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Women's perceptions of journeying towards an unknown future with breast cancer: the 'Lives at Risk Study'

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Review

Women’s perceptions of journeying towards an unknown future with breast cancer: the ‘Lives at Risk Study’

Abstract

Breast cancer risk classifications are useful for prognosis, yet little is known of their effect on patients. This study clarified women’s understandings of risk as they ‘journeyed’ through the healthcare system. Breast cancer patients and women undergoing genetic investigation were recruited (n=25) from a large UK Health Board, 2014 – 2015, completing a ‘Book of Experience’, and Bio-Photographic Elicitation Interview. Stakeholder and Participant Feedback Forums were undertaken with key Stakeholders, including patients, oncologists, funders and policy developers, to inform team understanding. Thematic and visual frameworks from multidisciplinary analysis workshops uncovered two themes: ‘Subjective understandings of risk’, and ‘Journeying towards an unknown future’. Breast cancer patients and women undergoing investigation experienced risk intuitively. Statistical formulations were often perplexing, diverting attention away from concrete life-and-death facts. Following risk classification, care must be co-defined to reduce patients’ foreboding about an unknown future, taking into consideration personal risk-management strategies and aspirations for a cancer-free future.

Introduction

Breast cancer is the most common form of cancer in women. In 2011 the World Health Organization estimated that over 508,000 women died of the disease worldwide (World Health Organization, 2013). In the United Kingdom (UK) alone, nearly 50,000 people are diagnosed and over 1,000 die annually (Cancer Research UK, 2016), with one in eight women likely to develop breast cancer in their lifetime. Most developed countries provide breast cancer patients with a care pathway, treatment plan, and risk prognosis (Cancer Research UK, 2014) which are also offered, to a more limited degree, to women who are undergoing genetic investigation for risk of breast cancer, as a result of a possible familial predisposition (Hilgart, Coles, & Iredale, 2012; Huiart et al., 2002). More extensive treatment planning for this group is only discussed if cancer is subsequently identified. Risk is still investigated in detail, with information provided about preventative approaches and how to remain vigilant. Early detection of carcinogenic cells and access to specialist oncology services can increase a woman's long-term survival rate (Cancer Research UK, 2016). Currently more than eight out of 10 women from the UK (85%) survive breast cancer beyond five years, and recent predictions indicate that 78% of women diagnosed in 2010/11 are likely to survive more than ten years after treatment, compared with 40% of women, 40 years ago (Cancer Research UK, 2016).

Classifying Risk

Risk prognosis assesses the likelihood of a person developing breast cancer across their lifespan and is followed by a risk status allocation (also known as risk classification), which adds vital information about overall health. Risk assessment takes place during the early stages of cancer investigation, or during active genetic investigation. The purpose of which is to improve survival rates through early detection of cancer (through screening

programmes) or to detect changes in cancer diagnosis in order to improve access to optimal treatment and management of patient care (Foot & Harrison, 2011). Oncologists and geneticists use prognostic tools such as the Nottingham Prognostic Index, or Adjuvant!© to direct consultations with patients and to formulate decisions around care and treatment (Hearne, Teare, Butt, & Donaldson, 2015). Risk is conveyed to patients using the terms: ‘low risk’ (also known as ‘population-level risk’); ‘moderate risk’ (also known as ‘raised risk’); and ‘high risk’ (also known as ‘increased risk’) (National Collaborating Centre for Cancer, 2013). On the basis of these classifications, risk status is often presented in percentage terms (Hearne et al., 2015), indicating a person’s survival rate five years post-diagnosis and treatment. How risk status is presented to a woman (be she at high, moderate or low risk) is also influenced by a clinician’s decisions regarding the likelihood of, for example, systemic (or distant) recurrence, a woman’s cancer stage, age, emotional state, and whether she is consulting prior to, or following, breast cancer treatment or other therapies.

Impact of Risk Assessment and Risk Classification

There are clear clinical advantages of risk classification for the oncology team to help them assess and deliver appropriate treatment and care or discuss treatment decisions with women. These options and discussions can affect a woman deeply, influencing her decisions about treatment and lifestyle, and views on survival (Chalmers & Thomson, 1996; Collins & Street, 2009; Hearne et al., 2015). Recent studies have identified incongruence between actual levels of risk and perceived levels of risk and the extensive impact that risk assessment and classification have on wider social networks. For example, even for those women undergoing genetic investigation and those classified as at low or moderate risk, classification can lead to raised anxiety levels (Audrain et al., 1997; Gilbar & Borovik, 1998; Miron et al., 2000; Petrisek, Campbell, & Laliberte, 2000; Wellisch et al., 1999). A recent United States

(US) study found that nearly 85% of women identified as high risk failed to attend a breast cancer screening program (Vaidya, Chetlen, & Schetter, 2015), while a United Kingdom (UK) survey identified that 17% of women diagnosed with breast cancer delayed General Practitioner (GP) visits after bodily changes, with 5% delaying for six months (Breast Cancer Care, 2015). Women's understanding of risk and subsequent differences in psychological response have been put down to age, gender and lifestyle, and for some this can often lead to mental distress continuing well into treatment (Hjörleifsdóttir, Hallberg, Bolmsjö, & Gunnarsdóttir, 2007). While conversations around risk can be highly informative (Li & Loke, 2014), they can also engender concern (Huiart et al., 2002), leading to greater risk-taking and other health-related negative outcomes (Ginter & Braun, 2016; van Dooren et al., 2004).

