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**A qualitative investigation of the experiences of women with breast
cancer between surgery and adjuvant therapy**

And Clinical Research Portfolio

Volume 1

(Volume 2 bound separately)

Lauren McAllister, BA Honours

Submitted in partial fulfilment of the requirements for the degree of
Doctorate in Clinical Psychology

Institute of Health and Wellbeing
College of Medical, Veterinary and Life Sciences
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Chapter 1: Systematic Review

Women's experiences of making treatment decisions for early stage breast cancer: a qualitative systematic review

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Abstract

Purpose: Healthcare policy increasingly emphasises the importance of including patients in treatment decision-making. This review aimed to synthesise qualitative literature examining women's experiences of treatment decision-making for early-stage breast cancer.

Methods: Meta-ethnography was used to select and synthesise published qualitative research exploring women's experiences of treatment decision-making. The quality of the literature was also assessed.

Results: The search strategy yielded 18 studies. Seven were excluded on the basis of quality appraisal. The remaining 11 studies were synthesised. Five themes were identified: women's role in decision-making, emotional impact of breast cancer, patient-doctor relationship, managing information, and family and friends.

Conclusions: Women experience decision-making as a dynamic, complex process that continues throughout diagnosis and treatment. They may adopt different roles in decision-making at different points in their care. Treatment decisions are made in the context of women's emotional response to their breast cancer diagnosis. Interpersonal relationships with healthcare professionals and family and friends are important. Limitations and directions for future research are discussed.

Introduction

Breast cancer is the most common cancer among women in the United Kingdom (UK), accounting for 30% of new cases in women (Cancer Research UK, 2012). Women diagnosed with breast cancer face many treatment decisions over the course of their illness, including decisions about surgery, adjuvant treatments, and hormonal treatments. The National Institute of Clinical Excellence Guidelines for early and locally advanced breast cancer (NICE, 2009) state that patients should have the opportunity to make informed decisions about their treatment, in conjunction with healthcare professionals. In terms of surgical treatment, mastectomy and breast conserving surgery (BCS) are equally efficacious (Katz & Hawley, 2007). It might be expected that more women would choose BCS where this is an option for them, but rates of BCS and mastectomy remain variable within the UK (Sauven et al., 2003). Adjuvant treatments can have unpleasant side effects and may only have modest benefits for some women in terms of overall survival (Duric & Stockler, 2001). Women must weigh up the potential benefits and harms of such treatment. The role of the patient in decision-making is therefore of interest.

Current policy emphasises the importance of shared decision-making between patients and providers when deciding on treatments (The Scottish Government, 2010). Shared decision-making can be defined as “a process in which clinicians and patients work together to select tests, treatments, management or support packages, based on clinical evidence and the patient’s informed preferences. It involves the provision of evidence-based information about options, outcomes and uncertainties, together with decision support counselling” (Coulter & Collins, 2011, p.vii). This is particularly important where comparable treatments are available or where outcomes are uncertain or risky. In these cases, patient participation in decision-making allows decisions to be made that are consistent with their values and preferences (Broadstock & Michie, 2000). In addition, there is some evidence that participation in treatment decision-making may reduce psychological morbidity. For example, Hack, Degner, Watson and Sinha (2006) followed up 255 women with breast cancer for 3 years following surgical treatment. Those who indicated they were actively involved in treatment decision-making had significantly higher quality of life than those who felt they had a passive role. Similarly, a cross-sectional survey of 636 women found that perceived involvement in treatment decision-making for breast cancer was associated with better health-related quality of life at 2, 5 and

10 years post-diagnosis (Andersen, Bowen, Morea, Stein & Baker, 2009).

Research on decision-making in cancer care has sought to understand patient preferences for involvement in decision-making and factors that may influence this, such as patient and physician characteristics. Although shared decision-making is viewed as preferable, not all patients want to take an active role. A review of 31 papers examining preferences for involvement in decision-making in people with cancer found that preferences vary considerably (Hubbard, Kidd & Donaghy, 2008). While most people preferred a collaborative role in decision-making, a significant minority wanted a more passive or more active role. There is also evidence to suggest that preferences for involvement are not always met. Tariman and colleagues (2010) systematically reviewed 22 studies examining preferred and actual decision-making roles in people with cancer. Across all cancer types, patients preferred a greater degree of involvement in decision-making than they experienced. There was also evidence that role preferences changed over time. These reviews demonstrate the difficulty in predicting patient preferences for involvement in treatment decision-making.

A range of factors may impact preferences for involvement in treatment decision-making, including type and stage of cancer, age, and education level. A literature review suggested that perceived risks and benefits of surgery, impact on body image and sexuality, and patient perception of surgeons' choices may impact on women's surgical decision-making for early-stage breast cancer (Sivell, Edwards, Elwyn & Manstead, 2010). Jansen, Otten and Stiggelbout (2004) reviewed potential determinants of women's preferences for adjuvant therapy. Although some patient and clinical characteristics predicted preferences, such as personal experience of treatment and having young children, preferences could not be fully explained by these factors. The authors suggest cognitive and emotional factors, such as fear of recurrence, may be more salient. In addition, they posit that some patient and clinical characteristics could have an impact through cognitive and emotional pathways – for example, patient perception of tumour size and its meaning to them, rather than the actual tumour size.

Hubbard et al. (2008) note that findings regarding potential determinants of preference for involvement in decision-making are contradictory. For example, some studies found no association between age and decision-making style, whereas others found younger age was

associated with more collaborative and active styles. This may be due, in part, to the methods used to assess preferences. Studies tend to use decisional preference scales (e.g. Degner et al., 1997). A qualitative study investigating the process of answering structured questions about decision-making from patients' point of view (Entwistle et al., 2004) found that these are not always an effective measure of decision-making, as they do not reflect context and explanations for particular responses are not always consistent with the interpretation of the responses themselves.

Real life medical decision-making is considerably more complex and may be influenced by a number of factors, including relationships with professionals, previous treatment experiences, patient concerns and social circumstances, as well as the interaction of these factors (Broadstock & Michie, 2000). Context and emotional and cognitive factors may also play a role (Katz & Hawley, 2007). Based on studies that found that achieving preferred involvement in treatment decision-making is associated with satisfaction regardless of surgical treatment received (e.g. Sabo, St-Jacques & Rayson, 2007), Katz and Hawley (2007) argue that the process of treatment decision-making is as important as the decision itself. It is therefore important to understand how women with breast cancer experience and make sense of the decision-making process. Qualitative research is well-suited to developing a deeper understanding of their experiences.

Qualitative research aims to explore in depth peoples' experiences and understandings (Ring, Ritchie, Mandava & Jepson, 2011). Such approaches may explain conflicting findings from quantitative research and explain the interactions identified in these studies (Atkins et al., 2008). Ring et al. (2011) argue that synthesising qualitative studies can make it easier to generalise findings. This is particularly important in light of the increasing importance of considering the needs and preferences of service users in healthcare. This review will therefore examine studies that have taken a qualitative approach to understanding women's experiences and perceptions of treatment decision-making for breast cancer. It will focus on the experiences of women with early stage breast cancer, as this the most commonly diagnosed stage (Cancer Research UK, 2012). Studies that address the overall experience of treatment decision-making or focus on a specific area (e.g. surgical decision-making) will be included. This will help to build up a comprehensive picture of women's treatment decision-making, given that this is a complex process and there may be influences on decision-making across the whole illness

experience.

Aim

The aim of the present review is to explore women's perceptions and experiences of treatment decision-making for early stage breast cancer by synthesising published qualitative research in this area. A further aim is to examine the quality of studies.

Review Question

What is the experience of treatment decision-making for women diagnosed with early stage breast cancer?

Methods

Search strategy

The Ovid interface was used to search the MEDLINE and Embase databases. The EBSCOHost interface was used to search the PsychINFO and CINAHL databases. The Web of Science database was also searched. Searches were conducted in February 2015.

A combination of subject headings and free-text terms was used to search each database. Search terms were clarified by a librarian. The following terms were used:

1. breast neoplasms OR carcinoma, ductal, breast OR (breast adj2 (cancer* OR neoplasm* OR malign* OR tumo?r*))

AND

2. decision-making OR patient participation OR medical decision-making OR patient decision-making OR ((shared OR treatment OR patient) adj2 decision*))

AND

3. qualitative research OR hermeneutics OR qualitative OR ethnograph* OR interview* OR narrative* OR experienc* OR perception* OR perceiv*

The inclusion and exclusion criteria were used to sort the search results. Reference lists of full-text articles retrieved for potential inclusion were hand searched for further references. The journal *Psycho-Oncology* yielded the highest number of relevant articles and was therefore hand-searched for relevant papers published in the last five years.

Inclusion and exclusion criteria

Inclusion criteria:

- Studies exploring women's experience of treatment decision-making for early stage breast cancer
- Studies using qualitative methodology
- Participants aged 16 or over
- Studies published in peer-reviewed journals

Exclusion criteria:

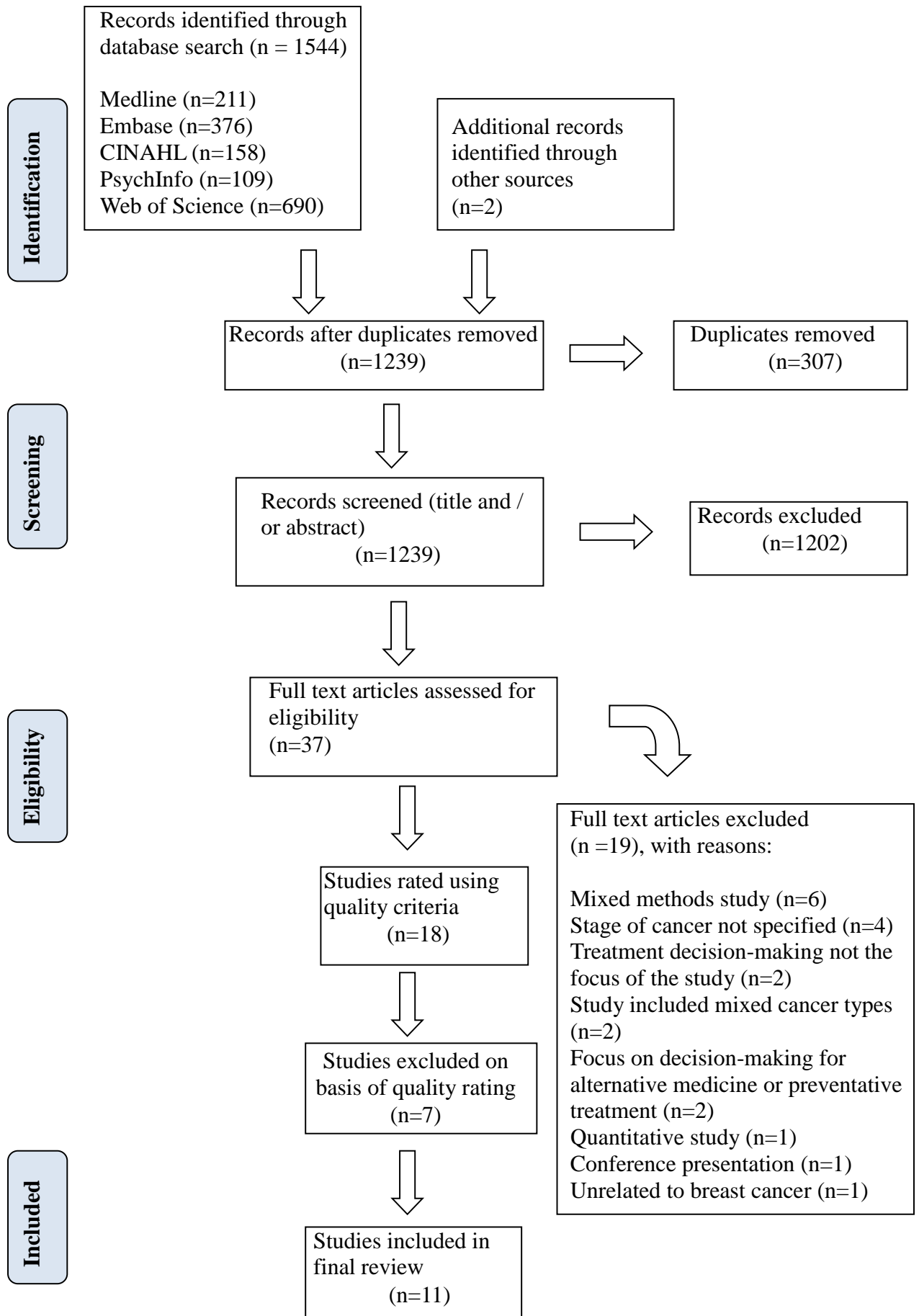
- Case studies
- Studies that only include women with recurrent or metastatic breast cancer
- Studies that do not focus on primary treatment for early-stage breast cancer – for example, studies that focus on decision-making for preventative treatment
- Mixed method studies
- Studies examining decision-making for complementary and alternative treatments
- Studies using quantitative methodology
- Studies not published in English

Although some papers included women with recurrent or metastatic breast cancer in their samples, the decision was made to include these where more than half the sample was women with early stage breast cancer.

Results of search strategy

The results of the search are shown in Figure 1.

Figure 1: Flowchart detailing search strategy



Quality appraisal

There is debate about application of quality criteria to qualitative research. Some have argued that it should not be subject to quality appraisal, whereas others contend that tools specific to qualitative research can be usefully applied (Dixon-Woods, Shaw, Agarwal & Smith, 2004). It has been suggested that the inclusion of poor quality studies may lead to poor quality meta-syntheses (Walsh & Downe, 2006). In addition, the inclusion of good-quality research allows policy-makers and practitioners to have confidence in the results of a review (Attree & Milton, 2006). Therefore, it was decided to appraise the quality of studies eligible for inclusion in the present review and to exclude those judged to be of poor quality.

Walsh and Downe's (2006) criteria for appraising qualitative research was selected to evaluate the studies. The authors drew on existing quality appraisal check-lists and frameworks to develop twelve essential criteria covering various aspects of qualitative research: clear statement of, and rationale for, research question / aim / purposes; study thoroughly contextualised by existing literature; method / design apparent, and consistent with research intent; data collection strategy apparent and appropriate; sample and sampling method appropriate; analytic approach appropriate; context described and taken account of in interpretation; clear audit trail given; data used to support interpretation; researcher reflexivity demonstrated; demonstration of sensitivity to ethical concerns; and relevance and transferability evident. Full details of the framework, including specific prompts for each essential criterion, can be found in Appendix 2.

To allow for evaluation and comparison of quality, studies were allocated 2 points if the criterion was fully met, 1 point if there was partial evidence and 0 points if there was no evidence that the criterion was met. This gave a possible total score of 24. Studies were rated as "good" if they received a score of 18 or more (75%), "adequate" if they scored 12 or more (50%), or "poor" if they scored 11 or less (less than 50%). An independent researcher rated the quality of the papers. Agreement was 79% and disagreements were resolved through discussion.

Method of synthesis

Meta-ethnography (Noblit & Hare, 1988) was used to combine the results of the studies. This involves translating the concepts of the studies into each other, in order to develop new interpretations. Meta-ethnography has a number of advantages. Although there are various methods of combining qualitative data, Britten and colleagues (2002) argue that meta-ethnography is the most well developed method of synthesis. It has been described in further detail by authors including Campbell et al. (2003) and Atkins et al. (2008). Meta-ethnography preserves the interpretive properties of the primary data. It is a method that involves induction and interpretation, and therefore resembles the methods of the studies it aims to synthesise. In this way, it can produce significant new insights on a given topic. Meta-ethnography can allow for synthesis of studies with similar themes (a reciprocal translation) and those with contradictory themes (a refutational translation), although refutational syntheses are less well-described in the literature (France et al., 2014). In addition, it has been employed for syntheses in health care (e.g. Atkins et al., 2008). There is some debate about the suitability of meta-ethnography for synthesising studies from a wider range of qualitative methodologies (Dixon-Woods, Agarwal, Young, Jones & Sutton, 2004). It was originally intended as a method for synthesising ethnographic research, and Jensen and Allen (1996) argue that it should only be used to synthesise studies within a single paradigm. More recent research, however, has demonstrated that it is possible to employ meta-ethnography to synthesise studies from varying qualitative traditions (e.g. Campbell et al., 2003). It was therefore decided that meta-ethnography was appropriate for the purpose of the present review.

Meta-ethnography involves seven steps; these are described in Table 1 (based on Noblit & Hare, 1988 and Atkins et al., 2008). Papers were synthesised in chronological order, to ascertain the impact, if any, of any changes in breast cancer treatments or decision-making practices over time.

Table 1: Process of meta-ethnography

| Step | Description |
|------|---|
| 1 | Getting started – defining a research question |
| 2 | Deciding what is relevant to initial interest - searching for studies and defining inclusion criteria; appraising quality of studies |
| 3 | Reading the studies – becoming familiar with the studies and extracting themes and concepts |
| 4 | Determining how the studies are related – considering the relationships between concepts and themes from each paper |
| 5 | Translating the studies into one another – compare themes and concepts of paper one with those of paper two and the synthesis of these papers with paper three and so on. |
| 6 | Synthesising the translations |
| 7 | Expressing the synthesis |

Results

The results of the quality appraisal are shown in Table 2. Seven studies judged to be of poor quality were excluded from the synthesis.

Table 2: Results of quality appraisal

| Study | Score (out of 24) | Percentage | Category |
|---|--------------------------|-------------------|-----------------|
| Caldon et al. (2011) | 20 | 83 | Good |
| Charles, Redko, Whelan, Gafni and Reyno (1998) | 16 | 67 | Adequate |
| Covelli, Baxter, Fitch, McCreedy and Wright (2015) | 19 | 79 | Good |
| Fang, Shu and Fetzer (2011) | 8 | 33 | Poor |
| Freedman (2003) | 6 | 25 | Poor |
| Halkett, Arbon, Scutter and Borg (2007) | 21 | 88 | Good |
| Husain, Collins, Reed and Wyld (2008) | 16 | 67 | Adequate |
| Kenny, Quine, Shiell and Cameron (1999) | 10 | 42 | Poor |
| Kreling, Figueiredo, Sheppard, and Mandelblatt (2006) | 10 | 42 | Poor |
| Lally (2009) | 16 | 67 | Adequate |
| Lam, Fielding, Chan, Chow and Or (2005) | 21 | 88 | Good |
| McVea, Minier and Palensky (2001) | 11 | 46 | Poor |
| O'Brien et al. (2008) | 20 | 83 | Good |
| O'Brien et al. (2013) | 18 | 75 | Good |
| Pierce (1993) | 8 | 33 | Poor |
| Pieters, Heileman, Maliski, Dornig and Menten (2012) | 19 | 79 | Good |
| Sheppard, Adams, Lamdan and Taylor (2011) | 11 | 46 | Poor |
| Weber, Solomon and Meyer (2013) | 17 | 71 | Adequate |

The majority of studies partially or fully provided a rationale for the research. One study failed to do this (Freedman et al., 2003). Existing literature was used to contextualise the research by most studies. Five papers (Fang et al., 2011; Freedman et al., 2003; Kreling et al., 2006; McVea et al., 2001; Pierce, 1993) did not do this – for example, they failed to link findings to previous research. Reporting of method and design was variable. Seven

papers did not adequately describe study design (Fang et al., 2011; Freedman et al., 2003; Kenny et al., 1999; Kreling et al., 2006; O'Brien et al., 2008; Sheppard et al., 2011). Some papers gave a rationale for using qualitative methods but failed to state their epistemological or ontological grounding. Data collection strategy was at least partially appropriate for most studies. Only Fang et al. (2011) did not specify data collection strategy. Three studies did not describe their analytic approach (Charles et al., 1998; Kenny et al., 1999; Kreling et al., 2006). For the remaining studies, the analytic approach was partially or fully appropriate. The appropriateness of analysis was difficult to judge where studies had not stated a qualitative method – for example, Weber et al. (2013) used the constant comparative method to analyse data but did not explicitly state that they were using Grounded Theory.

