancer everyday'.
- Many women describe ongoing physical, emotional, psychological and social challenges as 'constant reminders'.
- When in treatment, women encounter challenges in everyday environments through invasions of privacy from strangers. Replaying these encounters in closed groups reduces stress through shared understanding.
- For those further along the cancer continuum, daily challenges created by the side effects of treatment are supported through social media use.
- Women proactively use Twitter and Facebook to bring support to them by broadcasting hospital visits and treatments in situ. YouTube is used for practical guidance on how to alleviate challenging side effects.
- Some women use multiple social media platforms to draw on different types of support – informational, emotional and instrumental - when trying to alleviate the effects of lymphedema, for instance.
- While some women use social media to find solutions to alleviate the discomfort caused by side effects, others experience anxiety when treatment regimens (tamoxifen use) is rejected by women LwBBC. This creates dissonance and anxiety.
- Others experience validation by reading posts that express LwBBC as 'a bit shit' and reject the 'heroic survivor' identity.
- Some of the commentary points to wider society being immature in its understanding of the ongoing impact of LWBBC and the undermining nature of casual comment by the general public.
- Finally, emotional proximity between members of closed Facebook groups requires women to navigate their own mortality, loss and grief on a regular basis; collectively and separately; in public and in private.

If anything occurs to you, make a note and send it back. Be great to hear your thoughts.

Theme Three: (Re)gaining a sense of control

Women use social media to exert some sense of control over aspects of LwBBC. This was shown in two ways. Firstly, women use platforms to try to manage the extent of the emotional impact on themselves and their family. Secondly, platforms create opportunities for productivity. Through 'being productive' women re(gain) a sense of control over aspects of their lives.

Subtheme One: Being productive



'I'm going to go and see him about this new chemotherapy' "... which she'd Tweeted about ...so she asked him and he said: 'yes, go on that if you want.' So, that's quite amazing isn't it? That patients are actually being ... are driving this change with ... they're actually saying what they want' (Jo).

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- Women LwBBC find multiple ways to use their experience productively. Social media enable women to 'be productive' from their own keyboard.
- One-way women (re)gain control is through taking a significant role in creating contemporary social media based health resources. These are often borne out of the lack of service provision and is shown in the proliferation of 'niche' sites including Facebook groups and Twitter chats. This enables women to develop a supportive community for themselves and others benefitting from 'globalised local' knowledge and learning.
- Women experience positive benefits from sharing their personal experiences with women more recently diagnosed.
- Women describe being productive through sharing their experiences with others for research purposes too. Involvement provided a sense of purpose. It enables women to feel that their experience contributes to something larger than themselves.
- Being productive through providing support can lead to women becoming increasingly immersed in their new 'social' worlds, which can be draining. However, it may also be the case that women feel they must 'give back'. This may influence how women feel about how they live their lives after a breast cancer diagnosis
- Women found knowledge growth from social media use supportive in gaining positive outcomes clinically. Engaging with oncologists on social media platforms, through sharing new evidence, supported women in influencing their their own healthcare.
- Examples of successful advocacy were acknowledged by others LwBBC as something to 'learn from'.
- Some participants regularly share photographs and 'update' posts to encourage others LwBBC to engage in positive self-management behaviours. They use social media to inform, educate, and try to encourage others to maximise their chances of future treatments or surgical procedures through a focused approach to healthy, active living.
- Other women use social media to educate others about the realities of LwBBC. Women proactively challenge cancer narratives that circulate in the mainstream press and online. This countering of narratives or 'right to reply' provides emotional release and learning across wider communities. Women LwBBC use social media to take opportunities to reduce a sense of being disempowered by reframing the conversation.

If anything occurs to you, make a note and send it back. Be great to hear your thoughts.

Subtheme Two: Managing the emotional impact on self and others



This sub-theme explores how women use social media to manage the emotional impact on self and others

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'I think it's a lot more difficult for them [her family] because they hear 'cancer' and all that and..., whereas for me, I'm in control so I feel quite OK about it. If I don't, I don't. It's kind of scary thinking about the future probably really, although I have got an OK, a good outlook you know' (Sarah M).