Prognostic Estimate

The UK's National Institute for Clinical Excellence (NICE) is a public body that provides clinical guidance, including guidance for risk assessment, aimed at supporting healthcare professionals and recommending treatments and services in relation to cost effectiveness (National Institute for Health and Care Excellence, 2016). Guidance from NICE has been refined over the years, following their early recommendations regarding prognostic estimates of risk being criticized by the likes of Jain (2007). Jain suggested early recommendations of NICE and others about prognostic estimates were: *'stunningly specific ... and bloodlessly vague'* (Jain, 2007, p. 78, p78), saying that for women diagnosed with breast cancer: *'you will only die or not die; you will not 70, or 42, or 97 per cent die'* (Jain, 2007, p. 81, p81). Jain (2007) used the term *'statistical panic'* to emphasize the peculiar power of statistics, echoing Woodward's (1999) view that:

If we generally regard statistics as a depersonalizing force ... we see that when we apply them to ourselves, creating our own emotional dramas out of them, they can

have an overwhelming power, orienting us to the world in a particular way
(Woodward, 1999, p 186).

Although patients may actively maneuver, reframe and discount the odds surrounding risk, they are nevertheless: *‘absorbed into the truth of prognosis, a truth that recursively projects a future as it acts as a container for a present’* (Jain, 2007, p79). It is little wonder, therefore, that Frank (1991) talks of a remission society where people never feel fully cured (Frank, 2002). Remission is an ambiguous term (Comaroff & Maguire, 1981), both clinically and experientially, concerned with whether the retreat of symptoms can ever be considered total. According to the literature in this context (Han et al., 2013; Kaplowitz, Campo, & Chiu, 2002; Khanom et al., 2015; Ohnishi et al., 2002), some patients may prefer qualitative to quantitative expressions of risk and probability, with subjective expressions and descriptions a more meaningful way of indicating one’s chances of survival (Thorne, Hislop, Kuo, & Armstrong, 2006).

The Cancer Journey and the Care Continuum

For both breast cancer survivors and women with a familial history of breast cancer the cancer journey and the ‘care continuum’ (how care pans out across the whole of a person’s cancer experience) can be convoluted and extensive. Women may need to make a number of return visits to hospital to undertake further investigations and genetic testing (Kirshbaum et al., 2016). Women with cancer and those under investigation for risk of cancer can receive different advice and guidance on each occasion, meet different healthcare professionals and have treatment plans change, as test results come in. The convoluted and complex nature of this can affect a woman’s general sense of anxiety (Khanom et al., 2015), as can the sharing of healthcare across multidisciplinary teams (MDTs), if a clinician’s role and responsibility is not clear to patients. We have indicated elsewhere that being moved

1
2
3 between healthcare professionals may help support patients' needs at different points on the
4 care continuum, but may also add to their sense of disjointed working practices and
5
6 incoherent care planning (Khanom et al., 2015). As a result, to understand risk we also need
7
8 to understand the broader aspects of the care continuum. This includes the patient's cancer
9
10 journey, the treatments and drugs prescribed, the patient's care experiences, relationships
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12 with healthcare professionals and others, and aspirations for the future. By looking at all of
13
14 these aspects together, and considering not only women who have had cancer but also those
15
16 being investigated for the risk of getting cancer, in a more fluid way, we will garner a deeper
17
18 understanding about the patient experience.
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23 **Services for Breast Cancer Survivors and those with a Familial History**

24
25
26 There is a plethora of epidemiological studies dedicated to investigating services for breast
27
28 cancer survivors, including those with a familial history, that examine risk factors, treatment
29
30 pathways, drug adherence, clinical outcomes and prognoses (Gandini, Merzenich, Robertson,
31
32 & Boyle, 2000; Gilbar & Borovik, 1998; Hjörleifsdóttir et al., 2007; Stacey, DeGrasse, &
33
34 Johnston, 2002; van Dooren et al., 2004). However few have explored the subjective
35
36 experiences of women or women's understandings of a continuum of care, for both women
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38 undergoing genetic investigation and women with a previous breast cancer history. Nor have
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40 these wide-ranging cohorts been considered together in terms of: subjective notions of risk,
41
42 impact of risk on people's lives, and how risk classification affects women at different stages
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44 of their involvement with healthcare systems. We need to recognize that risk means different
45
46 things to different people at different stages of their lives and cancer experience. While
47
48 researchers have talked of the '*cancer journey*' (Thorne et al., 2006), few have defined what
49
50 that means for individuals and how it impacts on risk perception (Mackillop & Quirt, 1997).
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54

55 **Purpose of this Article**

The unique contribution of this study is to provide an insight into women’s understandings of breast cancer risk, across the disease lifespan, and women’s views and experiences of the care continuum and the role they play in the cancer journey. This is irrespective of whether they are undergoing genetic investigation for the risk of cancer, or being treated for cancer, and regardless of the stage they might be at in their investigations and treatments. By working with different women at different stages, taking into account women’s perspectives, the study aimed to establish how the care continuum, which includes risk assessment and risk management consultation, affects women’s lives. This was achieved by delving deeply, using novel data collection methods, including Books of Experience and Bio-photographic elicitation interviews (see Methods), to disclose the implications of cancer and risk status for women, and how discovering more about one’s state of health affects subsequent decision-making. While the article highlights women’s perceptions in specific clinical scenarios (for example, a woman at risk of systemic recurrence, who is considering chemotherapy and a mastectomy, or a woman wanting to know the implications of genetic investigation for other family members), it does so in order to contextualize how the clinical situation and clinical decisions affect women’s experiences. This encourages emergent issues to come to light from the data from a patient perspective, whilst the study aims clearly concentrated on perceptions of risk and women’s journeys through cancer (see below).

Theoretical Stance

From the foregoing, we can establish our theoretical stance. Conceptually, we were looking at risk (Hilgart et al., 2012; Huiart et al., 2002), seeking to apprehend how it was constituted and enacted from the participants’ point of view. We also wanted to understand the context of their illness and embrace a conceptual model which viewed our participants as undergoing a complex, iterative, unfurling, sometimes enervating, sometimes enlightening

and sometimes enabling journeys. Therefore, our conceptual-theoretical model was one of journeying across time from the patients' perspective as they encountered risk. In addition, no research can ignore the instantiated mental models of the researchers who initiated, ran, and interpreted the study. Our theoretical stance approximated to that of social constructivists (Berger & Luckmann, 1966), i.e., we held that are own and our participants' knowledge was socially constructed and experienced. We favoured mixed methods for this, to understand complex phenomena from multiple perspectives, applying complexity science understandings to our work (Braithwaite et al., 2017).