Context was partially or wholly accounted for in all but two studies (Fang et al., 2011; Sheppard et al., 2011). Studies omitted details such as who conducted interviews and where. Four studies showed no evidence of a clear audit trail (Fang et al., 2011; Freedman et al., 2003; Pierce, 1993; Sheppard et al., 2011). In seven studies, data was not used to support interpretation (Fang et al., 2011; Husain et al., 2008; Kenny et al., 1999; Kreling et al., 2006; McVea et al., 2001; Pierce, 1993; Sheppard et al., 2011) – for example, failing to provide quotes to illustrate themes. Only two studies provided any evidence of researcher reflexivity. Halkett et al. (2007) and O'Brien et al. (2008) referred to the use of reflective diaries by researchers, but did not explore the impact on the research. The majority of studies reported sensitivity to ethical concerns, although it is striking that five studies did not state that they had received ethical approval (Freedman et al., 2003; Kenny et al., 1999; Lally, 2009; McVea et al., 2001; Pierce, 1993). Lally (2009) carried out a secondary analysis of previously collected data, but did not state if ethical approval and participant consent had been sought for this. Nearly all studies provided partial or full evidence of relevance and transferability. Only two did not do this (McVea et al., 2001; Pierce, 1993). Studies tended to omit discussion of limitations and exploration of relevance to theory and practice.

Table 3 describes the 11 studies selected for inclusion in the synthesis. It should be noted that the studies by O'Brien et al. (2008) and O'Brien et al. (2013) relate to different cohorts.

Table 3: Characteristics of included studies

| Study | Country | Method | Participant Characteristics | Themes |
|-----------------------|---------|------------------------|---|--|
| Caldon et al. (2011) | UK | Framework approach | <p>Number 65</p> <p>Age range 33-73 years</p> <p>Cancer stage Early stage breast cancer (stages not specified)</p> <p>Point in treatment Following surgery – average time since surgery was 6 weeks</p> | <p>Most reassuring treatment option</p> <ul style="list-style-type: none"> • Safety and fears • Anecdotal information <p>Least disruptive option</p> <ul style="list-style-type: none"> • Minimise impact on life • Minimise psychosocial impact of surgery <p>Information content and style</p> <ul style="list-style-type: none"> • Contextual information • Framing of information • Accessibility of information <p>Time and process of decision-making</p> <p>Autonomy</p> |
| Charles et al. (1998) | Canada | “Qualitative approach” | <p>Number 20</p> <p>Age range 42-78 years</p> <p>Cancer stage Stage I and stage II (numbers in each group not specified)</p> <p>Point in treatment All women had already had surgery. Some were having consultations about adjuvant treatment and some had already begun treatment.</p> | <p>Perception of choices for adjuvant treatment</p> <ul style="list-style-type: none"> • The extent to which women perceive meaningful choices <p>Weighing up benefits and risks</p> <ul style="list-style-type: none"> • Developing lay constructions <p>Patient’s role in decision-making</p> <ul style="list-style-type: none"> • Taking action |

| Study | Country | Method | Participant Characteristics | Themes |
|-----------------------|-----------|--------------------------------|---|--|
| Covelli et al. (2015) | Canada | Grounded theory | Number 29 Age Range 36-84 years Cancer stage Stage I (n=15) Stage II (n=14) Point in treatment Completed – women had undergone mastectomy in the previous 9-12 months. | Decision-making experience <ul style="list-style-type: none"> Shock and fear at diagnosis Discussion of treatment options Sources of information Understanding of recurrence and survival rates Reasons for mastectomy <ul style="list-style-type: none"> Elimination of risk Post-operative outcomes <ul style="list-style-type: none"> On-going physical and psychological concerns Taking control of cancer |
| Halkett et al. (2007) | Australia | Hermeneutic phenomenology | Number 18 Age range 39-77 years Cancer stage Stage I and stage II (numbers in each group not specified) Point in treatment Surgical and adjuvant treatments completed within previous year | Decision-making characterised by five existential themes <ul style="list-style-type: none"> Being challenged Getting ready Surviving Sharing the challenge Interrogating the future |
| Husain et al. (2008) | UK | “Qualitative research methods” | Number 21 Age range 76-91 years Cancer stage Stage I and stage II (numbers in each group not specified) Point in treatment Follow-up; time | Attitudes toward cancer diagnosis Attitudes towards seeking treatment information Attitude towards surgery Attitude towards primary endocrine therapy Role of age Post-treatment experiences |

| Study | Country | Method | Participant Characteristics | Themes |
|-------------------|-----------|-----------------|---|---|
| | | | from diagnosis ranged from 6 months to 15 years | |
| Lally (2009) | USA | Grounded theory | Number 18 Age range 37-87 years Cancer stage Stage 0 (n=3) Stage 1 (n=11) Stage 2 (n=4) Point in treatment Before surgery; average of 12 days since diagnosis | Treatment decision-making characterised by <ul style="list-style-type: none"> • Information processing • Contemplating options • Interacting with others |
| Lam et al. (2005) | Hong Kong | Grounded theory | Number 22 Age range 23-88 years Cancer stage Stage 0 (n=5) Stage 1 (n=4) Stage 2 (n=8) Stage 3 (n=5) Point in treatment Post-surgical treatment; women were interviewed within 3 days of having surgery | Four stages of decision-making: Causal conditions <ul style="list-style-type: none"> • Discovery of cancer • Emotional response to diagnosis Gamble of treatment choices <ul style="list-style-type: none"> • Uncertainty • Prioritising personal aims • Seeking and evaluating information • Time pressure Anticipated consequences of choices <ul style="list-style-type: none"> • Fear of death • Paying the price of treatment • Living in uncertainty Coping |

| Study | Country | Method | Participant Characteristics | Themes |
|-----------------------|---------|-----------------------------------|--|--|
| | | | | <ul style="list-style-type: none"> • Keeping busy • Being optimistic • Believing in fate • Social comparison |
| O'Brien et al. (2008) | USA | "Qualitative analytic techniques" | Number 21 Age range 34-79 years Cancer stage Early stage breast cancer (stages not specified) Point in treatment Two groups of women – those having a surgical consultation (n=6) and those having an adjuvant consultation (n=15) Time since treatment N/A | <p>Four themes related to women's perception of the treatment decision-making process:</p> <ul style="list-style-type: none"> • Information seeking about treatment options and resources prior to consultation • Most women identified a preferred and non-preferred treatment option prior to consultation • Information from the surgeon and family doctor was important to women's subsequent decision-making about adjuvant treatment • Women considered different adjuvant treatment options using numerical information about recurrence <p>Two themes related to women's observations about their experiences:</p> <ul style="list-style-type: none"> • Women valued physicians' treatment recommendations • Some women did not expect to be offered a role in decision-making |
| O'Brien et al. (2013) | USA | Descriptive qualitative methods | Number 19 Age range 40-74 years Cancer stage Early stage breast cancer (stages not specified) Point in treatment Women were considering surgical treatment options (n=6) or adjuvant treatment | <p>Women described involvement in various stages of decision-making but not everyone described being involved in every stage. The stages were:</p> <ul style="list-style-type: none"> • Information gathering • Deliberating about options • Making the final treatment decision |

| Study | Country | Method | Participant Characteristics | Themes |
|-----------------------|---------|--------------------------------|---|--|
| | | | options (n=13) | |
| Pieters et al. (2012) | USA | Constructivist grounded theory | Number 18 Age range 70-94 years Cancer stage Early stage breast cancer Point in treatment Treatment completed within the previous 3 to 15 months | Instrumental relating (relating spontaneously) was used by women as a way to connect with others and to get the information they needed to make decisions. <ul style="list-style-type: none"> • Mutual caring for self and others • Ways of relating <ul style="list-style-type: none"> • Obtaining information • Interpreting healthcare providers • Deciding on trustworthiness of providers • Decision-making <ul style="list-style-type: none"> • Making the best decision • Making their own decision |
| Weber et al. (2013) | USA | Constant comparative method | Number 44 Age range 33-69 years Cancer stage Stage 0 (n=13) Stage 1 (n=9) Stage 2 (n=12) Stage 3 (n=5) Unsure (n=5) Point in treatment Time since diagnosis ranged from a few months to 24 years | Five decision-making styles were identified: <ul style="list-style-type: none"> • Medical expert • Self-efficacy • Relationship-embedded • Inhibition • Constellation of information These were underpinned by a continuum of <ul style="list-style-type: none"> • Low to high information needs; and • Self focus versus other focus |

Meta-ethnography can lead to reciprocal translations or refutational translations. The themes from papers in this review appeared to be similar and therefore gave rise to a reciprocal translation. Five superordinate themes were identified: women's role in decision-making, emotional impact of breast cancer, patient-doctor relationship, managing information, and family and friends; these are explored below, with relevant quotes to illustrate. A summary of the main themes and how they are represented in each study can be found in Appendix 3.

Women's role in decision-making

Across all studies, women adopted a range of treatment decision-making roles for themselves. Some appeared to choose a passive role, preferring their doctor to make decisions for them as they perceived the doctor as the expert (see “patient-physician relationship”). One woman stated:

“No (I didn't ask questions), I just took it that they know what they're doing and that's it” (Husain et al., 2008, pg. 413)

On the other hand, many women perceived that they had made the final treatment decision themselves, although their doctors had influenced the process of decision-making through the provision of information and opinion. One woman described this as such:

“And that was important for me too, to be informed. Not just from one telling me this is what you should do. Or this is what you shouldn't do. But for me to know that having the medical team look at my charts and my files and present this ... that was their recommendation. Now the choice was mine to make.” (Charles et al., 1998, pg. 83)

A process of sharing decision-making was evident in the narratives of many women. This was not always done with their doctors, but could encompass family or friends. One woman described a decision making process that included her doctor and her husband:

“Dr. [medical oncologist] presented us with the two treatment options ... So we left that day and even driving home I was thinking, well, I should probably go with the

Canadian one just because, I feel comfortable with that [...] So I had to think about that for a bit, but, we had a week to decide on that So we decided on that, on the Canadian regimen, last Friday.” (O'Brien et al., 2013, pg. 1721)

For those that felt they had made the decision about treatment, either alone or in conjunction with others, this was associated with a feeling of taking control of their disease and their lives. Pieters et al. (2012) reported that participants in their study made their own decisions, which were best for their individual circumstances; this allowed women to feel in control of their lives. In another study, one woman commented:

“I didn't want somebody to just tell me 'You're going to have it.' I want to be in control, you know? I have to be in control of what happens to me.” (Covelli et al., 2015, pg. 387)

Although none of the studies in this review examined decision-making longitudinally, women described changes in their thoughts about treatment decisions over time. In three studies (Lally, 2009; O'Brien et al., 2008; O'Brien et al., 2013) women stated that they had preferences for particular treatments prior to consultations. They tended not to share these, however, preferring to gather further information from their doctor and consider this before making a decision. Halkett et al. (2007) reported that women in their study perceived treatment choices were made by their doctor, and thus were out of their control. After decisions had been made, however, women began to recover a feeling of control by seeking further information about their treatment and the disease in order to fight it. In addition, women were sometimes unprepared for involvement in decision-making and required time to adjust to this. One woman described changes in her feelings about decision-making and the sense of control she experienced:

“I've changed my mind as things have progressed ... initially I was angry ... I thought they should make the choice, they're the experts. But now I'm glad that I had the choice because I've made the choice and I've got to live with it. And I'm quite sure that I made the right choice.” (Caldon et al., 2011, pg. 1555)

This suggests that women's role in treatment decision-making is evolving and dynamic and dependent on a range of factors at different points in their cancer journey. These factors

are explored in the themes below.

Emotional impact of breast cancer

Ten studies identified the emotional impact of breast cancer diagnosis as a key factor in decision-making. Several studies described the shock of diagnosis and the feelings of fear and anxiety this engendered. One woman stated:

“I was completely surprised and unprepared for the level of terror and horror that I felt; or how dreadful it is to be affected by it” (Halkett et al., 2007, pg. 325)

For many women survival became a priority, and they wanted the treatment that they perceived would give them the best chance of surviving. Women's treatment choices were, at least in part, driven by fear and worry. Choosing the treatment that they felt would give the best chance of survival helped women to manage these emotions by providing a sense of reassurance. One woman commented:

“By having chemo and radiation I have done everything that I can do now [...] you’ve done all the treatments, then you’ve taken every step you can ... to protect your future” (Charles et al., 1998, pg. 78)

This is perhaps particularly clear where women who had the option of mastectomy or BCS chose mastectomy, despite equal survival rates. For example, one woman said:

“I preferred a lumpectomy because of the changes in the shape of my body but I was afraid of recurrence. I decided to have a mastectomy because the most important factor for decision-making about mastectomy, was that of recurrence” (Covelli et al., 2014, pg. 387)

Worries about survival were also bound up in fear of cancer recurrence. Against such emotional turmoil the choice of treatment became highly significant and many women continued to experience uncertainty about their future. In some cases, this led to rumination about the treatment chosen and whether the right choice had been made.

“So, there's been the thought in my mind, did I make the right decision [lumpectomy] and I think I did. But, I also have a tendency to try to go back and agonise over decisions. But, I do keep coming back to the same spot, [which is] that I think I made the right decision.” (Lally, 2009, pg. E261)

Other emotionally salient concerns were reported to impact upon treatment choice in some studies, including body image disturbance and side effects of further treatments. Caldon et al. (2011) reported that some participants wavered between concern about body image and anxiety about surviving. Some women described anxiety about adjuvant treatments, which impacted their decisions for surgery.

“Avoiding the radiation was important but here was also possibility of chemo. Well, I chose the mastectomy so I didn't have to do radiation.” (Covelli et al., 2015, pg. 386)

Patient-doctor relationship

The majority of studies explored the impact of the doctor on women's decision-making. When women discussed doctors, they almost exclusively referred to surgeons and oncologists. Within and between studies there was variation in how women described their relationship with their doctors and the role they perceived them as having in decision-making. Many women viewed their doctor as the expert on breast cancer, and therefore gave more weight to the information and advice they provided. For example, one woman commented:

“Well they are professionals. They know more about it than I do. I really don't know a damn thing about cancer” (Charles et al., 1998, pg. 83)

Despite the perception of the doctor as an expert, the roles women wanted for doctors in decision-making were varied. Some women thought that their doctor should be responsible for treatment decisions:

"I just left it in their hands, whatever they did was right, is how I felt." (Husain et al., 2007, pg. 413)

On the other hand, some women positioned the doctor as someone who could give them expert advice that would then enable them to make a decision about treatment themselves. One woman commented:

"I wouldn't like the decision to come from a physician. I think the physician can advise you ... but it is up to you to take his advice ... or to say no." (Charles et al., 1998, pg. 83)

The expertise of the doctor was also related to their perceived trustworthiness, a factor which was important to many women.

"I think the doctor was, the doctor and the person that actually read my MRI ... for some reason the trust was there ... I trusted him because I also heard very good things about him ... I trusted he was doing what he needed to do." (Weber et al., 2013, pg. 415)

Other significant qualities mentioned by women included warmth and empathy. A sense of being cared for was important, and seemed to reassure women that their doctor would give them the best treatment possible. The personal qualities of their doctor and the quality of the relationship they had with them were important. For example:

"When someone asks you 'How are you?' you can see in their face that they really care; there's something about the eyes. There's something like compassion, kindness, and when they explain things to you, they're gentle" (Pieters et al., 2012, pg. E15)

Four studies noted that even where the doctor did not explicitly state an opinion on the best treatment option, some women attempted to identify this based on signs such as the order of presentation of treatment options (Husain et al., 2008; Lally, 2009; Lam et al., 2005; O'Brien et al., 2008). Searching for an indication of their doctor's opinion may function as a way to manage the uncertainty of making their own treatment choice, by reassuring

women that the best choice had been made. One woman described being reassured by the surgeon's framing of treatment choices:

"He told me that [mastectomy] is the standard treatment. But it is also possible for me to preserve my breast if I want to. I thought if [mastectomy] is the standard treatment, I should go for the standard one." (Lam et al., 2005, pg. 8)

Managing information

Women in all studies gathered or received information from a range of sources, including medical professionals, friends, family, books, leaflets, and the internet. Information was used throughout cancer journey. The way in which women sought and used information varied within and between studies. This suggested that women engaged in a process of managing information, by deciding how and when to seek and use it. This depended to an extent on the personal meaning they attached to the information and the emotional salience of that information to the individual.

Women received information about the various treatments available to them, including survival and recurrence rates, and risks and benefits of treatment. They transformed the information they received to make it personally meaningful to them. Women often developed highly idiosyncratic understandings of this information. For example:

"Beth: According to the surveys ... the odds are better. It [chemotherapy] reduces the chances of recurrence."

Interviewer: Do you know ...

Beth: From 70 per cent to 30 per cent ... so that is a substantial difference. So because of that you have to look at ... ok ... do I live 10 years or do I live 30 years, so take your choice! Do you want to live or do you not want to live? Some women might choose 10 [years] if they don't like their husband, they don't like their kids."
(Charles et al., 1998, pg. 81)

In the same study, a woman presented with identical figures did not view them as significant to her, stating *“I know intellectually in my head the numbers don't mean a thing”* (Charles et al., 1998, pg. 81). Women's subjective conceptualisation of risk was therefore more important than the facts.

Information could also be used as a way to cope – for example, by preparing to make decisions or preparing for treatment.

“I think it's involved enough to know the information ... give me the summary version so that way I can make a decision. So I think, myself, I'm the type of person who likes information.” (O'Brien et al., 2013, pg. 1719)

The emotional impact of information was closely tied to how women chose to use that information in their decision-making. While some experienced information as reassuring, others found it fear-inducing. Fear appeared to make information more salient. This seemed to be particularly true of information pertaining to others' personal experiences of cancer and its treatment. Hearing about others' negative experiences made certain treatment choices more likely.