- Women made use of messaging services when initially diagnosed to inform others. This was seen as protective to psychosocial health through removing uncertainty around sharing the 'diagnostic narrative' and afforded a sense of control through framing experience to influence the type of response required
- Women use social media to shield aspects of their experiences from others. In closed groups, women described social media use as enabling conversations, which they felt they could not have, or did not want to have, with close family and friends. In closed Facebook groups, women articulated the ability to be 'more honest', to be able to say things they would not 'dream of' to their family and friends and to find an expressive outlet 'to scream'.
- For women soon after diagnosis, social media use mediated conversations with others who 'know', and with whom they are not invested. This enables them to process worries, concerns and to gain information without putting additional 'burden' on loved ones.
- Women 'scale' their social media use depending on a range of factors related to intimacy, privacy and previous connectedness. For instance, WhatsApp supported ongoing intimate, personal sharing of aspects of LwBBC between an existing friendship group.
- Where women did not use WhatsApp and were not members of closed Facebook groups but were Facebook users, they posted to achieve responses that were (emotionally) manageable.
- Women use social media to compartmentalise aspects of their experience to help them 'not fall to pieces'.
- Social media use was also reported as threatening. Women articulate the challenges access to 24-hour information about breast cancer brings, and the need to find ways to control access to other women's experiences and continual contact with 'support' groups; or particular types of content. Women adopt different strategies to combat this sense of threat.
- Women described strategies to master controlling content so that it did not impinge negatively on their psychological health. This included prompt closing of content identified as having the wrong 'atmosphere' but also included flexible strategies of joining and leaving groups, and conversations, to reduce negative impact on their sense of well-being.
- Women demonstrate themselves as discriminating consumers of social media content, focused on building knowledge in line with their own capacities to process the information available. Any sense of information threat is met with a change of strategy including avoidance and adaptation.
- Benefit is most experienced when women control their access to Facebook community posts rather than the community being present in their lives by default, through push notifications.

If anything occurs to you, make a note and send it back. Be great to hear your thoughts.

What has happened with the results so far? And, what is next?

So far, information about the study has been presented at the British Psycho-social Oncology Conference (2017) and abstracts of poster presentations were published in the journal *Psycho-Oncology*. Further presentations will be made at conferences and aspects of the research will be published in academic journals.

As you can see from the number of bullet points, these findings provide considerable insightful information. I hope the findings will provide insight for healthcare professionals, and other relevant organisations into the embedded nature of social media use as a self-management tool for women LwBBC and the benefits (and challenges) it provides.

What do you think?

Most women participating in this study were active contemporary social media users. It would be useful to understand the extent to which these findings resonate with you. It would also be useful to understand how you think the research could be used to advance understanding of the role social media plays or has played in supporting you.

Get in touch:

Email me: c.m.ure@edu.salford.ac.uk

Write to me: Cathy Ure, L817, School of Health Sciences, Allerton Building, Frederick Road Campus, Salford. M6 6PU.

If you want me to give you a call, send me an email and I will get back in touch.

Appendix 27: Specific permission to publish photographs of children

Specific permission to publish photographs of children

Living with and beyond breast cancer: Exploring women's use of social media to support psychosocial health. Researcher: Cathy Ure

This form refers to photographs you provided as part of the photo-production study you kindly participated in. The photographs below have been included within my thesis. My thesis will be published online as part of the University of Salford e-theses collection (USIR). Also, as I seek to share the results of this study more widely, I may also want to include these photographs in reports, presentations, publications and exhibitions arising from the study. This form seeks specific consent from, or on behalf of the children, captured in the photographs. In line with the Children's Commissioner's report on children's digital rights (2017), I am mindful to ensure, where possible, children have the option to control what appears on the internet relating to themselves. Please could you and your children (where practical) sign one of the boxes below to indicate whether or not you are happy for the attached photographs to be used for these purposes.

Please sign either 1, 2 or 3 below:

1. I am happy for these photographs to be used in reports, presentations, publications, to go on websites (USIR), and in exhibitions.

Signed (Parent) Date.....

Signed (Child) Date.....

Signed (Child) Date.....

OR 2). I am happy for the photos to be used if the/my face is pixelated out.

Signed (Parent) Date

Signed (Child) Date

Signed (Child) Date

OR 3) I am not happy for any of these photographs to be used.

Signed (Parent) Date

Signed (Child) Date

Signed (Child) Date

If you have any queries about this form, please email me at c.m.ure1@salford.ac.uk