Aims

- A) Identify how risk is defined by women, at various stages of investigation, diagnosis, treatment, and care for breast cancer, leading up to remission,
- B) Describe the different journeys women take along the care continuum, and their own expressions of need and experience as they move through the healthcare system towards better health.
- C) Disclose the views of a wide range of female patients, from those undergoing genetic investigation for risk of breast cancer to those undergoing post-breast cancer treatment.

Method

Study Design

This study adopted a multi-stage, multi-method, qualitative study design. It took place in the UK between March 2014 and March 2015. During Stage 1 Books of Experience were completed and analyzed and once analyzed Stages 2 and 3 commenced: Bio-photographic elicitation interviews; and Participant Feedback and Stakeholder Forums (see details below).

Selection of Sample and Recruitment

In order to work with a wide range of women, from initial investigation right through to treatment and remission, we recruited women at different stages of their treatment and care. This included women who had experienced breast cancer (who might be concerned with systemic recurrence), and women only starting out on their breast cancer journey, undergoing genetic investigation. To aid in the selection process, and assist in clarifying what stage a woman was at we recruited in two cohorts, Group A: those women who had already had breast cancer and Group B: those undergoing genetic investigation because they were at risk of developing breast cancer. These divisions were not made for comparative reasons, to contrast group characteristics and views, but rather to add clarity to recruitment and sampling and respond most appropriately to the study aims. Recruitment was undertaken purposively to fulfil the sampling requirements (see inclusion criteria below and Table 1) with the support of a Clinical Liaison Officer, whose input reduced the likelihood of researcher coercion in choosing participants. This was assured by the Clinical Liaison Officer: a) maintaining all study information, b) offering information about the study to patients accorded to a carefully scripted and balanced information sheet that already had ethical approval, c) avoiding the use of any persuasive tactics, d) ensuring no potential participants came into contact with study team members before consent forms were signed, and e) withholding confidential patient information from the research team until consent forms were signed. Recruitment was predominantly across two departments: The Cancer Care Unit and the Cancer Genetics Department in one large University Health Board (Abertawe Bro Morgannwg University Health Board, UK). Women were recruited over a two-month period, as they came in for consultation. In Group A women were included if: they had previously experienced breast cancer but were not currently receiving active treatment, and if they were assessed as at risk by the Cancer Care Unit. In Group B, women were included if: they had no previous personal history of breast cancer but a familial link, and if they were assessed as at risk by the Cancer

Genetics Department. After the initial recruitment phase took place, snowball sampling (Patton, 2002) was used, to identify any potential candidates for whom a period of time might have elapsed since initial diagnosis and treatment, and to identify women with family members also undergoing genetic investigations for breast cancer.

Ethics

Ethical approval was sought from a UK Research Ethics Committee (14/WA/0051) in addition to Research Governance permissions from the local University Health Board (IRAS:148062). The project team included two patient and public representatives who were active in the Advisory Group, and provided guidance and opinions on project delivery and data collection approaches.

Data Collection

Data were collected in three stages: Stage 1) Books of Experience, Stage 2) Bio-photographic elicitation interviews, Stage 3) Stakeholder and Participant Forums. Data were collated and analyzed as they were collected, to build on emergent findings across cohorts (see Analysis). Women received an information pack in the clinics, and following consent, were contacted by a study researcher, who explained the study in more detail. The researcher met each participant three times, 1) to outline research support (and refer to counselling services if needed), 2) to provide a blank Book of Experience, and 3) to conduct Phase 2 interviews.

Stage 1: Participants received a large, hard-bound book, to create a personalized Book of Experience (Figure 1).

Figure 1: Book of Experiences

[insert Figure 1].

A specific brief was avoided to minimize researcher influence, based on previous work of the team using methods of in-depth enquiry (Rapport, Doel, & Jerzembek, 2009b), but a broad Guide was offered (see Appendix 1). The Guide asked women to reflect on their own personal experiences of investigation, treatment and care, in accordance with specific categories derived from the oncology literature on: 'journeying with cancer', 'the care continuum', and 'risk assessment and management', and aligned to the study aims. The categories were: Impact on your life; Support and care; Future expectations; Tests, treatments and drugs; Risk classification; and Time periods (Audrain et al., 1997; Beatty, Oxlad, Koczwara, & Wade, 2008; Li & Loke, 2014). The Guide's categories were left specifically broad, to be appropriate for both women undergoing genetic investigation and women who had had a cancer episode, and to ensure key moments within the cancer journey could be recorded. Women were encouraged to include multi-media presentations in their Books, using imagery and text (such as photographs, postcards, posters, drawings, notes, letters, clinic information or formal correspondence). They were instructed that the arrangement, choice and use of the materials was their decision. The Guide was presented to women when they were given their Books. The Guide also asked participants to indicate to which time periods, during their cancer journey, their entries referred (see Appendix 1). Women were offered the opportunity to discuss the categories with the study researcher, if they needed clarification, or were unsure what to put against any of the categories, before they commenced completing the Book. The team encouraged participants to reflect in their own way according to the category headings.

Women were given three weeks to create their Books of Experience. This time span respected the need for women to conceptualize their Books first, before defining the content. Women could respond by using the Books to follow the course of their disease, up until the time that the Books were created, or they could work according to a specific timeframe of

their own choosing. Women were free to offer their own and their family's views of their situation, as long as the final Book was something they alone had made.