“My aunt, she had a lumpectomy originally and the cancer came back. That's when she decided to have the mastectomy. So, she was like, 'Just do it.'” (Covelli et al., 2015)

In order to manage the emotional impact of information, some women chose to avoid seeking it or using it. One woman described feeling overwhelmed by information, and managing her emotions through avoidance:

“If I don't like what I'm reading, I don't read it. If I don't want to know the side effects of a drug, I don't read it ... If I have to take it, I have to take it. I'll deal with it as I'm taking it.” (Lally, 2009, pg. E259)

Family and friends

The role of family and friends in women's decision-making was discussed in nine studies. Family and friends appeared to influence decision-making in direct and indirect ways. In some cases, family members, particularly partners, had a direct role in decision-making – for example, they were present in the consultation or gave an opinion on what the woman should do. One woman stated:

“I mainly discussed with my family. I asked my sisters ... as both are nurses. I had great confidence in (them). I was so confused.” (Lam et al., 2005, pg. 10)

They could also provide support and reassurance for women's decisions, even if they were not directly involved in making those decisions. Halkett et al. (2007) noted that, for their participants, the support of others strengthened their sense of having made the best decision.

Directly involving others in consultations and decision-making was problematic for some women, because others were unable to provide the required support or wanted support for themselves. These women described having to manage the involvement of others. They attempted to balance their need for support with others' needs. One woman took her daughter to an oncology appointment to help her understand her decision not to have chemotherapy:

“My daughter is [was] there and I says, 'I want you to hear that it's my choice.' I said that so she can prepare herself for the fact that I am getting older.” (Pieters et al., 2012, pg. E13)

Family and friends could also have an indirect impact on women's decisions – for example, where women considered the consequences of their treatment choices for their relationships with others. This is illustrated by one woman for whom family was the driving force behind her decisions:

“Probably the biggest influence would be to be there for my kids. That was the first thing that ran into my mind ... I had to do this so I could be with them long term.”

(Weber et al., 2013, pg. 416)

Pieters et al. (2012) also reported that women in their study made decisions that took into account their wider responsibilities, such as caring for others. Treatments that minimised the impact on their lives were favoured.

Discussion

Meta-ethnography revealed a range of themes across women's descriptions of making treatment decisions for early-stage breast cancer. The results did not suggest a linear process of decision-making, but rather a range of factors that appear to operate dynamically throughout diagnosis and treatment. Decisions took place in the context of women's emotional response to breast cancer, and their relationships with their doctors and significant others.

The results of this synthesis are consonant with the conceptual model of women's decision-making for early-stage stage breast cancer proposed by Halkett, Arbon, Scutter and Borg (2005). They suggest decision-making is determined by the emotional impact of diagnosis, previous knowledge of cancer, urgency, supportive others, information provided, body image and demographics. They also include the role of the relationship between women and their doctors. The synthesis adds support to this model, and extends the understanding of the important elements in women's decision-making.

This meta-ethnography suggests that women adopt a variety of treatment decision-making roles, including passive, active and shared roles. There was some evidence that these roles are dynamic and change over time, in response to different demands and concerns. At times women made an active choice to assume a passive role or to avoid particular information, in order to cope emotionally. Different models of decision-making have been proposed, such as informed decision-making, where patients use information provided by healthcare professionals to make their own decision, and paternalistic decision-making, whereby the doctor makes the decision (Charles, Gafni & Whelan, 1999). Charles et al. (1999) propose a dynamic model of decision-making, in which decision-making styles can change within and between consultations. Rather than label one way of making decisions

as “good” or bad”, they suggest the value of the approach should depend on patient and contextual factors. This synthesis lends support to this conceptualisation of decision-making as a complex, fluid process.

The emotional impact of cancer was an important theme in women’s decision-making. The need to survive and fear of recurrence were particularly salient factors. This is consistent with a systematic review which found that fear of recurrence was women’s predominant concern (Fiszer, Dolbeault, Sultan & Bredart, 2014). Zikmund-Fisher, Fagerlin and Ubel (2010) posit that emotions may be more influential than facts in decision-making. This was also evident in the theme “managing information”, which suggested that women’s emotional response to cancer influenced their interpretation of information. Some women may choose mastectomy instead of BCS, where this is an option, as they perceive mastectomy as a way to “get rid” of the cancer, and thus experience this as a more reassuring option.

In addition, this meta-ethnography suggested that women engage in a process of managing information. They appeared to use information to help them balance fear with hope. Women make sense of information in the context of their own lives, and decide what to do with that information. A meta-ethnography of information-seeking during the cancer journey (Germení & Schulz, 2014) supports this interpretation. Information-seeking behaviours changed over time, and participants could both seek and avoid information. This suggests that patients do not have static information needs, but rather engage in a dynamic process of managing information in response to their emotional and practical needs.

Women’s decision-making took place in the context of relationships with others, particularly their doctors, family and friends. Research consistently demonstrates that the relationship between patients and healthcare professionals is vital (Arora, 2003). The results of this synthesis suggest that the role of the doctor goes beyond that of information-giver. The interpersonal relationship with the doctor is essential. The perceived trustworthiness of doctors and their personal qualities made women feel cared for. Given the emotional impact of breast cancer, feeling cared for may allow women to feel safe and reassured they are getting the best treatment possible. Studies focusing specifically on doctor-patient communication lend support to this theme. Wright, Holcombe and Salmon

(2004) found that women's perception of doctors' expertise was more important than the content of their communication. Perceived expertise engendered trust in their doctors. Although information was important, the way in which it was delivered was more important; patients wanted doctors to do this in a way that maintained hope.

Some research supports the importance of significant others in women's decision-making. Arora and colleagues (Arora, Rutten, Gustafson, Moser, & Hawkins, 2007) found that 71% of women with breast cancer in their study received helpful decision-making support from family at 2 months post-diagnosis. Although this demonstrates that others are important in decision-making it does not determine how they influence the process. The results of this synthesis suggest that they exert influence in direct and indirect ways, which may not be evident in a consultation – for example, where treatment is chosen to minimise impact on others. Further research is needed to examine how women and significant others perceive and negotiate decision-making.

The influence of demographics was not evident in this synthesis. Halkett et al. (2005) suggest that such factors could include age, education level, culture and geographical location. It may be that participants in the included studies did not view these factors as relevant to their decision-making, or the content of particular concerns may vary depending on factors such as age. For example, fertility may be a pertinent issue for younger women (Thewes, Butow, Girgis & Pendlebury, 2004). The qualitative research reported here may tap into core processes of decision-making rather than the details of those processes.

Researcher reflexivity

As with primary qualitative research, it is important to consider the impact of the researcher on the synthesis of qualitative studies. During the writing of this review, the researcher was conducting research into women's experiences between surgery and adjuvant treatment for breast cancer. It seems likely that this would have affected the researcher's interpretation of themes in the present synthesis. As the researcher influences the synthesis, it is recognised that there may be other interpretations that are compatible with the included studies (Britten et al., 2002).

Limitations

Only published studies judged to be of high quality were selected for inclusion. It is likely that authors were constrained by limited word counts for journal publication. Quality appraisal may therefore relate to the quality of the published report rather than the actual study. To examine the impact of omitting poor quality studies, excluded studies were reviewed following completion of the synthesis. The themes identified in these studies were concordant with the results of the synthesis. For example, the emotional impact of breast cancer was present to some degree in all excluded studies. This suggests that inclusion of poor-quality papers would not have added anything original to the synthesis.

A number of methodological weaknesses should be addressed in future, to ensure that high-quality qualitative research is produced. In particular, researchers should clearly state the qualitative method used and the analytic method employed. Evidence of researcher reflexivity should be provided. The decision to exclude papers that did not give details of the stage of cancer may have resulted in a loss of valuable information. Without this information, however, the relevance and transferability of a paper cannot be adequately judged. Sufficient demographic information should therefore be included in reports.

The healthcare systems of different countries could have impacted women's decision-making. Themes from studies conducted in different countries were synthesised, which suggests that there may be commonalities underpinning women's decision-making. Alternatively, this may represent a limitation of the included studies, that they did not address the impact of the wider context on decision-making. There are a number of ways in which cultural and political differences across healthcare systems in different countries could impact treatment decision-making. Charles, Gafni, Whelan and O'Brien (2006) suggest that cultural differences can influence how illness is understood, how risk is understood, what is considered to be a good treatment outcome, what shared decision-making means, what patients want to know about their disease, and who is involved in making treatment decisions. Healthcare policies in different countries may mean certain treatments are available whereas others are not (Sinding & Wiernikowski, 2009). Healthcare policy may also impact on how shared decision-making is conceptualised and put in into practice, as well as the importance attached to it. Other factors could include the cost of healthcare and whether this is free at point of contact or is paid for through

health insurance. Sinding and Wiernikowski (2009) also point to the availability of health and social care services beyond the immediate treatment decision, and how these could influence patients' decisions. Interestingly, one of the studies excluded from the present synthesis on the basis of quality (McVea et al., 2001) examined the experiences of low socio-economic status women in Canada, but found that financial considerations were a minor aspect of participants' decision-making considerations. Nonetheless, the impact of cultural and political differences on decision-making is an area that requires further investigation.

It should also be noted that there was huge variety of time-points at which interviews occurred, both between and within studies. For example, Lam et al. (2005) interviewed participants within 3 days of surgery, whereas time since diagnosis ranged from 3 months to 24 years for participants interviewed by Weber et al. (2013). This could have a number of implications for the results. It is possible that healthcare practices and treatments could have changed over time, which could impact on the interpretation of the results. Recall of the decision-making process may be impacted by the length of time since treatment, although Blane (1996) argues that highly significant events are not necessarily recalled inaccurately. The outcome of treatment could also bias participants' responses – for example, if they are satisfied with the outcomes, they may reflect more positively on their experiences. The results of the present synthesis should therefore be interpreted in light of these contextual factors.

Finally, it is possible that combining studies that vary in stage and type of treatment and time point of interview may have resulted in a loss of richness of detail regarding particular treatments or points in treatment. The similarity of themes across the studies, however, suggests that there is value in synthesising such varied studies. Several papers reported that decision-making appears to be an iterative process that continues throughout the cancer journey (Charles et al., 1998; Halkett et al., 2007; Lally, 2009; O'Brien et al., 2008; O'Brien et al., 2013).

Implications

The present findings have a number of implications for research and clinical practice.

Decision-making is a complex, dynamic process and medical professionals should aim to respond flexibly to women's needs (Charles, et al., 1999). Additionally, women may need more time to consider their options, given the emotional impact of a breast cancer diagnosis. Medical practitioners should also assess women's understanding of information and its personal relevance to them, in order to ascertain the impact on their decision-making.

In terms of future research, only two studies in this review mentioned the role of other healthcare professionals, such as breast care nurses, in women's decision-making (Halkett et al., 2007; Lally, 2009). Women may not perceive other professionals as having a role in decision-making, or researchers may not have explored this in sufficient detail. Further research could address this area. In addition, some studies included women with recurrent or advanced stage disease, but failed to examine if this was a factor in decision-making. As prognostic information and treatment options will differ for women with advanced stage disease, qualitative research focusing specifically on decision-making in this group would be useful. Given the importance of the doctor-patient relationship, factors specific to the clinician will also be important, such as personal preference and the influence of medical guidelines (Halkett et al., 2005). Research could therefore examine how medical professionals perceive and manage decision-making in breast cancer treatment.

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Chapter 2: Major Research Project

A qualitative investigation of the experiences of women with breast cancer between surgery and adjuvant therapy

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Plain English Summary

Title: A qualitative investigation of the experiences of women with breast cancer between surgery and adjuvant therapy

Background: Information about treatment and good communication with healthcare professionals is important to people with cancer. These can help people to feel less distressed and may also improve engagement with treatment. Adjuvant treatment is treatment that helps other treatments be more effective. They are usually given after surgery. These treatments can include chemotherapy and radiotherapy.

Aims and Questions: The aim of this paper was to explore the experiences of women with breast cancer in the time between surgery and chemotherapy or radiotherapy. It also aimed to explore their views of communicating with the healthcare staff involved in their care, and their expectations of further treatment.

Method: Participants were women with breast cancer who had had surgery and were due to receive either chemotherapy or radiotherapy. They were asked to participate by their breast care nurse after their treatment was confirmed. Participants met with the researcher and semi-structured interviews were carried out. These were audio-recorded. Five women were interviewed in total. Two women were scheduled to receive chemotherapy and three to receive radiotherapy.

Main Findings: Participants' experiences were grouped into four main themes: uncertainty about adjuvant treatment, adjustment to cancer, knowing enough, and relationships with healthcare professionals.

Conclusions: The time between surgery and adjuvant treatment was a time of uncertainty for participants. They were anxious about having chemotherapy or radiotherapy, and worried about the potentially unpleasant side effects. Although they were anxious, it seemed that some uncertainty also helped women to stay hopeful that their treatments might not be as unpleasant as they expected. Women also continued to come to terms with their diagnosis of cancer in this time period. This shows that they have a lot to cope with at this time. Women wanted to know enough about treatment to prepare themselves, but

did not want to be overwhelmed with information. Women made efforts to seek information that was useful or helpful and avoid information that was upsetting. Healthcare staff were viewed as a trustworthy source of information. These relationships supported women's coping at this point in time. This study shows that it is important for healthcare staff to listen to women's individual needs at this point in time.

Abstract

Objectives: The aim of this paper was to explore the experiences of women with breast cancer in the period between surgery and adjuvant chemotherapy or radiotherapy. It also aimed to explore their perceptions of communicating with the professionals involved in their care, and their expectations of adjuvant treatment.

Design: Qualitative data were collected through in-depth semi-structured interviews

Methods: Five women were interviewed following surgery and prior to starting adjuvant treatment. Two women were scheduled to receive chemotherapy and three to receive radiotherapy. Interviews were audio-recorded, transcribed verbatim and analysed using Interpretative Phenomenological Analysis.

Results: Four themes were identified: uncertainty about adjuvant treatment, adjustment to cancer, knowing enough, and relationships with healthcare professionals.

Conclusion: The period between surgery and adjuvant treatment was characterised by uncertainty. This may be adaptive at this point, as it allowed women to maintain hope in the face of potentially unpleasant treatments. Women also continued to adjust to their diagnosis. They wanted to know enough about treatment to prepare themselves, but did not want to be overwhelmed. Women emphasised their own agency in managing information. Healthcare professionals were viewed as a trustworthy source of information, and these relationships supported women's coping in this time period. This study underscores the importance of responding flexibly to women's information and communication needs during treatment.

Introduction

Research suggests that individuals with cancer use information as a means of coping with their illness – for example, by supporting involvement in treatment and reducing distress (Mills & Sullivan, 1999). A review of 112 papers examining the information needs of cancer patients found that need for information was particularly high during diagnosis and treatment. Healthcare professionals were found to have a key role in providing information, although other sources, such as written information, the internet, and friends and family were also important (Rutten, Arora, Bakos, Aziz & Rowland, 2005). The most common factors found to contribute to patients' overall satisfaction with care are level of information given and interpersonal relationship with the provider. Satisfaction with care is associated with better co-operation with treatment, which is in turn associated with better clinical outcomes (Sandoval, Brown, Sullivan & Green, 2006). Sandoval and colleagues found that areas consistently rated as problematic by patients with cancer included: information about follow-up care, knowing the next step in treatment, and knowing who was available to answer their questions.

Cancer care can be conceptualised as a trajectory or pathway, comprising a number of stages. Morse & Fife (1998) delineate five key stages, including diagnosis, end of primary treatment, remission, relapse, and palliative care. Evidence suggests that patients' needs vary at different stages of their illness (Rutten et al., 2005). Investigation of communication in cancer care is further complicated when patients receive various treatments from a number of professionals in a range of settings. National policy (Scottish Government, 2008) emphasises the importance of support for people throughout complex care pathways, and the centrality of good information in reducing uncertainty about care and treatment. Qualitative methods may therefore be especially suited to examining patients' experiences and understanding the dynamic nature of their information needs and preferences.

Breast cancer

A number of studies have focused on the communication and information needs of women with breast cancer. This is an important area of research as breast cancer is the most

commonly diagnosed cancer in women in the United Kingdom (UK). The main treatments are surgery, chemotherapy, radiotherapy, hormone treatment and biological therapy; these can be used in isolation or in combination (NICE, 2009).

Quantitative and qualitative research indicates that information is important to women with breast cancer. A literature review (Rees & Bath, 2000) regarding the specific information needs of women with breast cancer found that women's greatest need during surgical and adjuvant therapies was for information about their treatments. Verbal information from healthcare professionals was the preferred source of information, although other sources, such as written information, were used. There is evidence that women's needs change over the course of their illness. A cross-sectional questionnaire based study (Raupach & Hiller, 2002) assessed the information needs of 266 women with breast cancer between 6 and 30 months post-diagnosis. They found a continued high need for information regardless of time since diagnosis. The results also suggested that this need was often unmet, and that information giving decreased over time. In contrast, a longitudinal study by Vogel, Bengel and Helmes (2008) found that women ($n = 135$) reported the highest information needs at the beginning of treatment, compared to 3 and 6 months follow-up. These studies suggest that women's information needs are high and may change over time but it is not clear why these change.

Other studies have adopted a qualitative approach. Thomsen, Pedersen, Johansen, Jensen and Zachariae (2007) interviewed 15 women with breast cancer about specific positive and negative communication experiences from their treatment 3 months after completion of adjuvant chemotherapy. Information giving and the meeting of emotional needs were key themes arising from the data analysis. The authors note that the relatively long gap between the end of treatment and interview, however, may have led to recall bias. Stephens, Osowski, Fidale and Spagnoli (2008) interviewed 200 women newly diagnosed with breast cancer who had recently received surgery. They identified a number of needs including the social, emotional, physical and spiritual needs. Participants also expressed anxiety about future treatments.

Qualitative and quantitative studies reveal conflicting results with regards to breast cancer patients' experiences of communication and information giving. Some studies have used relatively heterogeneous samples (e.g. a mixture of stages and types of cancer), which may

mask differences between patients with different cancers. The literature to date suggests that women's needs and experiences are dynamic and complex. Birchall, Richardson and Lee (2002) assert that the complexity of patient experiences may not be adequately captured by questionnaires, as these can often show a positive response bias and may constrain the responses people give on a topic.

Adjuvant treatment

Some research has examined the particular needs of women undergoing adjuvant treatments. Lerman et al. (1993) surveyed 97 women after surgery but before adjuvant treatment, and 3 months later. Most women experienced difficulties comprehending information and asking questions prior to adjuvant treatment. Communication problems at the first time point were associated with greater distress at follow-up. Graydon et al. (1997) used a questionnaire to assess the information needs of three groups of women with breast cancer at different stages in treatment (surgery, chemotherapy and radiotherapy). Each group reported a strong need for information, with no significant differences between the groups. Difficulties reported with getting information may relate to relationships with healthcare professionals, difficulties retaining information, and having too much information to take in (Skalla, Bakitas, Furstenberg, Ahles, & Henderson, 2004).

Evidence suggests that patients receiving chemotherapy experience considerable distress (DiLorenzo et al., 1995). The highest level of anxiety has been found to occur prior to the first treatment, perhaps because of patient expectations about chemotherapy (Jacobsen, Bovberg & Redd, 1993). Similarly, a literature review found that anxiety is generally highest before the first radiotherapy treatment (Stiegelis, Ranchor & Sanderman, 2004). Buick et al. (2000) compared women receiving chemotherapy with women undergoing radiotherapy at five time points before, during and after their treatment. Although patterns of distress for each therapy diverged over the course of treatment, both groups of women experienced similar levels of distress before treatment began. The authors suggest that the period between surgery and adjuvant treatment may be particularly stressful for women. Research tends to focus on women's experiences before or after treatment is completed. Receiving treatments such as chemotherapy and radiotherapy may be particularly stressful for women, as these have a number of unpleasant possible side-effects. Mishel's (1990)

uncertainty in illness theory proposes that uncertainty can be increased by illness events that are vague, ambiguous, unfamiliar, unpredictable, and complex. The healthcare environment can also contribute to uncertainty – for example, where treatments take place in different settings and a range of professionals are involved. Interviewing women in the period between surgery and adjuvant therapy may allow for a deeper understanding of the dynamic nature of their experiences at this point, when uncertainty and distress may be high.

West of Scotland Context

In the West of Scotland women diagnosed with breast cancer are usually seen by their surgeon first. Following surgery they are under the care of the Beatson West of Scotland Cancer Centre (BWoSCC) for adjuvant treatment, although they may be seen at satellite clinics in local hospitals for oncology appointments. Communication and information sharing may be particularly important during this period, as these may impact on women's expectations of adjuvant therapy and subsequent engagement with treatment. Women's experience of transition between the two phases of treatment is therefore of interest. To the author's knowledge, no studies have examined transitions in breast cancer care in Scotland.

In summary, research consistently suggests that information and communication are important in cancer care for a number of reasons including minimising patient distress and improving engagement with treatment. Difficulties with communication may have psychological consequences for patients. Care pathways can be complex and it seems likely that experiences will differ at each time point. Closer attention to different points in the cancer journey is therefore warranted.

Aims

- To gain insight into the experiences of women with breast cancer, particularly their experiences in the time between surgical and adjuvant treatments.
- To explore the expectations women have of adjuvant treatment.
- To explore their perceptions of communicating with the different professionals

involved in their care in order to gain more detailed information about their needs between these stages of treatment.

Methods

Design

A qualitative approach was used to understand women's experiences of the period between surgery and adjuvant treatment. Interpretative Phenomenological Analysis (IPA) was employed. Smith, Jarman and Osborn (1999) suggest that IPA is particularly appropriate for health psychology research. It involves 'the detailed examination of personal lived experience, the meaning of that experience to participants and how participants make sense of that experience' (Smith, 2011, p. 9). IPA also emphasises the role of interpretation by the researcher during analysis.

Sample

There are a number of different care pathways for women, depending on type and stage of cancer and treatment options. A purposive, well-defined homogeneous sample was recruited in terms of stage of breast cancer and treatment pathway, to allow detailed examination of similarity and variability within the sample (Smith, Flowers & Larkin, 2009).

Inclusion criteria:

- Women with primary early-stage breast cancer who had surgical treatment (such as mastectomy or breast conserving surgery) and were scheduled to receive adjuvant chemotherapy or adjuvant radiotherapy.
- Some women may have had both treatments; the focus of this research was on the first adjuvant treatment women received following surgery.

Exclusion criteria:

- women under 30 years old – there is a steep increase in age-specific incidence rates

from the ages of 30 – 34 onwards (Cancer Research UK, 2014). This was to allow a more homogeneous sample to be recruited.

- those for whom English was not their first language
- women who had started their adjuvant treatment
- women with a prior history of cancer
- those who had received chemotherapy or radiotherapy prior to surgery
- women who had a biopsy only
- women with ductal carcinoma *in situ* (DCIS), as research suggests that the experiences of these patients may be different (e.g. Kennedy, Harcourt & Rumsey, 2012)

IPA studies are typically based on small samples (Smith, 2011). Braun & Clark (2013) suggest a suitable sample size for an IPA study is small / moderate but large enough to convincingly demonstrate patterns across a data set. Smith et al (2009, p.52) have suggested that 4-10 interviews are suitable for studies conducted as part of a professional doctorate. Generalisability is not the aim of qualitative research; rather, the aim is to generate detailed accounts of individual experience. Smith et al. (2009, p.49) also state that IPA researchers usually try to find a fairly homogeneous sample for whom the research question will be meaningful.

Recruitment took place between December 2014 and June 2015. Five women were interviewed. The age range of participants was 44 – 71 years. Four women had breast conserving surgery and one had mastectomy. Two women were scheduled to receive chemotherapy and three were due to receive radiotherapy. Three women agreed to initial contact with the researcher but did not respond to follow-up contact. Two women agreed to contact with the researcher but did not meet inclusion criteria.

Ethical considerations

The study was approved by the West of Scotland Research Ethics Committee (Appendix 3) and NHS Greater Glasgow and Clyde Research and Development Management (Appendix 4). Approval for amendments to widen the inclusion criteria to include women having radiotherapy and to add recruitment sites was also granted (Appendices 5, 6 and 7).

Confidentiality was explained to all participants and written consent was gained before the interview commenced (Appendix 8). Participants were informed that they could withdraw at any point, with no impact on their medical care.

Recruitment

Women were identified by their breast care nurse at their first or second oncology appointment at the BWoSCC, Vale of Leven Hospital or Royal Alexandra Hospital following confirmation of their adjuvant treatment plan. Women identified as suitable were told about the study by their nurse, who gave them an information pack (Appendices 9 and 10) and invited them to contact the researcher if they wished to participate or to ask further questions. The decision about who to give information packs to was made by the breast care nurses, and the researcher had no contact with potential participants who did not receive information packs.

Telephone interviews were offered to all participants. It has been suggested that telephone interviews could result in the loss of non-verbal information, which could impact on data analysis; telephone interviews may, however, allow participants to feel comfortable and to disclose sensitive information (Novick, 2008). Sturges and Hanrahan (2004) found no significant differences in data quality between telephone and face to face interviews. One participant chose this option. There was no discernible impact on interview length or quality.

Research procedures

A semi-structured interview schedule was developed to facilitate the interview (Appendix 11). Relevant background research and discussion with supervisors and clinicians was used to develop the interview guide. The first interview was reviewed by the author and supervisors to ensure that the required information was elicited. The interview schedule was judged to be appropriate and was used in further interviews without modification. This interview was included in data analysis.

Interviews took place in a quiet room at the BWoSCC or the participant's local hospital. Interviews lasted between 40 and 59 minutes. Interviews were audio-recorded, transcribed verbatim, and then checked for accuracy and completeness. All interviews were anonymised for references to person or place.

Researcher reflexivity

The interpretative element of IPA involves acknowledging the role of the researcher and how their background and beliefs may influence data collection and analysis. The researcher had no personal or professional experience of women with breast cancer. Alongside data collection and analysis the researcher was carrying out a systematic review of women's experiences of making treatment decisions for breast cancer. This may have biased the analysis of the interviews, by making some themes more salient. Following completion of each interview, the researcher recorded reflections on the interview and any initial ideas, impressions or feelings. The researcher also kept a reflective diary during data analysis, in order to consider sources of bias and the impact these may have had on emerging themes.

Data analysis

Analysis began while recruitment was on-going. The first stage of analysis, as described by Smith et al. (2009), involved reading the transcript several times to become as familiar as possible with the data. In stage two, anything of interest in the transcript was noted. This included descriptive comments, which describe or summarise participants' accounts, language-based comments which attended to participants' use of language, and initial interpretations of the data. In the third stage of analysis emergent themes were developed from the initial notes. These were given a title or phrase to summarise the essence of the theme. Connections across the emergent themes were then explored, generating super-ordinate themes. Following analysis of each interview transcript, patterns and connections across interviews were explored. Super-ordinate themes were discussed in research meetings and two interview transcripts were analysed blind by the academic supervisor to

ensure the plausibility of the analysis (Smith et al., 2009, p.80). An excerpt from one interview can be found in Appendix 12.

Results

Four super-ordinate themes were identified; these are shown in Table 1, with sub-themes where these were identified. Pseudonyms are used throughout.

Table 1: Themes

| Super-ordinate Themes | Sub-themes |
|---|--|
| Uncertainty about treatment | <ul style="list-style-type: none">• Anxiety about side-effects• Preparation and avoidance |
| Adjusting to cancer | <ul style="list-style-type: none">• Staying positive• Staying normal• Staying present• Friends and family |
| Knowing enough | |
| Relationships with healthcare professionals | |

Uncertainty about treatment

Anxiety about side effects

All participants stated that they had been made aware of the possible side effects of treatment by their doctors, and referred to specific effects that had been discussed or leaflets they had been given detailing these. Women expressed anxiety about the potential side effects of treatment. Lucy explained some of her concerns about having

chemotherapy:

“But my – the only thing is you read through all the possibilities, and you’ve got to read them because they’ve got to tell you about the side effects that the chemotherapy can have and you’re thinking - It does go through your head. You know, somebody I know, their fingernails and their toenails – and I know it doesn’t happen to everybody – but even they fell off and I thought “ah, I don’t know if I’d like that”.” (Lucy)

For women having chemotherapy, hair loss and nausea were particular concerns. Concerns were also discussed by women who were scheduled to receive radiotherapy. These related particularly to tiredness and the possibility of being burned. Angela's language vividly conveys the fear she feels regarding potential side-effects. Her statement about the necessity of having adjuvant treatment seemed to help her manage some of these anxieties.

“but you know, I don’t want to get burnt, and I don’t want all the horrible things that happen. And I am anxious to come here every day. It’s going to be quite a trauma to come up here every day. But, em, it’s all for the good of me, so there’s a light at the end there for me” (Angela)

May's vivid description of the treatment process conveys her understanding of the impact it can have:

“Eh the surgery’s only one bit of it [...] the cancer’s gone but there’s still the potential for recurrence, and so the – the chemotherapy is really standard treatment. I think I’ve read somewhere it’s eh “slash burn” and eh what’s the third thing? “Poison” [laughs] “Slash, poison and burn” – that’s it! So you’ve got the surgery and then you’ve got the chemotherapy and then you’ve got the radiotherapy.” (May)

All women said that they still felt healthy. The contradiction of having treatment when they felt well seemed to heighten women's uncertainty about adjuvant treatment. This was amplified following surgery to remove the tumour. Sam described her feelings of shock that the tumour had been removed:

“I felt – one minute I had been told I had cancer and the next minute it’s kinda - And I know – I feel, I feel it won’t be totally gone until, you know, I complete my radiotherapy, but then I know it has gone but I think actual – that I’ll be able to say that I’m cancer free until I’ve finished all my treatment, if you know what I mean.”
(Sam)

Preparation and avoidance

Women appeared simultaneously to prepare for the possibility of treatment side-effects and minimise the possibility of experiencing these. All participants discussed potential side-effects but stated that these might not happen to them. For example, Lucy had prepared for chemotherapy by buying a wig and had made other practical preparations, including buying a thermometer and a soft toothbrush. On the other hand, she stated:

“But still in my head I’m thinking, no two people are the same, so that might not happen to me, or that might not happen to me. So, there’s no point in me thinking that I’m going to get all this big list of things, cause I might only get two or three or four of them. Cause there is a big list of possible things [laughs] but I might only get a few of them, so.” (Lucy)

In preparation for radiotherapy, Carol said that her family would share responsibility for caring for her grandchildren during her treatment in case she was too tired. She later stated that tiredness was normal for her. This seemed to be a way to negate any additional fatigue as a result of radiotherapy. In this way, she appeared to both prepare for treatment and downplay the possibility that she would experience the side-effects.

“But you don’t know what like it is til you – you don’t know what like something is til you get it yourself. That’s just the way I feel, so just need to take each – each day as it comes. And they say – they say that you get tired with radiotherapy, but I get tired quite a lot – that’s part of my life.” (Carol)

The way in which women acknowledged potential side-effects but minimised the

possibility of these happening to them seemed to actively maintain uncertainty. In turn, this seemed to help women maintain hope that treatment would not be as bad as they feared.

Adjustment to cancer

All women referred to the speed with which they had been diagnosed and commenced treatment. Whilst all participants felt this was positive as it meant the cancer was being treated, it seemed that they had multiple demands on their coping resources at this point in time, including managing the shock of diagnosis and learning about further treatment and prognosis.

The shock of diagnosis was a recurrent theme in all participants' narratives. This suggests that at the time of interview women continued to try and adjust to their diagnosis. For example, Angela commented:

“I was in denial. Cause I had no lump. And to be told or not to be told, ehm [pause] that I – I had it, and I thought, how does that work? You know I don’t believe there’s anything wrong with me” (Angela)

Her switch to the present tense suggests that she continued to process the shock of her diagnosis. Angela's cancer was asymptomatic, but women who had a lump or other symptoms also experienced shock at their diagnosis. May stated:

“So I - I had a feeling I was in trouble anyway [laughs] because of the fact I had had this lump for a while and just [pause] thought well it can’t be cancer, but it was.” (May)

Staying positive

All women emphasised staying positive as a means of coping with their diagnosis and

subsequent treatments. For some women, this meant finding the positive in their diagnosis. For example, Lucy was reassured by the fact her cancer had not spread to the lymph nodes:

“But the good news was it wasn’t in my lymph nodes so that was like, em that’s a good thing cause it means it’s not spread, it’s mainly in the one area.” (Lucy)

Sam described finding her experiences of treatment positive, despite her diagnosis:

“That’s what I mean, from getting really bad news, everything’s quite positive afterwards. I’m sure it’s not the same experience for everybody, but obviously I’m feeling happy because it’s the best of a bad situation really.” (Sam)

Other women related their positivity to being strong for other people in their lives. Angela commented:

“And it’s something kicks in in your head that – that makes you very positive. And I had - I’m on my own with two children [...] and I had to stay positive because he was going through the middle of all of that [exams]. So my emotions, I was – it was as if I was in denial of it. I’ve not got this, I’ll deal with it, it’s fine.” (Angela)

Angela's description of staying positive suggests that, for her, positivity was a necessity. Denial of her own feelings about her diagnosis was necessary for her to stay positive, in order to get through treatment. Some women mentioned denial as strategy that was useful to them in the short-term. For example, Lucy described not wanting to think about requiring a wig and then facing up to this:

“So I kind of put off phoning her and then I realised I had to have a wig and phoned her and went down.” (Lucy)

Another way in which the women appeared to maintain positivity was through engaging in downward comparisons (Willis, 1981) with those they perceived as worse off than themselves. These comparisons were both general and specific. For example, May stated:

“There’s always people round about you far worse off. When you go into the public

domain and talk to other people you realise you're very lucky." (May)

For Carol, recalling her sister-in-law's difficult experiences with chemotherapy reassured her that her own upcoming radiotherapy might be manageable.

"My sister in law had breast cancer and she's okay, and she was worse than what I was. She got chemo before she got her surgery. She had quite a hard time of it, but she sailed through it. So I just kinda look at her and think "well, if she can do it, I can do it."" (Carol)

Staying normal

All the women attempted to maintain some form of normality. All had returned to work or their usual activities following surgery and anticipated that they would continue this during their adjuvant treatment. Sam commented:

"Em, well alright, I'm just obviously trying to work my way through it. I've been off work, em, I took two weeks off after the surgery. Em, but I'm trying to let it not disrupt my work too much." (Sam)

This also appeared to function as a way of rejecting the cancer patient identity. Lucy described this as such:

"But for me I just kept going to work and doing all the things I normally do cause I thought, well I'm not going to sit down now and put my head in my hands and think "oh no, I've got cancer and that's it." Because if I'm like that at the beginning who knows what state you'll be in by the time you get to this stage, so I think maybe I'm just a positive person." (Lucy)

Staying present

Three women described coping with their situation by staying in the present. Carol

commented:

“That’s just the way I feel, so just need to take each – each day as it comes.”

(Carol)

Balancing this with hope for the future was important. All participants mentioned future plans, such as holidays.

Family and friends

Although the women interviewed spoke about individual strategies, the influence of family and friends on their adjustment was also evident for three of the women. For some, this was a general sense that others were supportive of them:

“It makes you realise how fortunate you are having a sort of loving circle. A circle of friends, an outer circle as well, people I used to work with [...] Ehm, all that is great, you know to have people, you know they’re rooting for you.” (May)

The practical help that others offered was also discussed. One of Lucy's work colleagues had established a charity to assist women with cancer during treatment. The practical and emotional aspects of this were important for Lucy:

“She was lovely, she spoke about all her experiences and everything and em we looked through books and different colours and everything [...] And it makes you feel somebody knows what you’re going through, that’s been through it all and knows what you’re talking about.” (Lucy)

Knowing enough

Women described multiple sources of information which impacted their expectations of treatment, including healthcare professionals, written information, friends and family, and the internet. Throughout the women's narratives, a process emerged of information

unfolding over the course of diagnosis and treatment. It was important for women to feel prepared for the next phase of their treatment. How much information was enough varied between women. For some women, this did not necessarily entail knowing exactly what would happen, but rather knowing that they would find out more in due course. This is illustrated by Lucy:

“I’m not going to know until I have my first appointment here [cancer centre], about the chemo. Cause the [hospital 2] don’t give you too much. They tell you like, you know, it’s going to be – they told me it would be six rounds of chemo and they’re usually three weeks apart [...] Em, [pause] but really other than that, that was - I knew I would get more of it, more information when I came here [cancer centre], they’d go more into depth with it and more about different things that you might experience, the effects and all that. But I kinda knew I wouldn’t hear any of that. So although folk were asking me questions, I didn’t know, but I didn’t expect to know til I came here because to me this is obviously the specialist place” (Lucy)

This conveys a sense that she was reassured and contained by the healthcare system. It also suggests that information was paced in part by healthcare professionals. This was echoed by Sam, who said:

“But certainly it was, em – probably didn’t explain – go into it in too much detail [surgeon] but I knew that would come with the oncology appointment to be honest so, em, when I went to the oncology appointment I got a further leaflet and it was explained in a lot more detail than on the Monday.” (Sam)

The concept of knowing enough was idiosyncratic. Women did not define what knowing enough meant for them in terms of content, but discussed this in terms of their emotional reaction to the information. For all participants, information could both reassure and overwhelm. Carol described how information reduced her fears about treatment:

“Aye well it’s made me – it’s made me aware. I kinda know better now what my sister-in-law went through, but it’s not as scary as what I thought it was.” (Carol)

Information could also be perceived as frightening or overwhelming. Sam read

information about possible life expectancy and found this too difficult to think about:

“Em, because another thing it talks about – your life expectancy after it, which is, em, another tool on a website you can use for that. Still I found that a bit like - your life expectancy is maybe ten years and I was like “does that mean I just have another ten years to live?” I found that slightly - I’m not even going to look at that any more, I don’t know.” (Sam)

Participants also emphasised their own agency in ensuring that they knew enough. May read everything she could about her prognosis and treatment. This seemed to reassure her.