Stage 2: Face-to-face Bio-photographic elicitation interviews were undertaken with all participants (Rapport, Doel, & Elwyn, 2007). The method has been used extensively by this team and reported previously (Lian & Rapport, 2016; Rapport et al., 2009b; Rapport, Doel, & Wainwright, 2008), derived in part from the photo-elicitation work of Radley and Taylor (2003), which was conducted in a hospital setting (Radley & Taylor, 2003). Bio-photographic elicitation uses photographs and other visual data as stimuli for interviews (Harper, 2002). The technique is specifically designed to encourage interviewees to reflect on visual and textual data at one and the same time and is predominantly data participants have previously created. These types of interviews develop in line with the data under consideration as it triggers new thoughts or deeper reflections. Bio-photographic elicitation interviews are directed by interviewees themselves (Rapport et al., 2009b; Rapport et al., 2008), who are encouraged to undertake a self-reflective approach to discussing data created, and to use the data as a way of concentrating on the triggers that arise as a result of that self-reflection, that lead to new revelations. They are semi-structured in nature, so that interviewees can determine the path that the discussion takes. They can lead to disclosures that are both expected and unexpected, which on reflection may come as a surprise to the interviewee. they can allow an interviewer to examine the reasons behind participants' responses, rather than lead interviewees in directions they do not wish to go. They draw on both visual and textual data equally and corroboratively (Rapport et al., 2009b) Unlike photovoice method, which aims to capture culturally-sensitive data reliant on ethnographic methodology (Sutton-Brown, 2014), Bio-photographic elicitation interviews within this domain support extensive reference to health behaviors, actions and interactions. They can stimulate very individualized discussions, and are useful for dealing with emotive and sensitive data.

Interviews were conducted by a health services researcher with a background in working with vulnerable groups, including younger people, disenfranchised groups, and disadvantaged patients. In this study, as far as was possible, the researcher avoided projecting her own worldview into the interview (Creswell, 2007), and while she kept a detailed research diary, to be aware of changes to her views as time progressed, she ensured that any prompts used during the interviews strictly related to the study's aims and the Guide. Interviews were undertaken at the participants' own homes, a local support center, or the University, with questions driven and directed by women's own self-reflections. Interviews were digitally recorded and transcribed, with transcripts compared with recordings for accuracy.

Stage 3: A half-day Stakeholder Forum was undertaken with a mixture of oncology clinicians (from teams of breast cancer oncologists and geneticists who worked with the women in this study), funders, voluntary bodies, special interest groups, service organizations, patient representatives from the Study Advisory Group, and core team members. A separate Participant Feedback Forum was also undertaken with attendees representing patients who had taken part in Stages 1 and 2 of the study (equally represented across both groups). During the events, details were provided about the study design and processes, and excerpts of anonymized data were shared with attendees, alongside some preliminary findings. Discussions were facilitated by core study team members (i.e., the researchers represented in the author group) and observers from this team took notes. The events led to extensive cross-fertilization of ideas and findings. This was enabled at each Forum event by tabled discussions of mixed-Stakeholder groups around key thematic findings and group exercises that promoted the sharing of ideas and views across multidisciplinary groups of healthcare professionals, patients and other Stakeholders (for example, policy makers, oncologists, geneticists, etc.). Data from the Forum events,

irrespective of the Stakeholder groups from which they derived, underpinned the next stage of data analysis and dissemination planning.

Data Analysis

Multiple, extended, multidisciplinary analysis workshops supported a rich analytic framework (Rapport et al., 2007). The workshop technique built on previous study work of this team (see for example Hutchings, Rapport, Wright, & Doel, 2013; Rapport et al., 2010)). Workshops were held over a full morning or afternoon, and took place over the course of three-months, to allow time for researchers to build on their understanding of the subject. They were attended by the full core study team, comprising a range of academics including: health services researchers, psychologists, statisticians, human geographers, and medics. On occasion, members of the wider study team, including healthcare practitioners and patient representatives, attended. Workshops became the focal method of assessment for all Books and Bio-photographic elicitation interview transcripts. Later workshops included discussions of the Forums to enhance findings. Before each workshop, individual researchers undertook initial coding of major and minor themes in narrative and visual formats (Rapport et al., 2007; Rapport et al., 2008). Themes were considered by different team members in the workshops, who were allocated a single category from the topic Guide, to ground their work. Each category and thematic revelation was discussed in detail in relation to textual and visual examples, from within and across the raw data. Visual analysis also included a visual taxonomy that highlighted women's use of: different kinds of imagery, frequency of presentation, formatting, clustering, and affect. The taxonomy had been validated through previous work by members of the study team, and was chosen for its comprehensive nature, the researchers' proficiency in the method, and its ability to provide a detailed analytic framework specifically adapted to visual data collected in healthcare contexts (Rapport et al.,

2007; Rapport, Doel, & Jerzembek, 2009a; Rapport et al., 2008). Images and texts were compared during the group workshops, and differences in presentational style were noted. Workshops ensured researchers achieved consensus opinion on major and minor themes, provided rigorous peer review, and added veracity to the final framework. Whilst the core team of researchers undertook the five workshops together, an additional two workshops were added, to include oncology clinicians, who had a direct role in patient interaction around treatment decisions, risk assessment and risk management, and patient representatives, who sat on the study Advisory Group. These additional workshops allowed for specific elements of the data, that were either highly clinical or very personal to a patient’s perspective, to be discussed, to enhance core team understanding. Workshops were informed by: study aims, a literature search, and the Guide’s categories (see Table 1). Interview data provided quotations confirming the completeness of the framework.

Table 1: Risk level assigned to patients according to group and location

[insert Table 1]

During all stages of analysis, rather than concentrate on risk as purely a clinical definition or a clinical implication, in line with the stated purpose of this study, the notion was treated broadly. Analysis also considered women’s own fears, beliefs and expectations (irrespective of where women were in their treatment cycle, what they had gleaned about medical risk presentations, or where they were in the care continuum) to provide a report that was both fluid and inclusive of the patient story. The range of data women had provided, including the recollections of those undergoing genetic investigation, those being treated (including surgical mastectomy), and those at risk of systemic (or distant) recurrence, following breast cancer treatment were considered.

Findings

Twenty-five women were recruited across both cohorts: 14 in Group A, and 11 in Group B (see Table 2 for patient characteristics).