“There’s very, very good websites, eh, online where I’ve read um – You know, the breast awareness website, so – So I’ve read all the, all the – the information there is out there for patients [pause] and I suppose I got a lot from that. And from that I was able to ask “well what stage of cancer have I got?” and, and I was able to look at the odds and so on.” (May)

Other participants made decisions about what information to avoid, or when to seek information. Angela stated:

“I’ve deliberately not done it, because the internet can be a scary place if you go too deep into it, so I just thought, I’ve found a useful website, that’s what I’ll stick to, so I’ve not looked anywhere else.” (Angela)

Interestingly, four women stated that looking at information online could be overwhelming, and chose to avoid this, or limit their exposure. Sam explained her decision to digest information in stages, rather than all at once:

“I think you’re just a bit rabbit in the headlights that day anyway, you know, so I had a quick kinda sift through it [information pack], but I was just like “no, I’m not going to read too much into that.” Cause I think it can scare you as well sometimes if you read all of that, because obviously it’s giving you [...] the worst case scenario, so you know, you maybe don’t want it at that stage, to be reading that. I mean, [...] I think it’s more helpful to deal with it at each stage that you’re going

through rather than reading it all at once.” (Sam)

Women also had to manage information received from family and friends. Lucy's description captures the dynamic nature of managing the information from others, as well as the positive and negative aspects of this:

“At first I was a bit “I don’t really want to speak to people who have experienced it” because I thought, well, they tell you a lot of negative stuff and I don’t want the negative, I want the positive. But there’s two side to it you know, what people tell you. I suppose you really need to open your eyes, this could happen to you, you might feel like this. [...] I’ve spoken to a few folk, so I know that it’s – it’s not just me, it’s perfectly normal to feel tired, to feel down, to feel a bit not great or whatever, that’s a normal experience to have.” (Lucy)

Being able to ask questions about their diagnosis and treatment was discussed by four of the women. They valued the opportunity to ask questions, particularly where they had not understood something or felt that shock had prevented them from fully comprehending the information. Two participants emphasised the importance of having enough information in order to ask relevant questions. Angela commented:

“To be prepared, eh, and to give you the opportunity to – to ask questions, because you don’t know what you don’t know when you walk in, and it’s after you walk out that you think of questions.” (Angela)

Her quote conveys a sense of being on unfamiliar terrain and needing some information as a baseline in order to seek further information.

Relationships with healthcare professionals

Women's relationships with the healthcare professionals were a key feature of their narratives. All women spoke positively about their experiences. They tended to speak in general terms about the content of communication from healthcare professionals, and focused on their interpersonal qualities. For example, Angela commented:

“The way I’ve been treated. The way I’ve been treated. Em, everybody has been so compassionate with me and very understanding, and – because it is an awful situation.” (Angela)

The words women used to describe their healthcare professionals included “*lovely*”, “*approachable*” and “*understanding*.” This was also evident in the actions of healthcare professionals. Sam described the way in which her nurse answered her questions:

“The nurse had kind of - she had then taken the time to write down all the answers on the booklet for me, everything that I was asking, so that I do have it all written down.” (Sam)

Sam's sense that her nurse had gone beyond what she expected of her seemed to help her to feel cared for.

Trust in their doctors was important to all the women. This allowed them to feel confident that they were getting the best treatment. May's description of her surgeon illustrates this:

“And I had eh also eh went online and saw that eh [name of surgeon] had a great reputation – international reputation - eh for her work with research and em she em was a very experienced surgeon [pause]. And I had a breast nurse who I could phone if I had any problems. So I really felt that I was in a system where they had seen all this before and felt very confident.” (May)

Perhaps as a consequence of their perceived trustworthiness, healthcare professionals were a valued source of information for all women. Doctors' communication was important, and all women recalled a specific occasion when their doctor or nurse had said something that made them feel positive about their prognosis and treatment. It may be that having confidence in healthcare professionals allowed the women to manage the uncertainty associated with their treatments.

Women appeared to actively make sense of professionals' communications. For example, Lucy interpreted her surgeon's matter-of-fact communication style as being a sign that her

prognosis was good.

Lucy: “Dr [breast surgeon], who was the lead over there for the breast surgery, she just tells you it as it is [laughs]. She said “there’s cancer here, here, here and here”. I suppose, probably she’s saying it all day every day, to everybody. I’m not saying she wasn’t pleasant, but she was very, em [pause]”

Interviewer: “She sounds very matter of fact.”

Lucy: “Uh-huh! [laughs] That’s it exactly. Well, I think sometimes, for me, it was – I – I could maybe cope with that better. I think it’s when people start to be kinda too – too nice to you that it makes you feel, you know, that there’s really, there’s really, something really bad wrong with you. And when people are more matter of fact it makes you think, you know, people are going through this all the time, it happens to loads of people.” (Lucy)

Women viewed the role of their doctors and breast care nurses differently. This was both explicit and implicit in their narratives. Doctors were seen as being in charge of women's overall care, as well as providing information about treatment and its side effects. Nurses appeared to have a role in clarifying and expanding on information provided by the doctor. May commented:

“I also was introduced to the breast nurse and I thought it was quite clever the way she, em, said “Right tell me now what [pause] you’ve been told by the oncologist so that I’m not repeating myself.” [...] I realise this is a clever way of finding out if you’ve remembered anything! [laughs]” (May)

For some women, the role of the nurse was also tied closely to the provision of practical and emotional support. Angela stated:

“Do you know, and I found this quite funny, if you are talking to the oncologist or the surgeon or whatever, she wasn’t in the room then all of the sudden she was in the room. What’s it got to - it’s as if she jumped out of a cupboard or a filing cabinet or something, it’s like just she just appeared from, em – [...] they just seem to be

there by your side.” (Angela)

Angela's experience conveys a sense that her needs were anticipated before she was fully aware of them. Nurses also seemed to provide a sense of continuity for the women, as they had contact with one or two nurses over the course of their treatment. Four of the women spoke about the importance of knowing who was there if they had questions or needed to speak to someone. For all women, this was their breast care nurse. Sam commented:

“Yeah, I mean certainly, it was reassuring to know that there is someone there on the end of a phone that you can call when you do have questions. Cause, you know, hospitals are big places so you wouldn't know how to start to get hold of people to get questions answered. So yeah, no, I find that very helpful.” (Sam)

Discussion

This study explored the experiences of women in the time period between surgery and adjuvant treatment for breast cancer. This time was characterised by anxiety and uncertainty about adjuvant treatment. Women expected that further treatment might be unpleasant. Their efforts to manage uncertainty at this time point took place in the wider context of their adjustment to the diagnosis of cancer. Coping was supported by relationships with healthcare providers and the information they received.

Women in the present study had to cope with the uncertainty associated with adjuvant treatment. They had experienced a disruption to their normal lives through surgical treatment and attempted to regain normality by returning to their usual activities. Adjuvant treatment seemed to represent a further threat to normality, both in terms of disruption of daily life routines and potential side effects. Women anticipated disruption, but experienced uncertainty about the nature of this disruption. Previous research has demonstrated that people experience uncertainty throughout the cancer journey. Waiting for treatment may be a particularly uncertain time. Drageset, Lindstrom, Giske & Underlid (2010) interviewed women with breast cancer prior to surgery. Women experienced high levels of uncertainty related to their treatment and prognosis. A review (Shaha, Cox, Talman & Kelly, 2008) found that uncertainty in cancer care related to three main areas:

uncertainty regarding treatment and prognosis, uncertainty about coping, and uncertainty related to insufficient information.

Uncertainty in illness theory (Mishel, 1990) proposes that uncertainty is the difficulty in ascribing meaning to illness related events. Two factors are hypothesised to influence individuals' experience of uncertainty – cognitive capacity and resources available to help them make sense of the experience. Resources include education, social support and credible authority. Individuals then appraise the meaning of their experienced uncertainty. Uncertainty can be evaluated as a threat or as an opportunity. Women in the present study seemed to engage in a process of preparing for side effects whilst downplaying the possibility of experiencing these. Uncertainty may be adaptive for women at this point in time, as it could represent an opportunity to maintain hope and optimism in the face of potentially unpleasant treatments.

Perhaps unsurprisingly, given the time scales involved, women continued to adjust to their diagnosis. Stress and coping theory offers a way to understand women's experiences at this point (Lazarus & Folkman, 1984). It delineates two broad types of coping strategies that people use in response to a threatening event, such as illness. Problem-focused coping strategies include efforts to manage cause of the stress. Emotion-focused coping strategies are directed toward reducing emotional distress. Emotion-focused coping is more commonly used when events are perceived as less controllable (Lazarus & Folkman, 1984). Women in this study seemed to use a mix of emotion-focused and problem-focused coping strategies. These included: attempting to stay positive, maintaining normality, staying in the present, and utilising support from family and friends. Given that women are unable to predict what side-effects they will experience and what they may be able to control, this mix of coping strategies might be expected.

The present research suggests the women wanted to know enough about their treatment to reduce uncertainty, but did not wish to overwhelm themselves with information that was fear-inducing. Information appeared to unfold over the course of diagnosis and treatment, as women negotiated the healthcare environment. Women engaged in a process of controlling information in order to meet their individual needs, which were highly idiosyncratic. Research increasingly demonstrates that information needs in cancer care are dynamic and change over time, as a function a number of factors, including the stage of

treatment, the individual's personal circumstances and interactions with others (Rutten et al., 2005). The results of this study show that women actively manage the information they receive. This is important, as early research did not consider how women actively shape and manage information.

Recent studies lend support to this interpretation. Furber, Bonas, Murtagh and Thomas (2015) analysed interviews with five people with cancer following their first oncology appointment, using IPA. They reported a dynamic interplay between the need for information and the desire to avoid certain bits of information. Similarly, a meta-ethnography of qualitative studies examining information-seeking in people with cancer found that seeking information and avoiding information may not be separate behaviours, but rather part of a dynamic process of controlling information in order to meet individual needs (Germeni & Schulz, 2014). They suggest five factors which prompt people to seek or avoid information: the shock of diagnosis, the desire for control, trust in healthcare professionals, a desire to maintain hope, and the need to return to normality. Avoiding or seeking information can fulfil each of these goals.

Healthcare professionals were a valuable source of information for participants. The interpersonal aspects of professionals' communication were as important as the information they shared. Trust in professionals was important to participants. Feeling that professionals are in control of the illness perhaps allows individuals to feel more in control themselves (Walker, Jackson & Littlejohn, 2004). This could support women's attempts to cope. Information-giving might allow women to develop trust in their doctors, which in turn facilitates the sharing of information (McWilliam, Brown & Stewart, 2000). According to uncertainty in illness theory (Mishel, 1990), healthcare professionals represent a source of credible authority – that is, they can support the management of uncertainty by providing information about the illness and treatment. The important role of nurses in providing practical and social support, as well as a sense of continuity, fits with findings from previous research (Liebert & Furber, 2004).

Limitations

In line with IPA a homogeneous sample was recruited, consisting of women with early-

stage breast cancer undergoing specific treatments. Therefore, the results may not be applicable to women with metastatic breast cancer, where concerns are likely to be different, or to women receiving different treatment combinations, such as chemotherapy before surgery. In addition, women who had already agreed to their adjuvant treatment plan took part in this study. It should also be noted that four of the five participants said they had been accurately prepared for further treatment by their surgeon. This does not capture the experiences of women who were undecided about adjuvant treatment, those who did not wish to pursue further treatment, and those who received a treatment different from that which they anticipated. Interviewing women post-surgery but prior to confirmation of their adjuvant treatment may have captured this uncertainty, but it was identified that asking women about expectations of further treatment when this had not been confirmed would be ethically problematic. Nonetheless, the themes of the present study and earlier research (Shaha et al., 2008) suggest that uncertainty pervades across the cancer trajectory. It may be that the content of women's worries changes at different stages.

Recruitment of participants was difficult. There may be a number of reasons for this. Women receive a great deal of information about treatment at the first oncology appointment, particularly those who will be having chemotherapy. They may also be asked to enter clinical trials at this point. Women perhaps feel overwhelmed by the volume of information they receive at this time. In addition, women's distress levels might be higher at this time. Participants in this study emphasised their attempts to maintain a positive outlook. It may be that these women represent a sub-group who cope particularly well and therefore felt more able to discuss their experiences. The manner of recruitment to the study may also be a source of bias. Potential participants were selected by their breast care nurses. It may be that nursing staff chose women experiencing less distress, those who were satisfied with the service they had received so far, or those who seemed more able to articulate their experiences. Therefore, participants in this study may not represent the full range of experience in terms of care received. Future research could consider different recruitment strategies that may reduce this source of bias – for example, the use of posters.

Future Directions and Implications

Although they were interviewed at one time point in their treatment, all women described a dynamic process of information unfolding and changing. Further research could take a longitudinal perspective by interviewing women at different points during diagnosis and treatment, to capture their experiences at each stage. The experiences and needs of women with different treatment pathways could also be examined.

Although all the women interviewed experienced worry about their adjuvant treatment, there was evidence of some differences between radiotherapy and chemotherapy. These related largely to the anticipate side effects. For example, women about to undergo chemotherapy discussed concerns about hair loss, nausea and vomiting and other unpleasant potential side-effects, whereas women awaiting radiotherapy discussed concerns related to fatigue and being burned. All participants anticipated that treatment and possible side effects would be disruptive to their daily lives. This suggests the importance of ascertaining women's specific concerns about treatment and how these relate to their own lives and situations. Further exploration of treatment-specific concerns and comparison of differences is warranted.

This study adds to a growing body of literature demonstrating that information needs are complex and dynamic. Communication with healthcare professionals is vital. Interpersonal qualities and human connection are as important as information giving. This suggests that the focus should be on supporting women to articulate their particular needs at different times in different situations, and on supporting healthcare professionals to respond flexibly.

Conclusion

The results of this study suggest that the period between surgery and adjuvant treatment is characterised by uncertainty. Women's efforts to manage this uncertainty are important, as is the information and support they receive from healthcare professionals. Information needs are met in an interpersonal context, in which women feel cared for and supported. Healthcare professionals should respond flexibly to women's information needs.

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Chapter 3: Advanced Clinical Practice I – Critical Reflective Account

Formulation: getting it right?

Abstract

Formulation is one of the key competencies of clinical psychologists (Division of Clinical Psychology, 2010). In this account I reflect on my experiences of formulation over the course of training, and how my ideas and feelings have changed. In particular, I focus on my concerns about needing to do formulations the “right” way and how this has changed over the course of training. Johns' (2004) Model of Structured Reflection is used to structure reflections on specific experiences and the Integrated Developmental Model (IDM; Stoltenberg & McNeill, 1997) is used to think about my experiences in the context of my overall development as a clinical psychologist. Finally, I reflect on the experience of writing the account and the impact of the wider context in which we practice. Future directions for developing my skills in formulation are also discussed.

Chapter 4: Advanced Clinical Practice II – Critical Reflective Account

A reflection on my experiences of delivering teaching and training to others

Abstract

Clinical psychologists are increasingly expected to share psychological knowledge and skills with others (The Scottish Government, 2011). One way in which this is done is teaching and training of other staff. In this account I reflect on two experiences of delivering teaching to others. The first experience, in second year, was one that did not go so well and the second experience, in third year, was one that seemed to be better. Rolfe, Freshwater and Jasper's (2001) framework for reflective practice is used to structure my reflections, by considering the questions “what?” “so what?” and “now what?” in relation to these experiences. Reference is also made to the Integrated Developmental Model (IDM; Stoltenberg & McNeill, 1997) to set these experiences in the context of my development as a clinical psychologist. In this account I discuss my concerns about delivering teaching and training and how my feelings vary depending on context. Finally, areas for future learning and professional development are considered.

Appendix 1: Author Guidelines for Submission to the British Journal of Health Psychology

The aim of the British Journal of Health Psychology is to provide a forum for high quality research relating to health and illness. The scope of the journal includes all areas of health psychology as outlined in the Journal [Overview](#).

The types of paper invited are:

- papers reporting original empirical investigations, using either quantitative or qualitative methods;
- theoretical papers which may be analyses or commentaries on established theories in health psychology, or presentations of theoretical innovations;
- review papers, which should aim to provide systematic overviews, evaluations and interpretations of research in a given field of health psychology; and
- methodological papers dealing with methodological issues of particular relevance to health psychology.

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

Papers should normally be no more than 5000 words (excluding the abstract, reference list, tables and figures), although the Editor retains discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

3. Editorial policy

The Journal receives a large volume of papers to review each year, and in order to make the process as efficient as possible for authors and editors alike, all papers are initially examined by the Editors to ascertain whether the article is suitable for full peer review. In order to qualify for full review, papers must meet the following criteria:

- the content of the paper falls within the scope of the Journal
- the methods and/or sample size are appropriate for the questions being addressed
- research with student populations is appropriately justified
- the word count is within the stated limit for the Journal (i.e. 5000 words)

4. Submission and reviewing

All manuscripts must be submitted via [Editorial Manager](#). You may like to use the [Submission Checklist](#) to help you prepare your manuscript. The Journal operates a policy of anonymous peer review. Authors must suggest three reviewers when submitting their manuscript, who may or may not be approached by the Associate Editor dealing with the paper. Before submitting, please read the [terms and conditions of submission](#) and the [declaration of competing interests](#).

5. Manuscript requirements

- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
- Manuscripts should be preceded by a title page which includes a full list of authors and their affiliations, as well as the corresponding author's contact details. A template can be downloaded from [here](#).

- For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions.
- Statement of Contribution: All authors are required to provide a clear summary of ‘what is already known on this subject?’ and ‘what does this study add?’. Authors should identify existing research knowledge relating to the specific research question and give a summary of the new knowledge added by your study. Under each of these headings, please provide 2-3 (maximum) clear outcome statements (not process statements of what the paper does); the statements for ‘what does this study add?’ should be presented as bullet points of no more than 100 characters each. The Statement of Contribution should be a separate file.
- The main document must be anonymous. Please do not mention the authors’ names or affiliations (including in the Method section) and always refer to any previous work in the third person.
- Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript but they must be mentioned in the text.
- Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi. All figures must be mentioned in the text.
- For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full and provide doi numbers where possible for journal articles. For example:

Author, A., Author, B., & Author, C. (1995). *Title of book*. City, Country: Publisher.

Author, A. (2013). Title of journal article. *Name of journal*, 1, 1-16. doi:

10.1111/bjep.12031

- SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.
- In normal circumstances, effect size should be incorporated.
- Authors are requested to avoid the use of sexist language.
- Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright. For guidelines on editorial style, please consult the [APA Publication Manual](#) published by the American Psychological Association.
- Manuscripts describing clinical trials are encouraged to submit in accordance with the [CONSORT statement](#) on reporting randomised controlled trials.

6. Supporting information

Supporting Information can be a useful way for an author to include important but ancillary information with the online version of an article. Examples of Supporting Information include appendices, additional tables, data sets, figures, movie files, audio clips, and other related nonessential multimedia files. Supporting Information should be cited within the article text, and a descriptive legend should be included. Please indicate clearly on submission which material is for online only publication. It is published as supplied by the author, and a proof is not made available prior to publication; for these

reasons, authors should provide any Supporting Information in the desired final format. For further information on recommended file types and requirements for submission, please visit the [Supporting Information page](#) on Author Services.

7. OnlineOpen

OnlineOpen is available to authors of primary research articles who wish to make their article available to non-subscribers on publication, or whose funding agency requires grantees to archive the final version of their article. With OnlineOpen, the author, the author's funding agency, or the author's institution pays a fee to ensure that the article is made available to non-subscribers upon publication via Wiley Online Library, as well as deposited in the funding agency's preferred archive. A full list of [terms and conditions](#) is available on Wiley Online Library.

Any authors wishing to send their paper OnlineOpen will be required to complete the [payment form](#).

Prior to acceptance there is no requirement to inform an Editorial Office that you intend to publish your paper OnlineOpen if you do not wish to. All OnlineOpen articles are treated in the same way as any other article. They go through the journal's standard peer-review process and will be accepted or rejected based on their own merit.

8. Author Services

Author Services enables authors to track their article – once it has been accepted – through the production process to publication online and in print. Authors can check the status of their articles online and choose to receive automated e-mails at key stages of production. The author will receive an e-mail with a unique link that enables them to register and have their article automatically added to the system. Visit [Author Services](#) for more details on online production tracking and for a wealth of resources including FAQs and tips on article preparation, submission and more.

9. Copyright and licences

If your paper is accepted, the author identified as the formal corresponding author for the paper will receive an email prompting them to login into Author Services, where via the Wiley Author Licensing Service (WALS) they will be able to complete the licence agreement on behalf of all authors on the paper.

For authors signing the copyright transfer agreement

If the OnlineOpen option is not selected the corresponding author will be presented with the copyright transfer agreement (CTA) to sign. The terms and conditions of the CTA can be previewed in the samples associated with the [Copyright FAQs](#).

For authors choosing OnlineOpen

If the OnlineOpen option is selected the corresponding author will have a choice of the following Creative Commons Licence Open Access Agreements (OAA):

- Creative Commons Attribution Non-Commercial Licence (CC-BY-NC)
- Creative Commons Attribution Non-Commercial -NoDerivs Licence (CC-BY-NC-ND)

To preview the terms and conditions of these open access agreements please visit the [Copyright FAQs](#) and you may also like to visit the [Wiley Open Access Copyright and Licence](#) page.

If you select the OnlineOpen option and your research is funded by The Wellcome Trust and members of the Research Councils UK (RCUK) or the Austrian Science Fund (FWF) you will be given the opportunity to publish your article under a CC-BY licence supporting you in complying with your Funder requirements. For more information on this policy and the Journal's compliant self-archiving policy please visit our [Funder Policy](#) page.

10. Colour illustrations

Colour illustrations can be accepted for publication online. These would be reproduced in greyscale in the print version. If authors would like these figures to be reproduced in colour in print at their expense they should request this by completing a [Colour Work Agreement](#) form upon acceptance of the paper.

11. Pre-submission English-language editing

Authors for whom English is a second language may choose to have their manuscript professionally edited before submission to improve the English. A list of independent suppliers of editing services can be found in [Author Services](#). All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

12. The Later Stages

The corresponding author will receive an email alert containing a link to a web site. The proof can be downloaded as a PDF (portable document format) file from this site. Acrobat Reader will be required in order to read this file. This software can be downloaded (free of charge) from [Adobe's web site](#). This will enable the file to be opened, read on screen and annotated direct in the PDF. Corrections can also be supplied by hard copy if preferred. Further instructions will be sent with the proof. Excessive changes made by the author in the proofs, excluding typesetting errors, will be charged separately.

13. Early View

British Journal of Health Psychology is covered by the Early View service on Wiley Online Library. Early View articles are complete full-text articles published online in advance of their publication in a printed issue. Articles are therefore available as soon as they are ready, rather than having to wait for the next scheduled print issue. Early View articles are complete and final. They have been fully reviewed, revised and edited for publication, and the authors' final corrections have been incorporated. Because they are in final form, no changes can be made after online publication. The nature of Early View articles means that they do not yet have volume, issue or page numbers, so they cannot be cited in the traditional way. They are cited using their Digital Object Identifier (DOI) with no volume and issue or pagination information. Eg Jones, A.B. (2010). Human rights Issues. *Journal of Human Rights*. Advance online publication. doi:10.1111/j.1467-9299.2010.00300.x

Appendix 2: Quality Rating Criteria (adapted from Walsh & Downe, 2006, pp. 114-115)

| Area of Study | Essential Criteria | Specific Prompts | Score (2,1,0) |
|-------------------|---|--|---------------|
| Scope and purpose | Clear statement of, and rationale for, research question/aims/purpose | <ul style="list-style-type: none"> • Clarity of focus demonstrated • Explicit purpose given, such as descriptive/explanatory intent, theory building, hypothesis testing • Link between research and existing knowledge demonstrated | |
| | Study thoroughly contextualized by existing literature | <ul style="list-style-type: none"> • Evidence of systematic approach to literature review, location of literature to contextualize the findings, or both | |
| Design | Method/design apparent, and consistent with research intent | <ul style="list-style-type: none"> • Rationale given for use of qualitative design • Discussion of epistemological/ontological grounding • Rationale explored for specific qualitative method (e.g. ethnography, grounded theory, phenomenology) • Discussion of why particular method chosen is most appropriate/sensitive/relevant for research question/aims • Setting appropriate | |
| | Data collection strategy apparent and appropriate | <ul style="list-style-type: none"> • Were data collection methods appropriate for type of data required and for specific qualitative method? • Were they likely to capture the complexity/diversity of experience and illuminate context in sufficient detail? • Was triangulation of data sources used if appropriate? | |
| Sampling strategy | Sample and sampling method appropriate | <ul style="list-style-type: none"> • Selection criteria detailed, and description of how sampling was undertaken • Justification for sampling strategy given • Thickness of description likely to be achieved from sampling • Any disparity between planned and actual sample explained | |
| Analysis | Analytic approach appropriate | <ul style="list-style-type: none"> • Approach made explicit (e.g. Thematic distillation, constant comparative method, grounded theory) • Was it appropriate for the qualitative method chosen? • Was data managed by software package or by hand and why? • Discussion of how coding systems/conceptual frameworks evolved • How was context of data retained during analysis | |

| | | | |
|-------------------------------|--|---|--|
| | | <ul style="list-style-type: none"> • Evidence that the subjective meanings of participants were portrayed • Evidence of more than one researcher involved in stages if appropriate to epistemological/theoretical stance • Did research participants have any involvement in analysis (e.g. member checking) • Evidence provided that data reached saturation or discussion/rationale if it did not • Evidence that deviant data was sought, or discussion/rationale if it was not | |
| Interpretation | Context described and taken account of in interpretation | <ul style="list-style-type: none"> • Description of social/physical and interpersonal contexts of data collection • Evidence that researcher spent time 'dwelling with the data', interrogating it for competing/alternative explanations of phenomena | |
| | Clear audit trail given | <ul style="list-style-type: none"> • Sufficient discussion of research processes such that others can follow 'decision trail' | |
| | Data used to support interpretation | <ul style="list-style-type: none"> • Extensive use of field notes entries/verbatim interview quotes in discussion of findings • Clear exposition of how interpretation led to conclusions | |
| Reflexivity | Researcher reflexivity demonstrated | <ul style="list-style-type: none"> • Discussion of relationship between researcher and participants during fieldwork • Demonstration of researcher's influence on stages of research process • Evidence of self-awareness/insight • Documentation of effects of the research on researcher • Evidence of how problems/complications met were dealt with | |
| Ethical Dimensions | Demonstration of sensitivity to ethical concerns | <ul style="list-style-type: none"> • Ethical committee approval granted • Clear commitment to integrity, honesty, transparency, equality and mutual respect in relationships with participants • Evidence of fair dealing with all research participants • Recording of dilemmas met and how resolved in relation to ethical issues • Documentation of how autonomy, consent, confidentiality, anonymity were managed | |
| Relevance and transferability | Relevance and transferability evident | <ul style="list-style-type: none"> • Sufficient evidence for typicality specificity to be assessed • Analysis interwoven with existing theories and other relevant explanatory literature drawn from similar settings and studies | |

| | | | |
|--|--|--|--|
| | | <ul style="list-style-type: none"> • Discussion of how explanatory propositions/emergent theory may fit other contexts • Limitations/weaknesses of study clearly outlined • Clearly resonates with other knowledge and experience • Results/conclusions obviously supported by evidence • Interpretation plausible and ‘makes sense’ • Provides new insights and increases understanding • Significance for current policy and practice outlined • Assessment of value/empowerment for participants • Outlines further directions for investigation • Comment on whether aims/purposes of research were achieved | |
|--|--|--|--|

Appendix 3: Summary of themes as expressed in each study

(NB: X indicates theme not expressed in study)

| | Themes from meta-ethnography | | | | |
|------------------------------|--|---|--|---|--|
| | Women's role in decision making | Emotional impact of breast cancer | Patient-doctor relationship | Managing information | Family and friends |
| Charles et al. (1998) | <ul style="list-style-type: none"> - Some women wanted the doctor to make the decision - Some wanted shared decision-making - Some wanted final say - Decision-making as a dilemma for women | <ul style="list-style-type: none"> - Doing nothing is not an option – women feel a need to do everything they can to fight cancer - Maintaining hope and positivity | <ul style="list-style-type: none"> - Some women see doctor as expert who should make the decision - Some wanted doctors' advice to enable own decision | <ul style="list-style-type: none"> - Weighing up benefits and risks of treatment - Developing an idiosyncratic understanding of information - Transforming risk data into personally meaningful categories | X |
| Lam et al. (2005) | <ul style="list-style-type: none"> - Women felt responsible for decision-making - Experienced uncertainty and indecisiveness | <ul style="list-style-type: none"> - Some form of treatment is the only choice - Emotional response to cancer – fear, uncertainty - Perceived seriousness of cancer - Survival is highest priority – choices are driven by fear of death / recurrence - Uncertainty about decision | <ul style="list-style-type: none"> - Identifying surgeons' preferences - Women trust surgeons' knowledge and expertise - Wanting doctors to choose for them | <ul style="list-style-type: none"> - Difficulty assimilating information due to fear - Prioritising personal aims – weighing information based on factors relevant to individual - Seeking and evaluating information from a range of formal and informal sources - Seeking and avoiding information as a means to cope | <ul style="list-style-type: none"> - Prioritising personal aims – preserving relationships with significant others and minimising life disruption - Seeking opinions of family |
| Halkett et | - Women make many | - Survival – decisions are | - Establishing relationships | - Getting ready – | - Sharing the challenge – |

| | | | | | |
|------------------------------|--|---|---|--|---|
| al. (2007) | decisions; not all are overt and all impact on the others - Lack of control over decisions – trusting doctor to make decision - Regaining control afterwards | characterised by a need to survive - Cancer as a challenge to existence and sense of self – threat of death - Interrogating the future – wondering about recurrence | with doctors - Putting trust in medical practitioners - Support from medical practitioners | developing understanding through information and discussion with others | family and friend can actively support women - Support and reassurance - Choosing who to involve - Some actively involved in decisions but some need own support |
| Husain et al. (2008) | - Reliance on medical professionals to make a decision - Doing what the doctor thinks is best | - Diagnosis of cancer – worry about fear of metastases and recurrence | - Relying on healthcare professionals to decide - Doing what the doctor says - Listening for clues to doctors' treatment preferences | - Women did not ask questions or seek treatment information – reliance on healthcare professionals to tell them | X |
| O'Brien et al. (2008) | - Some women surprised to be offered a choice - Some identified a preferred treatment pre-consultation - Some women wanted the doctor to decide | - Women wanted a treatment that would give them the best chance of survival | - Some women want the doctor to decide - Doctors' recommendations are valued – gave women confidence in their own decisions - Trying to infer doctors' preferences where these are not explicit | - Seeking information about options pre-consultation (formal and informal sources) - Using information to make a decision – idiosyncratic understanding - Some women did not get as much information as they wanted from doctors | - Seeking information from others about treatment options – social network - Considered options with family and support network |
| Lally (2009) | - Some women had strong treatment preferences pre-consultation, but did not tend to share these | - Choices motivated by desire to eliminate future inconvenience and worry about cancer | - Interacting with doctors - Surgeon instils trust and feeling of being cared for - Wanting a | - Managing amount of information – information could be overwhelming - Formal and informal | - Informal sources of information, such as friends, used - Interacting with others – |

| | | | | | |
|------------------------------|---|--|---|--|--|
| | <ul style="list-style-type: none"> - Women tended to make their own choices based on interactions with medical professionals - Informed decision-making | <ul style="list-style-type: none"> - Some women worried about having made the right decision | <ul style="list-style-type: none"> recommendation from doctors - Taking confidence from doctors' support of decisions | <ul style="list-style-type: none"> sources used - Information can help women avoid surprise - Some women avoided information and some approached it - Information, perceived knowledge and beliefs drove preferences | <ul style="list-style-type: none"> knowledge of other women's experiences - Family and friends provide reassurance and support for decisions - Deciding who to involve |
| Caldon et al. (2011) | <ul style="list-style-type: none"> - Variation in decision-making roles between women - Some women surprised to be offered choice - Most women wanted a role in decision-making - Some women acquiesced to doctor | <ul style="list-style-type: none"> - Most reassuring option chosen to reduce anxiety about recurrence - Vacillation between fear of recurrence and body image concerns - The shock of diagnosis | <ul style="list-style-type: none"> - Doctors are primary information providers - Surgeons' framing of choices influences decision - Doctor perceived as powerful – some women acquiesce | <ul style="list-style-type: none"> - Style and content of information is important - Context is important – the earlier women were told about making a decision, the more they seemed to choose mastectomy | <ul style="list-style-type: none"> - Choosing the least disruptive treatment option in terms of wider life commitments - Impact of surgery on sexual relationships |
| Pieters et al. (2012) | <ul style="list-style-type: none"> - Women made their own decisions – self-reliance; confidence - Making the best decisions for their circumstances – unique to each woman | <ul style="list-style-type: none"> - Impact of diagnosis – shock and uncertainty - Needing to make decisions quickly – feeling unprepared | <ul style="list-style-type: none"> - Asking clinicians questions to create a conversation - Interpreting healthcare providers – reading their dispositions - Determining trustworthiness | <ul style="list-style-type: none"> - Obtaining information from formal and informal sources. Creates conversations with doctors - Emotional appraisals more important than facts - Women actively seek information, but too much information unhelpful and overwhelming | <ul style="list-style-type: none"> - Mutual caring for self and others – deciding who to take to appointments - Making some decisions based on wider responsibilities - Asking family and friends for information |
| O'Brien et al. (2013) | <ul style="list-style-type: none"> - Variety in level of decision-making | X | X | <ul style="list-style-type: none"> - Women used formal and informal sources to gather | <ul style="list-style-type: none"> - Family and friends can be a source of information |

| | | | | | |
|------------------------------|---|--|---|---|---|
| | involvement - Most women involved in final decision - Decisions happen in and out with medical appointments - Deliberating about options - Some women had a strong preference beforehand | | | information - Information can be overwhelming - It can be difficult to understand some information | - Family and friends are sometimes involved in making the decision |
| Weber et al. (2013) | - A variety of decision-making styles were identified - Medical expert – doctor makes decision - Self-efficacy – women make decision - Relationship embedded - ensuring survival to spend more time with family - Inhibition – wanting to avoid negative outcome - Constellation of information – using information from various sources | - Inhibition style of decision-making based on fear – wanting to avoid a negative outcome (e.g. pain, death) | - Following the doctor’s advice – doctor is the expert - Trust in the doctor | - Women were on a continuum of low to high information needs - All women used information fluidly – sometimes approaching it and sometimes avoiding it | - Relationship embedded style of decision-making; ensuring survival to spend more time with family - Influence of significant others evident in all decision-making styles to some degree - Continuum of other- to self-focus |
| Covelli et al. (2015) | - Taking control of cancer – the final decision was made by women alone, | - Shock and fear of diagnosis - Understanding of | - Doctors as a source of information | - Subjective risk perception outweighs the facts | - Personal experiences of family and friends heighten fear |

| | | | | | |
|--|--|--|--|--|---|
| | although others were a source of support | recurrence and survival – fear of cancer returning - Mastectomy eliminates risk and means survival – fear and anxiety related to recurrence | | - Fear underpins information use - Emotional information most salient | - Family and friends provide support for decisions but women make decisions alone |
|--|--|--|--|--|---|

Appendix 4: West of Scotland Research Ethics Approval

WoSRES
West of Scotland Research Ethics Service



Dr Sarah L Wilson
Academic Unit of Mental Health & Wellbeing,
University of Glasgow
First Floor, Admin. Building
Garthavel Royal Hospital
1055 Great Western Road
G12 0XH

West of Scotland REC 1
Ground Floor - Tennent Building
Western Infirmary
38 Church Street
Glasgow
G11 6NT

Date 28 October 2014
Direct line 0141 211 6270
E-mail WoSREC1@ggc.scot.nhs.uk

Dear Dr Wilson

| | |
|-------------------------|---|
| Study title: | A qualitative investigation of the experiences of women with breast cancer between surgery and adjuvant chemotherapy |
| REC reference: | 14/WS/1103 |
| IRAS project ID: | 156961 |

Thank you for your letter of 20 October 2014, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a Sub-Committee of the REC on 27 October 2014. A list of the Sub-Committee members is attached.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Miss Kirsty Sime, WosRec1@ggc.scot.nhs.uk.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

| Document | Version | Date |
|---|---------|-------------------|
| Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [University Insurance Letter] | | 30 July 2013 |
| GP/consultant information sheets or letters [Letter to Clinicians] | 2 | 16 October 2014 |
| Interview schedules or topic guides for participants [Interview Schedule v2] | 2 | 11 August 2014 |
| Letters of invitation to participant [Letter to Participants v2] | 2 | 01 September 2014 |
| Participant consent form [Participant Consent Sheet] | 3 | 16 October 2014 |
| Participant information sheet (PIS) [Participant Information Sheet] | 3 | 16 October 2014 |
| REC Application Form [REC_Form_11092014] | | 11 September 2014 |
| Research protocol or project proposal [Protocol] | 8 | 20 October 2014 |
| Response to Request for Further Information [Response to Research Ethics Committee] | | 20 October 2014 |
| Summary CV for Chief Investigator (CI) [SW CV] | | 29 May 2014 |
| Summary CV for student [L McAllister CV] | | 13 August 2014 |
| Summary, synopsis or diagram (flowchart) of protocol in non technical language [Plain English Summary v1] | 1 | 11 August 2014 |

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

14/WS/1103

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

Abibat Adewumi

On behalf of
Dr Malcolm Booth
Chair

*Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments
"After ethical review – guidance for researchers"*

*Copy to: Ms Emma-Jane Gault
Dr Nathaniel Brittain, NHS Greater Glasgow & Clyde*

Appendix 5: NHS Greater Glasgow and Clyde Research and Development Management Approval



Administrator: Ms Lorn Mackenzie
Telephone Number: 0141 211 1743
E-Mail: Lorn.Mackenzie@ggc.scot.nhs.uk
Website: www.nhsggc.org.uk/r&d

R&D Management Office
Western Infirmary
Tennent Institute
1st Floor 38 Church Street
Glasgow, G11 6NT,

29/10/2014

Miss Lauren McAllister
NHS GG&C
Academic Unit of Mental Health and Wellbeing
University of Glasgow, First Floor, Admin Building
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow, G12 0XH

NHS GG&C Board Approval

Dear Miss McAllister,

| | |
|-------------------------------------|---|
| Study Title: | A qualitative investigation of the experiences of women with breast cancer between surgery and adjuvant chemotherapy. |
| Principal Investigator: | Miss Lauren McAllister |
| GG&C HB site | Beatson West of Scotland Cancer Centre |
| Sponsor | NHS GG&C |
| R&D reference: | GN14ON466 |
| REC reference: | 14/WS/1103 |
| Protocol no: | Version 8 - 20.10.14 |
| (including version and date) | |

I am pleased to confirm that Greater Glasgow & Clyde Health Board is now able to grant **Approval** for the above study.