Table 2: Patient characteristics

[insert Table 2]

All women produced Books of Experience of varying lengths using an assortment of headings from the Guide, and all took part in interviews. In some Books, imagery predominated; in others, text was the dominant medium. Most Books had equal amounts of imagery and text, and though the length of Books was in no means indicative of compliance, interest, or richness, this did relate to the length of subsequent interviews. On average, interviews with post-cancer patients lasted around 50 minutes (reflecting greater time spent in the healthcare system), while interviews with those undergoing genetic investigation lasted around 30 minutes. Seven group analysis workshops (five with the core team and two with the wider team of researchers, service professionals and clinicians, and patient representatives) lasted between three and four hours. One Stakeholder, and one Participant Feedback Forum was also held. The Participant Feedback Forum enhanced team understanding of what kinds of issues women faced at different stages in their treatment and care. While Books and interviews gave some detail, for example that anxiety could be triggered by consultations, having all women from across both Groups together in one room led to a conversation that encompassed many aspects of the care continuum, from the commencement of genetic investigation to considerations of transitioning out of hospital. One woman talked about having to make life-changing treatment decisions on the spot, which worried her, especially after she had left the consultation. This resonated with another woman's experiences, who felt she could have benefitted from a lot more clinical support

during consultations to help her overcome anxieties about the consequences of chemotherapy and radiation therapy on long-term survivorship (Rapport et al., 2009a).

We should emphasize that there were commonalities across all study participants, not least the fact that they felt a strong sense of concern in the face of this complex disease and its treatments and that this led to real worries about personal health and wellbeing, and the health and wellbeing of others.

Thematic Presentations

This article concentrates on findings relevant to both groups of women to enable a thorough elaboration of the topic. Two major themes were revealed across and within the two groups: ‘subjective understandings of risk’, and ‘journeying towards an unknown future’. These two themes form the basis of thematic presentation. They were both richly presented in relation to the Guide’s six categories and respond to the study aims. Each theme is discussed with verbatim quotations adding depth to explanations. All verbatim quotations, whether single phrases or longer sentences, are directly allocated to women from one of the two recruitment cohorts, and each quote is identified by a set of single quotation marks. It is worth noting that Books and interviews helped women explain their views (Khanom et al., 2015) and to lay down their experiences for their own and others’ benefit. Women found the process of taking part in the study cathartic, and commented that the Book’s production offered them a space in which to contemplate. While both groups covered all issues reported here, women in Group A had more to say about treatment, medical processes and risk classification in terms of journeying towards remission, transitions, and future aspirations than group B. Many participants enthused about the Books and cherished the artefact, seeing it as a legacy for generations to come; a truthful and personal account of what they had been

through. In this respect, Books took on a life of their own, giving a sense of permanency that far outstripped the study's end date, as one woman for Group A explained:

Doing the Book I found very therapeutic because everything I felt and everything that happened to me, it was all inside me, and now I've written this book [...] and it's like as if I've emptied my soul [...] and now I'm free to carry on and do what I like and I'm, I'm feeling positive. (Group A Participant)

Subjective Understandings of Risk

Risk assessment, risk status and risk classification. 'Risk assessment', 'risk status' and 'risk classification' were terms that rarely graced the pages of women's Books, and only featured in the in-depth interviews if women were specifically asked about risk. When women discussed their experiences, risk was a fleeting moment in a lengthy narrative around how it felt to suspect one might have, be concerned about getting, or anxious to treat, breast cancer. Women passed quickly over risk status, as they tried to make sense of the clinical encounters, tests, therapies and drugs. In this context, risk status was also unclear, and overshadowed by the many other issues that consumed their thoughts. Women were overcome by a general anxiety about breast cancer, and expressed mixed emotions, including fear and denial. On the rare occasion that a woman did mention risk without having to be prompted, it was to discuss her overwhelming desire to be well at any cost, which for some women in Group B, led to a temporary suspension of thoughts about risk, and a consequent delay in seeking medical attention. In many instances, women were unclear about whether they had ever been given a risk classification, or had a formal risk assessment, due to the battery of other tests. As one woman recalled: *'I can't remember if my risk status was ever told to me, but when I went to some appointments what the doctors told me did not sink in'*. (Group A Participant).

If women did remember, they were often unsure when they were assessed, and within which context. Consultations were frequently emotion-laden, and in a highly-charged atmosphere, details were hard to recollect. The complexities of what a woman might or might not wish to know, and what information could be absorbed, during brief, timed, consultations, seemed out of keeping with information provision. Thus, while women were grateful for clinicians' efforts, oncologists were often described as finding it difficult to tell what was going on at any one time. One Group A woman described her oncologist as always ready to discuss the next test in terms of the practicalities she thought she needed to know, without asking her what she wanted to know:

I wanted to find out myself what my relative level of risk was'... I wanted to see how bad this is. I didn't like the term grade 2 and the word invasive...She (oncologist) said straight that it was 8 over 8 oestrogen sensitive and I said that sounds like good news to me. And she said: 'yes it's good news', because they can treat me with Letrozol and whatever. (Group A Participant)

Consequently, facts around risk that related to a woman's own concerns were overshadowed by others' agendas.

Impact of risk on family members and close others. Within this context, what mattered most to women was: the negative consequences of risk for other family members; life being foreshortened; which treatments to pursue or avoid, and how to make the right decisions. Women questioned whether they should have been more vigilant, how to look out for bodily changes, and how best to protect their family, *'I did all the right things...I still got cancer! Was it my fault?'* (Group A Participant). All these concerns led to very real issues for them, not clinical issues genetics counsellors shared, but personal problems that filled their time, *'my guilt of passing it [the gene] on to my daughter has been awful...Sorry [sobs]'* (Group B

Participant). Finding oneself in this situation led to women reverting to the technicalities of the disease and disease containment. When they felt anxious, they resorted to shaping their stories around others' stories, to prepare for bad news. Women spoke of other support mechanisms: friends, family, self-help groups; and their wanting clear information. Wanting to know if they would live or die was a frequently expressed concern.