Conditions of Approval

1. **For Clinical Trials** as defined by the Medicines for Human Use Clinical Trial Regulations, 2004
 - a. During the life span of the study GGHB requires the following information relating to this site
 - i. Notification of any potential serious breaches.
 - ii. Notification of any regulatory inspections.

It is your responsibility to ensure that all staff involved in the study at this site have the appropriate GCP training according to the GGHB GCP policy (www.nhsggc.org.uk/content/default.asp?page=s1411), evidence of such training to be filed in the site file.

2. **For all studies** the following information is required during their lifespan.
 - a. Recruitment Numbers on a quarterly basis
 - b. Any change of staff named on the original SSI form
 - c. Any amendments – Substantial or Non Substantial
 - d. Notification of Trial/study end including final recruitment figures
 - e. Final Report & Copies of Publications/Abstracts

Please add this approval to your study file as this letter may be subject to audit and monitoring.

Your personal information will be held on a secure national web-based NHS database.

I wish you every success with this research study

Yours sincerely,



Lorn Mackenzie
Senior Research Administrator

cc: Dr S Wilson, University of Glasgow

Appendix 6: West of Scotland Research Ethics Approval Amendment



Dr Sarah Wilson
Senior Lecturer in Health Psychology
University of Glasgow
Department of Mental Health and Wellbeing
First Floor Administration Building,
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH

West of Scotland REC 1
Ground Floor - Tennent Building
Western Infirmary
38 Church Street
Glasgow
G11 6NT

Date 27 March 2015
Direct line 0141 211 6270
E-mail WoSREC1@ggc.scot.nhs.uk

Dear Dr Wilson

Study title: A qualitative investigation of the experiences of women with breast cancer between surgery and adjuvant chemotherapy
REC reference: 14/WS/1103
Amendment number: Amendment 01, 16th March 2015 (REC Ref AM01)
Amendment date: 16 March 2015
IRAS project ID: 156961

The above amendment was reviewed by the Sub-Committee in correspondence. It is proposed to change the inclusion criteria of the study to include women who are commencing adjuvant radiotherapy treatment following surgery for breast cancer. The reason for the change is because the numbers of women having chemotherapy were not sufficient for the study. Widening the criteria will allow for sufficient numbers to be recruited.

The main point of interest for the study is women's experiences of the transition from surgical treatment to adjuvant treatment and their communication with the different people involved in their care. Therefore, changing the inclusion criteria will not change the focus of the study.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

| Document | Version | Date |
|--|--|---------------|
| GP/consultant information sheets or letters | 3 | 16 March 2015 |
| Interview schedules or topic guides for participants | 3 | 16 March 2015 |
| Letters of invitation to participant | 3 | 16 March 2015 |
| Notice of Substantial Amendment (non-CTIMP) | Amendment 01, 16th March 2015 (REC Ref AM01) | 16 March 2015 |

| <i>Document</i> | <i>Version</i> | <i>Date</i> |
|---------------------------------------|----------------|---------------|
| Participant consent form | 4 | 16 March 2015 |
| Participant information sheet (PIS) | 4 | 16 March 2015 |
| Research protocol or project proposal | 9 | 16 March 2015 |

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

| | |
|-------------|--|
| 14/WS/1103: | Please quote this number on all correspondence |
|-------------|--|

Yours sincerely

Abibat Ackwumi

On behalf of
Dr Malcolm Booth
Chair

Enclosures: List of names and professions of members who took part in the review

*Copy to: Dr Nathaniel Brittain, NHS Greater Glasgow & Clyde
Ms Emma-Jane Gault, NHS Greater Glasgow & Clyde/University of Glasgow*

Appendix 7: NHS Greater Glasgow and Clyde Research and Development Management Approval - Amendment

Dear Miss McAllister

R&D Ref: GN14ON466

Ethics Ref: 14/WS/1103

Investigator :Dr Sarah Wilson

Project Title: A qualitative investigation of the experiences of women with breast cancer between surgery and adjuvant chemotherapy.

Protocol Number:V9 dated 16/03/15

Amendment: SA01 dated 16/03/15

Sponsor: NHS GG&C Health Board

I am pleased to inform you that R&D have reviewed the above study. Amendment and can confirm that Management Approval is still valid for this study.

| Reviewed Documents: | Version | Dated |
|--------------------------------|---------|----------|
| Sponsor authorisation email | --- | 16/03/15 |
| Notification of Amendment form | 3.5 | 16/03/15 |
| REC approval | --- | 27/03/15 |
| Interview schedule | 3.0 | 16/03/15 |
| Letter to clinicians | 3.0 | 16/03/15 |
| Letter to participants | 3.0 | 16/03/15 |
| Participants consent sheet | 4.0 | 16/03/15 |
| PIS | 4.0 | 16/03/15 |
| Protocol | 9.0 | 16/03/15 |

I wish you every success with this research project.

Yours sincerely

Lorraine

Lorraine Reid
Senior Research Administrator
Research & Development
R&D Management Office
1st Floor, Tennent Institute
Western Infirmary
Glasgow
G11 6NT
Tel: 0141 211 1743

Appendix 8: NHS Greater Glasgow and Clyde Research and Development Management Approval – Amendment

Dear Miss McAllister,

R&D Ref: GN14ON466

Ethics Ref: 14/WS/1103

Investigator: Dr Sarah Wilson

Project Title: A qualitative investigation of the experiences of women with breast cancer between surgery and adjuvant chemotherapy.

Protocol Number: V9 dated 16/03/15

Amendment: NSA (AM02) dated 19/05/15

Sponsor: NHS GG&C Health Board

I am pleased to inform you that R&D have reviewed the above study Amendment and can confirm that Management Approval is still valid for this study.

| Reviewed Documents: | Version | Dated |
|-----------------------------------|---------|----------|
| PIS (RAH) Clean &TC | V4 | 16/03/15 |
| PIS (VoL) Clean &TC | V4 | 16/03/15 |
| SSI Form (RAH) | V4.0 | 22/05/15 |
| SSI Form (VoL) | V4.0 | 22/05/15 |
| Head of Department Approval Email | --- | 29/05/15 |

Kind Regards,

Research and Development Department

NHS Greater Glasgow and Clyde

Research and Development Central Office

Tennent Institute 1st Floor

Western Infirmary

38 Church Street

Glasgow, G11 6NT

Scotland, UK

Appendix 9: Participant Consent Form



University
of Glasgow



Consent Form

Title of study: A qualitative investigation of the experiences of women with breast cancer between surgery and adjuvant therapy

Name of researcher: Lauren McAllister

Contact details: Academic Department,
First Floor, Admin Building,
Gartnavel Royal Hospital,
1055 Great Western Road
Glasgow, G12 0XH
Email: l.mcallister.1@research.gla.ac.uk

Please write your initial in each box if you agree with the statement:

1. I confirm that I have read and understand the information sheet
(version 4, 16/03/15) for the above study ☐
2. I confirm that I have had the chance to consider the information
and that the researcher has answered any questions to my satisfaction ☐
3. I understand that my participation is voluntary and that I am free to
withdraw from the study at any point without having to give a reason
and with no consequences ☐
4. I understand that I can ask for my data to be withdrawn from the
research at any point ☐
5. I understand that my information will remain confidential and that any
information that could identify me will not be made publicly available.
Representatives from NHS GG&C may look at my information for ☐

audit purposes

6. I give permission for my interview with the researcher to be
digitally recorded ☐
7. I give permission for anonymised quotations from my interview to be
used in reports about the research ☐
8. I give permission for the Consultant Oncologist in charge of my
overall care to be informed of my participation in this study ☐
9. I consent to being a participant in this project ☐

Name of participant

Date

Signature

Researcher

Date

Signature

Appendix 10: Participant Invitation Letter



University
of Glasgow



Dear

A qualitative investigation of the experiences of women with breast cancer between surgery and adjuvant therapy

My name is Lauren McAllister and I am a Trainee Clinical Psychologist studying at the University of Glasgow. As part of my training, I am carrying out a research study looking at the experiences of women with breast cancer in the period between surgery and adjuvant treatment. Adjuvant therapy is treatment that you have after surgery. This could be radiotherapy or chemotherapy. I enclose an information sheet for you to read over.

If you decide that you would like to take part in the study, I will contact you to arrange a time for an interview. This interview could take place in the Beatson West of Scotland Cancer Centre, or over the telephone if you would prefer. Either option would involve a discussion of up to 60 minutes to find out about your experiences.

The discussion will be recorded on a digital voice recorder to ensure that I gain a full understanding of your views. All information will be treated with the utmost confidentiality, however, if something is revealed during the discussion that suggests you or anyone else is at risk of harm, you will understand that it is then my duty to share this information with other appropriate health professionals. You will be able to take breaks during the interview at any time you wish for any reason. After recording, the interview will be transcribed word for word and any references to people or places will be made anonymous. Once the transcript has been checked for completeness and accuracy, the recording will then be destroyed. It will not be possible to identify you from the transcript as it will be given a code for identification. Information linking your name to the identifying code will be stored separately and securely from the rest of the data.

If you would like more information, please do not hesitate to contact me by telephone on 07979 495942 or by email at l.mcallister.1@research.gla.ac.uk.

Yours sincerely,

Lauren McAllister
Trainee Clinical Psychologist

Supervised by:

Dr Sarah Wilson
Senior Lecturer in Health Psychology
University of Glasgow

Dr Christopher Hewitt
Consultant Clinical Psychologist
Beatson West of Scotland Cancer Centre

Appendix 11: Participant Information Sheet



University
of Glasgow



Participant Information Sheet

Introduction

My name is Lauren McAllister, and I am a Trainee Clinical Psychologist enrolled at the University of Glasgow. You have been given this information sheet because you are being invited to take part in my final-year research project, which will be submitted as part of my Doctorate in Clinical Psychology. The project is supervised by Dr Sarah Wilson, Senior Lecturer in Health Psychology, School of Medicine, University of Glasgow and Dr Christopher Hewitt, Consultant Clinical Psychologist.

Title of study

A qualitative investigation of the experiences of women with breast cancer between surgery and adjuvant therapy

What is the purpose of the study?

I am interested in finding out about your experiences of the time between receiving surgery for breast cancer and starting adjuvant therapy. Adjuvant therapy is treatment that you have after surgery. This could be chemotherapy or radiotherapy. In particular, I am interested in your experiences of communicating with the different healthcare professionals involved in your treatment so far, and how these experiences have impacted on your expectations of your treatment.

Why have I been chosen as a potential participant?

You have been given this information sheet because you have recently had treatment surgery for breast cancer and are scheduled to undergo adjuvant therapy as part of your treatment.

Do I have to take part?

No. You do not have to take part in this study if you do not wish to. Participation in the study is entirely voluntary. Your care and treatment will not be affected in any way if you choose not to take part in the study. You are also free to withdraw from participation in the study at any point. You do not have to give a reason if you decide to withdraw from the study. You may also request that any information you have provided is withdrawn from the study.

What will happen if I choose to take part?

If you decide you would like to take part in the study, I will contact you to arrange a suitable time to meet with you. We will meet in a private room at the Beatson West of Scotland Cancer Centre. I will ask you to sign a consent form (Version 4, 16/03/2015) to confirm that you understand what is being asked of you and that you are happy to take part.

The interview will last for no more than one hour. I will electronically record the interview to make sure that I have an accurate record of what we have talked about.

Alternatively, if you decide you would prefer a telephone interview I will post a consent form (Version 4, 16/03/2015) to you before the interview, with a stamped addressed envelope for you to return the form. Once I have received your completed consent form, I will contact you to arrange a suitable time for the interview. The call to you will be made from a private room. The interview will last no more than one hour. Telephone interviews will also be recorded using a digital voice recorder to ensure an accurate record of what is discussed.

Are there any risks or disadvantages to taking part in the study?

There are no direct risks involved in taking part in this study, although you might find it distressing speaking about some of your experiences. You may take a break or stop the interview at any point if you choose to do so. If you need further support after the interview, arrangements can be made for this.

Are there any benefits of taking part in the study?

There are no direct benefits to you of taking part in this study; the findings from this study may lead to new knowledge, which could be used to help other people in a similar situation to you in the future.

Will my information remain confidential?

Any information you provide as part of the study will remain confidential. The only people who will have access to this information will be the lead investigator, the academic supervisor (Dr Sarah Wilson) and the field supervisor (Dr Christopher Hewitt). Representatives of the study Sponsor, NHS GG&C may also have access to your information to make sure the study is being conducted properly. Your information will be stored securely. The Consultant Oncologist in charge of your overall care will know that you are taking part in the study. They will not be told what you have said in the interview unless I have to break confidentiality if there was anything discussed in your interview that suggested there was a risk to yourself or to someone else. I would discuss this with you first.

What will happen to my information?

The results of the study will be written up as a report, which will be submitted as part of the lead researcher's Doctorate in Clinical Psychology. The results will also be submitted for publication in a scientific journal and may be presented at conferences. Quotes may be used from what you have said in the reports. However, any information that could identify you, such as your name or location, will be removed from any reports. You will also have the option to be notified when the study report is available.

Following your interview, the recording will be kept in a locked cabinet. Only the researchers will be able to access this. After the interview has been transcribed it will be deleted from the recording device and computers. Transcriptions will be stored on a secure password protected laptop.

Who has reviewed the study?

A member of the course team from the West of Scotland Doctorate in Clinical Psychology programme has reviewed the study. Approval has also been given by the West of Scotland Research Ethics Committee and NHS Greater Glasgow and Clyde Research &

Development department.

What to do next

If you have any further questions about the study or would like to discuss it further, please do not hesitate to email me on l.mcallister.1@research.gla.ac.uk or telephone me on 07979 495942. If you wish to find out more about taking part in research you can visit the INVOLVE website at <http://www.invo.org.uk/> . This is an independent website.

If you would prefer to discuss the project with a person who knows about, but is not directly involved in this research please contact Dr. Alison Jackson on 0141 211 0607.

If you decide that you would like to take part, please complete the opt-in form below and return it in the stamped addressed envelope provided. Once I have received this I will contact you to arrange a suitable time to meet with you. You have up to three days from receiving this information sheet to opt-in. This is because interviews will be carried out before your chemotherapy starts.

If you do not wish to take part you do not need to do anything else.

I would like to thank you for taking the time to read this information sheet.

Contact DetailsPrincipal Investigator

Lauren McAllister
Trainee Clinical Psychologist
Mental Health & Wellbeing,
First Floor, Admin Building,
Gartnavel Royal Hospital,
1055 Great Western Road
Glasgow,
G12 0XH

Academic Supervisor

Dr Sarah L. Wilson
Senior Lecturer in Health Psychology,
Mental Health & Wellbeing,
First Floor, Admin Building,
Gartnavel Royal Hospital,
1055 Great Western Road
Glasgow,
G12 0XH

Field Supervisor

Dr Christopher Hewitt

Consultant Clinical Psychologist
Beatson West of Scotland Cancer Centre,
1053 Great Western Road,
Glasgow,
G12 0YN

Research study: A qualitative investigation of the experiences of women with breast cancer between surgery and adjuvant therapy

Researcher: Lauren McAllister, Trainee Clinical Psychologist

I am interested in taking part in this study.

My preferred means of contact is*: post / telephone / email * delete as appropriate

Please provide details of your preferred means of contact in the space below

Address: _____

Telephone number: _____

Email address: _____

If you wish to be contacted by telephone, are you happy for a message to be left on an answering machine? Yes / No * *delete as appropriate

Participant name:

Date:

Signature:

Return Address:

*Lauren McAllister
Trainee Clinical Psychologist
Mental Health & Wellbeing,
First Floor, Admin Building,
Gartnavel Royal Hospital,
1055 Great Western Road
Glasgow,
G12 0XH*

Appendix 12: Interview Schedule



University
of Glasgow



Interview Schedule

Introduction

- introduce myself and my role as researcher / trainee clinical psychologist
- thank participant for agreeing to take part in the study
- remind participant about confidentiality and its limits
- remind participant that they can stop for a break at any point in the interview if they need to do so, and that they can withdraw from participation at any point
- demographic details – name and age

Interview questions:

- Please could you tell me about your experiences of treatment so far?
- How did you find the transition between the surgical team and the oncology team?
 - How have you coped with this?
 - Positive aspects?
 - Negative aspects?
- How were you prepared for further treatment following your surgery?
 - What were you were told
 - How were you told this?
 - How satisfied were you with this information?
- Can you tell me about your experiences of communicating with the different professionals involved in your treatment so far? For example, the surgeon, the breast care nurse, the oncologist, the GP.
 - Have there been any differences between these consultations?
 - In what ways have they been different?
 - Have these experiences impacted on your expectations of your treatment?
- How have your expectations of treatment changed as it has progressed?
- What were/are your expectations and feelings about receiving chemotherapy or radiotherapy?
 - What are these expectations based on?
 - Have you discussed these with anyone?
- What do you think about the information you have received about your care from

the people involved in your treatment?

- Before the breast surgery
 - After the breast surgery
 - When you came to the Beatson for the first time
 - What information would be most useful to you and when would it be most helpful to receive that information?
- Have you used any other sources of information to find out about any of your treatment?
 - If so, what are they?
 - How did you come to find these – for example, your own research, signposted by healthcare professionals, other patients etc.
 - Are there any communication issues you see as important for women in a similar situation?
 - Is there anything I haven't asked you about that you think it is important that I should know about?

Examples of general prompts that will be used throughout the interview:

- “Can you tell me a bit more about that?”
- “What was that like?”
- “How did it make you feel?”
- “Can you give me an example?”
- “What do you mean by ... ?”

Appendix 13: Excerpt from interview 2 with Lucy (pseudonym)

| Emerging Themes | Original Transcript | Exploratory Comments |
|-----------------------------------|---|--|
| Nurse's role | <p>So, em, so then the breast nurse takes you away after the doctor speaks to you then you get asked loads of questions. It's quite good when you have somebody else there because [husband] was asking things. Cause I was – she was just telling me things and I was thinking “right, okay, okay, okay” [laughs]. Just aye that's fine, but he was maybe thinking on things that I wasn't thinking to ask. He'd asked about hair loss and all different things. And they just tell you straight, yeah that you'll lose your hair and different things so you kinda go away - You know some bits will be tough but you don't know everything I don't think until you come then for your – My first appointment here, which was a couple of weeks ago now. It was just, it was all just about information, it wasn't starting. Em so I went in to see Dr [oncologist] first and she explained all about chemo and why you need it and what it does em [pause] the effects that it can have. She went through all your you know, your height and your weight and all this sort of stuff. Ehm then you go and you see another breast care nurse after that and she goes through more in detail. They get you a leaflet with all the different side effects but everybody's different so you can't - No two people will maybe have the same experience, you know, so some people are sick, some people are normal. But Dr [oncologist] told me they always try to, when they're giving you the different types, if you're not well with one particular type they will change it. It's not like before, they've come on leaps and bounds and what they'll do is they'll change it to try and suit you particularly. Em, so they told me all about that and hair loss and different things [pause] and the other nurse</p> | Nurses role – nurses add to what doctor says, validates, reassures. |
| Shock | | |
| Emotional response to information | | Shock stops her from fully engaging with the information. |
| Supportive others | | Factual information given upfront. |
| Knowing enough | | Hair loss most salient. Other side effects seem non-specific. |
| Side effects | | Information unfolds – you find out more as you go. Doesn't seem to be a problem for her. |
| Uncertainty | | |
| Information unfolding | | Pause - side effects seem hard to think about |
| Nurse's role | | Nurse adds to what doctor tells you – backs up, reassures. |
| Anxiety about side effects | | Receiving information |
| Minimising the possibilities | | Side effects might not happen to her – minimising possibility, staying hopeful. |
| Doctor reassures | | Hearing the reassuring information |
| | | Expectations of chemotherapy – what it was like in the past. |
| Side effects | | |
| Knowing enough | | Pause – are side effects hard to think about? |

| | | |
|-------------------------|--|---|
| Relationship with staff | basically it was just em she went through everything with a fine tooth comb and then gave me like a list of phone numbers and told me about yourself and she takes you round to see the chemo suite and where you'll sit and that. So I got bloods taken that day and that was great, it was very quick and painless, because some people can - I've had blood taken quite a few times and some people are better than others [laughs] trying to find your veins you know. I think today I'm getting it through my hand so that's okay cause my hands are really veiny but my arms aren't veiny but em - So that's - that's it, she showed me round, I got my bloods taken then and she says that'll do me for today and she explained then that what they'll do after today is they'll give me em - it'll be every three weeks for six - I'll be getting six sessions so that'll be eighteen weeks and what'll happen is three to four weeks after the last session then I'll get my surgery done. Em so I met the plastic surgeon and he was - he was lovely, in the Western. So we've had that whole em - Talked about different reconstruction types you can have and em [pause] he - he was explaining, he gives you the pros and cons of it all and you get a book to take home and a DVD which we haven't watched yet cause I haven't - I've kind of flicked through the book but I thought "Och nearer the time". Cause basically there's a choice of you can either get it taken off your back or your stomach or you can get an implant in. And he tells you all the pros and cons of them all but you have to go away and look and decide what's best for you. But also if you want it taken from your stomach it's all to do with your blood vessels so I had another MRI last week and that's for, for him, for forward thinking if I want to get it taken from my stomach so that they can see what your blood vessels are like and stuff. | Knowing who to contact |
| Knowing enough | | Some uncertainty |
| Information unfolds | | Knowing enough about what to expect. |
| Looking ahead | | Small details make a difference |
| Getting through it | | Timescales - she finds certainty in the uncertainty. |
| Coping with uncertainty | | Looking ahead - contrast to taking it a day at a time. |
| Managing information | | She chooses what to read and when. Controlling the information. |
| Coping | | Staying present - thinking about the here and now. |

Appendix 14: Major Research Project Proposal

MRP Proposal

Proposal Title A qualitative investigation of the experiences of women with breast cancer between surgery and adjuvant chemotherapy

Word Count 3809 (not including appendices)

Date of Submission 23rd June 2014

Version Number 5

Abstract

Background

Research shows that communication with professionals is key in cancer care. Difficulties with communication have been associated with increased psychological distress. Women with breast cancer often report high levels of unmet need in terms of information and communication. Research is further complicated by the fact that patients often receive treatment from a number of professionals in different settings.

Aims

This study aims to gain insight into the experiences of women with breast cancer of their transition from surgical to adjuvant chemotherapy. Of particular interest are the expectations women have of chemotherapy, and how these expectations are formed.

Method

Participants will be primary breast cancer patients who have undergone surgery and are scheduled to receive adjuvant chemotherapy. A qualitative design will be used and data will be gathered through use of semi-structured interviews. Interviews will be analysed using Interpretative Phenomenological Analysis (IPA).

Applications

The results will give insight into the experiences and needs of women with breast cancer at this point in the care pathway. This could allow for further development of ways of assessing and meeting needs, and minimising distress at this time. The results may also provide suggestions for further research.

Introduction

Much research has focused on the importance of communication and information-giving in cancer care. This suggests that patients with cancer seek information as a means of coping with their illness (e.g. Van der Molen, 2000). Indeed, the SIGN Guidelines (2013) for the treatment of primary breast cancer emphasise the importance of information provision to patients and their families. The most common factors found to contribute to patients' overall satisfaction with care are level of information given and interpersonal relations between the patient and provider. Satisfaction with care is associated with better co-operation with treatment, which is associated with better clinical outcomes (Sandoval,

Brown, Sullivan & Green, 2006). A literature review found that poor communication can have negative outcomes for patients, including poor engagement with treatment and increased psychological distress (Thorne, Bultz & Baile, 2005). Sandoval et al. (2006) found the areas that were consistently rated as problematic by the patients with cancer in their study included: information about follow-up care, knowing the next step in treatment, and knowing who to go to with questions. In addition, patients often show misunderstandings about their treatment, illness and prognosis. This may be in part due to lack of clear communication or withholding of information (Jefford & Tattersall, 2002). It seems therefore that information giving may help shape and form patients' expectations of their treatment.

Cancer care can be thought of as a trajectory or journey, comprising a number of stages. Some authors delineate five key stages, including diagnosis, end of primary treatment, remission, relapse, and palliative care (e.g. Morse & Fife, 1998). Evidence suggests that the information and communication needs of patients vary at these different stages. For example, a qualitative study examining the information needs of 6 patients with different cancers found that needs changed across the different stages of the cancer experiences, and that patients were less able to process information at certain times (Van Der Molen, 2000). Patients interviewed by Tsianakis et al. (2012) described feeling vulnerable at certain points in the care pathway. Their experienced lack of continuity of care appeared in part to be related to this.

Continuity of care

Investigation of communication in cancer care is further complicated by the fact that patients often receive treatment from a number of professionals in a range of settings at different stages of treatment. This may have a negative impact on patients' experiences of continuity of care (Harley et al., 2009). Continuity of care has been defined as 'the degree to which a series of discrete healthcare events is experienced as coherent and connected' (Haggerty et al., 2003; p. 1221). They emphasise that continuity is about how individuals experience the services they receive; qualitative methods may therefore be especially suited to examining patients' experiences.

A qualitative study by Nazareth et al. (2008) examined 7 patients' experiences of continuity in cancer care at different transition points. Communication between primary and secondary care, the role of different health professionals and administrative systems were found to influence continuity of care. This study, however, was based on people living with colorectal and breast cancer, which does not allow for examination of potential differences between patients with different cancer types.

Breast cancer

Some studies have examined the communication needs and experiences of women with breast cancer across the care pathway. Breast cancer is the most commonly diagnosed cancer in women in the UK. The incidence of breast cancer in Scotland is 127.1 people per 100,000 (Cancer Research UK, 2013). The main treatments are surgery, chemotherapy, radiotherapy, hormone treatment and biological therapy. These can be used in isolation or in combination.

Graydon et al. (1997) used a questionnaire to assess the information needs of three groups of women with breast cancer at different stages in treatment (surgery, chemotherapy and radiotherapy). Each group reported a strong need for information, with no significant differences between the groups. A cross-sectional questionnaire based study by Raupach and Hiller (2002) looked at the information needs of a sample of 266 women with breast cancer between 6 and 30 months since diagnosis. They found a continued high need for information about breast cancer issues regardless of time since diagnosis; their results also suggested that this need was often unmet, and that information giving decreased over time. In contrast, a longitudinal study by Vogel, Bengel and Helmes (2008) found that the women with breast cancer in their study (n = 135) reported the highest information needs at the beginning of treatment, compared to 3 and 6 months follow-up.

Other studies have adopted a qualitative approach. Thomsen and colleagues (2007) assert that questionnaire based studies of communication can often show a positive response bias, and may constrain the responses people give on a topic. They interviewed 15 women with breast cancer about specific positive and negative communication experiences from their treatment 3 months after completion of adjuvant chemotherapy. Information giving and the meeting of emotional needs were key themes arising from the analysis. The authors note that the relatively long gap between the end of treatment and interview, however, may have led to recall bias. Stephens et al. (2008) interviewed 200 women newly diagnosed with breast cancer who had recently received surgery, with the aim of identifying women's needs and concerns at this time. They identified a number of needs including social, emotional, physical and spiritual needs. Participants also identified anxiety about possible future treatments as a concern.

Qualitative and quantitative studies reveal conflicting results with regards to breast cancer patients' experiences of communication and information giving. Some studies have used relatively heterogeneous samples (e.g. a mixture of stages and types of cancer), which may mask differences between patients with different cancers. Some studies have waited until women have completed treatment to ask about their overall experiences. Retrospective recall may obscure potential differences across the cancer trajectory. Reporting experiences could also be affected by recall bias or by the outcome of treatment. Birchall, Richardson and Lee (2002) suggest that the complexity of patient experiences may not be adequately captured by questionnaires.

Adjuvant treatment

Fiszer and colleagues (2013) recommend that studies should attend to specific times in the breast cancer journey, to gain a dynamic understanding of women's needs at different stages. Some research has examined the particular information needs of women with breast cancer undergoing adjuvant treatments. Lerman et al. (1993) surveyed 97 women after surgery but before adjuvant treatment, and 3 months later. They found that most patients experienced difficulties with comprehending information and asking questions prior to adjuvant treatment. More communication problems at the first time point were associated with greater distress at follow-up. It has been suggested that information provision can reduce stress associated with adjuvant treatments (Adams, 1991).

A qualitative investigation of the information needs of 51 patients with mixed cancer types (including breast cancer) and 14 of their spouses, with regard to the side effects of chemotherapy and radiotherapy, suggested that patients generally wanted as much

information as possible about the process of treatment and possible side effects. The difficulties reported with getting this included access to and relationships with healthcare providers, difficulties retaining information, and too much information to digest (Skalla et al., 2004).

Several studies have examined the specific information needs of women undergoing radiotherapy. A literature review (Sutherland, 2014) found that women's needs change over the course of treatment, and that these needs are not always met. There has been less investigation of the needs of women undergoing adjuvant chemotherapy. Evidence suggests that patients receiving chemotherapy experience considerable emotional distress (DiLorenzo et al., 1995). The highest level of distress has been found to occur prior to the first infusion of chemotherapy, perhaps because of patient expectations about treatment (Jacobsen, Bovberg & Redd, 1993). It is unclear exactly how these expectations are formed and how women's experiences up until this point may have impacted on their expectations.

West of Scotland Context

In the West of Scotland women diagnosed with breast cancer are usually seen by their surgeon first. Following surgery they are under the care of Beatson West of Scotland Cancer Centre (BWoSCC) for adjuvant treatment. Communication and information sharing may be particularly important during this period as these may impact on women's expectations of adjuvant treatment and their subsequent engagement with treatment. Women's experience of transition between the two phases of treatment is therefore of interest. The BWoSCC serves a geographically diverse population, which may also impact on the experience of transitions of care – e.g. through patients travelling for treatment. To the best of the author's knowledge, no studies have examined transitions in cancer care in Scotland.

In summary, research consistently suggests that information giving and communication are important in cancer care for a number of reasons including minimising patient distress and improving engagement with treatment. Difficulties with communication may have psychological consequences for patients. Patients also have contact with a number of professionals over the course of treatment and care pathways can be complex. It seems likely that experiences of communication with differ at each time point. Closer attention to different points in the cancer journey is therefore warranted as these factors may impact on patients' expectations of and engagement with further treatment.

Aims / Objectives

The proposed study aims to gain insight into the experiences of women with breast cancer of their transition from surgical treatment to adjuvant chemotherapy. It will explore their perceptions of communicating with the different professionals involved in their care in order to gain more detailed information about their needs between these stages of treatment. Of particular interest are the expectations women have of adjuvant chemotherapy, and how these are formed.

Plan of Investigation

Design

This study will take a qualitative approach to understanding women's experiences of the period between surgery and adjuvant treatment, using Interpretative Phenomenological Analysis (IPA). Smith et al. (1999) suggest that IPA is particularly appropriate for health psychology research. IPA involves 'the detailed examination of personal lived experience, the meaning of that experience to participants and how participants make sense of that experience' (Smith, 2011, p. 9). IPA also emphasises the role of interpretation by the researcher during analysis.

Participants

There are a number of different care pathways for patients, depending on type and stage of cancer and treatment options. A purposive, well-defined homogeneous sample will be recruited in terms of type of breast cancer and treatment pathway. This will allow detailed examination of similarity and variability within the sample (Smith et al., 2009). The sample will consist of women with early breast cancer who are treated initially with surgery and are scheduled to receive adjuvant chemotherapy.

Inclusion and Exclusion Criteria

Inclusion criteria will include women with primary breast cancer (Stage I or II) who have had surgery and will receive adjuvant chemotherapy. Exclusion criteria will include:

- patients under 30 years old – there is a steep increase in age-specific incidence rates from the ages of 30 – 34 onwards (Cancer Research UK, 2014). This will allow a more homogeneous sample to be recruited.
- those for whom English is not their first language
- women with a prior history of cancer
- those who have received neo-adjuvant chemotherapy
- men diagnosed with breast cancer, as they represent a very small percentage of cases
- women with ductal carcinoma *in situ* (DCIS), as research suggests that the experiences of these patients may be different (e.g. Kennedy et al., 2012)

Recruitment Procedures

Women will be identified by their oncologist or their named nurse at their first or second oncology appointment at the BWoSCC following confirmation of their adjuvant treatment plan. Patients identified as suitable will be given an information pack. Potential participants will then complete a consent form giving permission for the researcher to contact them about the study (see Appendix A).

Given that this research will involve women whose physical health may be compromised, telephone interviews will be offered to all potential participants. It has been suggested that telephone interviews could result in the loss of non-verbal information, which could impact

on data analysis; telephone interviews may, however, allow participants to feel comfortable and to disclose sensitive information (Novick, 2008). Sturges and Hanrahan (2004) found no significant differences in data quality between telephone and face to face interviews.

Research Procedures

Interviews will take place on a one-to-one basis and will last for approximately one hour. Participants will be reminded before starting, of the purpose of the interview and their right to withdraw at any point if they so choose. The schedule will be semi-structured and topic guide will be developed to facilitate the interview (Appendix B). Relevant background research and discussion with supervisors and clinicians was used to develop the interview guide. Prompts will be used to encourage participant elaboration on topics. A non-directive approach will be adopted by the interviewer. Interviews will be recorded and transcribed verbatim, then checked for accuracy and completeness. All interviews will be anonymised for references to person or place.

Data Analysis

Interviews will be analysed using IPA. Transcription and analysis of data will begin following the first interview to help inform future interviews. A sample of interview transcripts will be analysed blind by the academic supervisor to ensure the plausibility (Smith et al., 2009; p.80) of the analysis. Once the first 2 -3 interviews have been conducted they will be transcribed and reviewed with the project supervisors to ensure that the topic guide is eliciting the right sort of material. The topic guide will then be reviewed if necessary. Data from these interviews will be included in the final analysis.

The first stage of analysis, as described by Smith et al. (2009), involves reading the transcript several times to become as familiar as possible with the data. In stage two, anything of interest in the transcript will be noted. Some of these notes will be descriptive comments which describe or summarise the participant's account. Other notes may explore the participant's use of language. There may also be some initial interpretations of the data at this stage. The third stage of analysis involves the development of emergent themes from the initial notes. These themes will be given a title or phrase to capture the essence of the theme. In stage four, the research will attempt to make connections across the emergent issues. These four stages will be carried out with each interview transcript. Patterns across cases will then be explored.

Justification of Sample Size

Power calculations are not appropriate for qualitative research because sample size is not pre-determined. In contrast to quantitative studies, generalisability is not the aim of qualitative research; rather, the goal is to generate detailed accounts of individual experience. Between 4 and 10 interviews will be sought in line with Smith, Flowers and Larkin (2009), who state that this is appropriate for research for a professional doctorate. Discussion with clinicians at the BWoSCC indicates that 2 women per week would meet the inclusion criteria for the study.

Settings and Equipment

Clinic rooms in BWoSCC will be used for interviews. Equipment required will include a digital voice recorder, a telephone recording device for telephone interviews and a computer for transcription of interviews. Telephone interviews will take place in a private room in the NHS Greater Glasgow & Clyde premises where the researcher is on placement.

Health and Safety Issues

Researcher safety issues

Interviews will take place at the BWoSCC during working hours when other staff will be in the building. Local safety procedures will be adhered to. If any participants choose a telephone interview a private office will be used.

Participant safety issues

Participants will have undergone surgical treatment and as such their physical health may be compromised. In addition it may be necessary to interview some participants after their chemotherapy has started, because of the time scales involved in treatment. The researcher will seek to provide a comfortable environment for interviews. Telephone interviews will be offered where travel time or physical discomfort would make face to face interviews difficult. It is also recognised that this study will involve the discussion of potentially distressing topics for participants. If participants become distressed during interviews this will be managed in a supportive manner by the researcher. Participants will be reminded of their right to withdraw from the research at any stage, or to take a break and continue when they are comfortable doing so. Participants who wish to seek psychological support will be advised of the referral process. If participants raise issues about their medical care they will be advised to speak to their named nurse.

Ethical Issues

Applications will be submitted to the West of Scotland Ethics committee and the Beatson Clinical Trials Executive Committee for ethical approval prior to data collection. Written information will be provided to all participants and they will have the opportunity to ask questions. Informed consent will be sought from participants. Participation in the study will be voluntary and participants will have the right to withdraw at any time without this impacting on their on-going medical care in any way. Data will be held in line with NHS GGC policy and the Data Protection Act. Data will be held securely on an NHS GGC computer or on a University laptop encrypted to NHS standards.

Financial Issues

Recording equipment, including a digital voice recorder and telephone recording device, and transcription equipment is available from the University. There will be costs of printing and posting information sheets (Appendix C).

Timetable

April 2014 – Submit major research proposal to course
August 2014 – Submit application to ethics committee
November 2014 – Begin data collection
November 2014 – March 2015 – Continuing data collection and analysis
March – June 2015 – Write up
July 2015 – Submit major research paper to course

Practical Applications

The results of this study will provide an in-depth understanding of the experiences of women with primary breast cancer of the transition between surgery and adjuvant chemotherapy in the West of Scotland. This will provide a greater understanding of women's needs at this point in the care pathway. This could allow for further development of ways of meeting these needs and minimising distress at this time. This could also help inform further development of tools to assess patient needs and staff communication styles. The results of this study may also provide suggestions for further research. A plain English summary is provided in Appendix D.

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