Women in both groups were wary of statistics and statistical presentations of risk, and requested information about not only risk but the implications of being at risk on their lives and the lives of family members, that might mean something specific to them. Nevertheless, while risk as a statistical probability, presented formulaically, was considered unhelpful, women held onto their own understandings of risk, for themselves and close others, and carried that into their lives: *'Were any of these [numbers] risk classifications? I don't know. But I felt a damn sight better for making my own decisions...I know the numbers are balls. The specifics don't matter. The working through was the important thing.'* (Group A Participant):

These things are only statistics. I think you can do better than average. They are going to tell you the average, you can do better than the average if you co-operate with the doctors but you help yourself as well. I don't think there is any point in scaring yourself. I mean certainly there is a significant proportion of people with breast cancer who still don't do all that well despite all the things they've got on offer. I don't actually want to focus on statistics ... I want to improve the odds. (Group A Participant)

Personal understandings of risk. Risk was a sense of: *'being'* or *'knowing'* one's body differently – knowing the disease as part of a new persona and taking control to reduce risk levels:

1
2
3 So I started reading about it. I guess with some of the medical sources they are
4
5 actually not all that reassuring. The chances of still being alive after five years has
6
7 improved a lot but they are not as good as I hoped ... I mean I forgotten it (Prognostic
8
9 index) again quite deliberately, because I think it is better not to think about it, but
10
11 certainly it shocked me into thinking I better make some effort myself, I had better
12
13 had attempt to reduce my risk if I can by improving my diet and looking into what I
14
15 can do to help myself. (Group A Participant)
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17
18

19 This made sense to participants, and with this came a new sense of realization – the
20
21 need to help others. Women got involved in raising money for cancer and took part in other
22
23 community acts. Some turned to faith, to better cope with their predicament. Seeking support
24
25 from others also allowed them to pass on some of the responsibilities for their situation.
26
27 Telling others, through close family connections, or social media such as Facebook, about
28
29 what had happened, helped contain a sense of rising panic, which was also juxtaposed with
30
31 awareness among women of the *'loneliness [of cancer] no one understands...unless you are*
32
33 *in the situation or involved personally it really is difficult to comprehend...brothers and*
34
35 *sisters couldn't deal with the situation'* (Group A Participant). For one woman in Group A,
36
37 her relationship with her daughter changed, following her cancer diagnosis, to the point
38
39 where her daughter actively sought to avoid conversations about cancer, and reduced their
40
41 contact.
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45

46 **Sharing information through healthcare professional involvement.** Once women received
47
48 a cancer diagnosis, they found themselves in a state of shock that prohibited them from fully
49
50 absorbing all the information from oncologists. In this situation, some women disassociated
51
52 themselves from the cancer, and in most cases, passed the care for their body to a third party:
53
54 *'let's deal with it, just get on with it'* (Group A Participant). Oncologists were the most likely
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1
2
3 candidates to help. Women often looked back on those early days as a time of great
4
5 confusion, and wished they had asked more questions, *'it dawns on me [after surgery] that I*
6
7 *have so far been spared detailed discussions of some of the potential side-effects of*
8
9 *treatment'* (Group A Participant). For those who did receive a personalized service they were
10
11 extremely grateful:
12
13

14
15 You know, your whole system is affected by the drugs and the radiation which they
16
17 don't tell you about and that is a question that is unanswerable really because if they
18
19 told you everybody would probably refuse, but I mean I knew about it and I still went
20
21 through it because I had to do it, I didn't want to, if I could have got through without
22
23 it. (Group A Participant)
24
25

26
27 For those who did not, they felt let down, and took refuge in the practicalities of
28
29 treatment: *'having chemo is frightening which is made worse by not understanding what I*
30
31 *was told at the outset of treatment'* (Group A Participant). The consultation was often said by
32
33 women to be the least likely place where information could be absorbed, *'in my experience*
34
35 *you always need someone with you as the information just doesn't sink in'* (Group A
36
37 Participant). This was especially true when it came to understanding notions of risk status and
38
39 risk calculation:
40
41

42
43 When I went to see Dr [name removed] (for a check-up) he turned around (spoke
44
45 about risk level) and I said to him that's the first time (anyone spoke about risk),
46
47 unless they told me earlier and because it is you know you're looking at them and
48
49 their mouth is moving, but you can't hear what they are saying...so that's the first
50
51 time I heard it (during a routine consultation). So, he had a look and told me after that
52
53 you are low risk, so you're lucky. I said aw well thanks you know...I thought then
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well I'm not really ill I shouldn't be here, it's low (risk), it's nothing. (Group A Participant)

As women progressed through treatment plans and cycles, so that life could return to 'normal', women appeared to feel dehumanized; a *'lab rat...imprisoned – no longer part of the human race'* (Group A Participant). They discussed how they felt: *'violated'* (Group A Participant) and experienced a loss of: *'dignity'* (Group A Participant) (See Figure 2).

Women in Group B worried that early cancer detection could be missed due to pressures on the National Health Service and primary care services:

What's so worrying is this that I know GPs are stretched and hospitals are stretched and you have to wait months for scans and because the NHS is under so much pressure ...my friend she was back and forth to her GP months and months complaining about abdominal pains, anaemia and she was passing blood in her stools, he sort of palmed her off with Crohn's disease and this that and the other. She told him that her mum had bowel cancer and survived and that was dismissed. (Group B Participant)

Figure 2: A Cartoon from a Book of Experience

[insert Figure 2]

Others, however, made an attempt to take control of the treatment process, *'I decided to wear this cold cap for every session of treatment [...] I wanted to look as normal as I could, and by keeping my hair I didn't look ill'* (Group A Participant). They were surprised that their risk status was an ongoing concern. Nearing discharge from hospital, women often entered a phase of heightened suspense, where they felt neither entirely healthy nor entirely unhealthy, and never truly free from risk: *'What I did not anticipate was the awful depression*

1
2
3 that occurred at the end of my journey through the medical maze' (Group A Participant), and
4
5 'my life will never be 'normal' again' (Group A Participant).
6
7

8 Women from Group B also feared that they may face some unpleasant surprises, even
9
10 if they were deemed cancer-free and frequently mentioned that they were living with a
11
12 'ticking time bomb' (Group B Participant). Once the statistical probabilities had been
13
14 identified, based on their family history, this became a time of: 'watch and wait' (Group B
15
16 Participant), as risk was not clearly defined, '[genetics counsellor] said there is no way of
17
18 telling (me) my actual risk' (Group B Participant).
19
20

21 **Service provision following risk assessment.** Women who were not at high risk (Group B)
22
23 were asked to contact the oncology services if there were noticeable changes in their breasts,
24
25 and were offered routine mammograms, which did little to ease their sense of imminent
26
27 foreboding. They describe how, after undergoing mammogram screening, they felt: 'a bit let
28
29 down, deflated, in the dark' (Group B Participant). In addition, many of the genetics patients
30
31 said they were given the wrong impression of what the service could offer, unduly influenced
32
33 by media portrayals of genetic testing that celebrities had undergone to identify their risk
34
35 status: 'I wouldn't have done anything but Angelina Jolie was on the radio at the time talking
36
37 about genetic testing...' (Group B Participant). Once patients realized that they may be at
38
39 risk, they assumed, for example, that they would be offered a genetic blood test, and that this
40
41 would provide them with a definitive answer about their risk status, 'this bit of knowledge
42
43 was all I needed' (Group B Participant). Instead they received: 'fuzzy answers', a clinician's:
44
45 'way of dealing with this' (Group B Participant).
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51 They sent me a letter saying that I could be at risk I need to have a mammogram. Well
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53 I thought a mammogram would have been a blood a test to see if I carried the
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gene...My daughter had a letter saying she wouldn't be at risk, I didn't see how she wouldn't be at risk – if am at risk then surely she is as well. (Group B Participant)

High risk women, who were offered genetic counselling, found that confiding in someone about their worries, and having the opportunity to discuss options, was a '*relief*' (Group B Participant):

Obviously, it was, not upsetting but daunting talking about all the family history, because she(geneticist) was going through everything and it brought up so many memories of all the family members that we have lost through cancer and what we had been through especially me since I was 17. It was a relief as well that something is being done you know my mum my sisters and myself felt that when we left the session that we are being kept an eye on. (Group B Participant)

In terms of risk assessment, women from both Groups wanted to concentrate on facts, access good support, and clarify stages in treatment and care:

It's a bit of a waiting game and you think, okay, if you're going to get it you're going to get it, but when you're told maybe that you're a higher risk; it's do you wait until you get it and then deal with it, or if the faulty gene comes back then do you decide then to go for mastectomy or hysterectomy. (Group B Participant)

This included: how best to speak to family members; how to progress from conversations about risk to the practicalities of preventative treatment; who should define risk status; and how to explain risk to the next generation. They wanted others to work out risk calculations for them. Women continued to ask the researcher whether an oncologist could be called upon to say more about their particular case.

Journeying Towards an Unknown Future

Undetermined consequences of cancer. For breast cancer survivors, there was significant recourse to the metaphor: *'the cancer journey'*. (This resonates with others' who have described cancer survival as a *'personal journey'* (Bennett & Bian, 2014). For women with cancer, the narrative was lengthier than for those undergoing genetic investigation, but nevertheless in both groups, women described 'the journey' as convoluted, unknown, and consequential. Waiting to go through each stage of treatment was distressing:

I think, you're always waiting for something, like either waiting, when chemo finished I had to wait a month before lumpectomy, just for, you know, the healing process and get the chemo out of your system and stuff and then it was waiting for results and then it was waiting again for the next lot of surgery (breast reconstruction). It was always waiting for something on this journey and you wish you could press fast forward really to just get through it. (Group A Participant)

Women in Group A talked about journeying towards the: *'unknown consequences of cancer'*, and the hope for freedom from cancer for themselves and family members: *'by God's grace she [her daughter] would never have it [cancer]; we would proceed with faith'* (Group A Participant). They felt under the destinal sign of 'Death', whilst recognizing some future beacon which they perceived as an obscure figure of 'Hope', *'80 percent of women are usually given the all clear and 20 percent of women are recalled'* (Group A Participant), and as this Group B participant elaborated:

In the future because obviously technology and science and things are always changing all the time, advancing, she (geneticist) said you never know maybe in a couple of years' time something new will come out and maybe we could be part of that study as well, so that's reassuring as well. (Group B Participant)

Death was a notion that was always there, bringing with it a mix of emotions, including a strong desire not simply for life, but for a newfound quality of life, or a quality of hope, that could only be dreamt of, or glimpsed at, in moments when the treatment results were more positive: *'I have begun to discover the sheer joy of living from day to day and daring to dream'* (Group A Participant).

Emotional impact of the cancer care continuum. The emotional upheaval of investigations affected both groups of women, but in different ways. For Group B, for example, emotions were part of the highs and lows of investigatory dialogue and exploratory examination: *'the risk classification came out of the blue'* (Group B Participant). For some with a family history of cancer, there was already a concern that the disease could show up at an early age:

I was aware of cancer at the age of 9 when my father's mum passed away. So, I have been aware of cancer from a young age, more so than my friends. When you're younger you associate cancer with older people. As you get older you realise it's not, age doesn't mean anything. (Group B Participant)

For Group A, emotions were more to do with a crusade to overcome a personal battle with cancer, and the sudden realization of the people who mattered in life: *'Not conquering this cancer was not an option. I owed it to my husband and my children and my grandchildren to be positive'*. (Group A Participant)

Not only did women think they must live for themselves, but also for others, and as a consequence live life to the full: *'have a reason for everything, even if it is totally insane. Find your purpose in life and LIVE IT'* (Group A Participant).

For women with a previous episode of breast cancer, the journey towards a place where they would be well enough to transition out of healthcare services and into the community was complex and unidirectional. Along the way, women hoped for a dedicated

1
2
3 team of health professionals to whom they could turn to seek advice and guidance on any
4
5 aspect of their treatment or investigation. When teams were available and consistent they
6
7 were highly praised. When teams changed and care changed hands, women felt demoralized
8
9 and anxious. Having to repeat stories, revisit past experiences, or re-examine test results with
10
11 new healthcare professionals was disconcerting, and left women feeling abandoned and
12
13 uncared for.
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17 As women moved towards a state of remission, as with the ‘before and after cancer’
18
19 experience (Figure 1), life back in the embrace of the community was a journey of no return.
20
21 There was no looking back, and no returning to a state of ‘normality’, but a new, unknown
22
23 state, where future aspirations became both painful and profoundly transformational: ‘*You*
24
25 *tend to block them off* [feelings] *after you had the operation and after you had your radium*
26
27 *you think that’s it, you can close the book. But you can’t really close the book on it*’ (Group A
28
29 Participant).
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31

32
33 ‘Everyone said how well I looked, but inside I was torn to pieces but felt I had to
34
35 stay strong... I have gone deaf through chemo, my heart is bad. Eyes weakened.
36
37 No one tells you these things may happen... Everyone thinks that because the
38
39 cancer has been removed and treatment, as in chemo and radio has finished, that I
40
41 should be healthy now, but I’m not.’ (Group A Participant)
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44
45 **A future in flux.** The future was, as with the present, ‘*a waiting game*’ (Group A
46
47 Participant)— waiting for something to happen, waiting to be told that the remission period
48
49 was over, waiting to know the next stage in one’s life waiting to see how it would affect
50
51 others. The future, as with the present, was in flux, and whilst there was a real notion of
52
53 freedom beyond the walls of the hospital, there was also trepidation – everything was put on
54
55 hold.
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3 The longer women were part of the system, the keener their sense of longing to be in a
4 better place, free from disease. Even for women in Group B, journeying within and across an
5 alien territory, to manage an unknown disease, according to unfamiliar treatments that would
6 result in unknown end points, was profoundly unsettling. Ironically, there was a clear
7 disconnect, expressed in multiple interviews, between women's desire, on the one hand, to be
8 in a better place away from regulated healthcare, and on the other hand, to continue under the
9 safe keeping of the hospital system. Within hospital, during regular visits, they could be seen
10 by trained oncologists, and there was always someone to turn to, quickly and easily, for
11 support and care: *'All of a sudden I was being told I didn't need to go there any more, I felt*
12 *apprehensive...I thought, well he's abandoning me now, and I thought well, what's going to*
13 *happen to me.'* (Group A Participant)
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28 From this transpired a set of future aspirations and current experiences, expressed in
29 subject-centered, processual, and experiential ways. Women's portrayals of encounters with
30 cancer, in which they tended to dramatize the agony of waiting, instilled a binary logic of
31 either Life or Death. Consequently, future considerations and the desire to remove oneself
32 from healthcare services, and by so doing be free of the grips of breast cancer, implied a
33 notion of risk that was difficult to conceive of in calculative and probabilistic terms, but
34 figured in recursive and deterministic terms. 'Cancer may or may not return', 'I may or may
35 not live', 'I may or may not ever leave the hospital care for a future that I now so desperately
36 desire'.
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48 In stark contrast, women with an actual or potential genetic pre-disposition to breast
49 cancer were given few readymade metaphors: a *'faulty gene,'* (Group B Participant) a *'typo*
50 *error in a book,'* (Group B Participant) a *'needle in a haystack'* (Group B Participant); and a
51 collective narrative: *'their family tree'* (Group B Participant). This engendered a de-centered,
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3 structural, and reflexive encounter with cancer, which tended to dramatize the agony of
4
5 uncertainty and foreground a fuzzy logic of ambivalence: ‘yes, but; no, but; maybe; perhaps’.
6
7 Nevertheless, some women used limited information to reevaluate their life and work towards
8
9 preventing the future onset of cancer: ‘*maybe I can limit or reduce the chances of me and my*
10
11 *family getting cancer...* [and therefore maintain a] *sense of being in control*’ (Group B
12
13 Participant). Those women who were offered the genetic test, reported a sense of normality
14
15 once a negative result had been confirmed:
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17

18
19 My mum did cry, she was so relieved for obviously her three daughters, cos when the
20
21 results came back early we thought it was bad news...I like to plan ahead so I was
22
23 thinking if these results come back, if they aren’t negative and I just wanted to know
24
25 would I be able to talk about having a double mastectomy (with my family), but
26
27 obviously that’s out of the picture now thankfully, it’s an early Christmas present, so
28
29 we can relax now and enjoy Christmas. (Group B Participant).
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32 Discussion

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35 This study has highlighted that women, whether undergoing genetic investigation for
36
37 breast cancer or already diagnosed with breast cancer, find clinical presentations of risk
38
39 difficult to understand, worrisome, and hard to relate to. Being given a risk status was
40
41 reported by women in this study as raising anxiety levels leading to a sense of
42
43 disenchantment and even “dehumanization”, especially when women were asked to explain
44
45 what happened to them when they entered into a discussion of risk during their routine
46
47 clinical consultations. This appears to be the case, whether risk status is high or low. In the
48
49 UK, Kirshbaum et al. (2016) have developed an open-access, supportive-care model for
50
51 feedback to patients, post-hospital assessment, in order to help support possible ongoing
52
53 anxiety for those at low risk of cancer. The model contains a “psycho-educational self-
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management programme” (p.3) to help women self-manage their emotions, with support from GP services. This model is described as foregoing the need for patients to return to hospital for follow-up appointments and is now embedded into UK services, but is yet to be tested in the Australian context. In our study, while women were not always able to remember the exact details of the consultations they had had in hospital, the fact that a discussion had taken place led them to dwell more on their own, and others’ mortality which they described as raising anxiety levels. This has also been confirmed through the work of van Dooren et al. (2004), who identified psychological distress in women with a BRCA1 or BRCA2 gene mutation, undergoing screening and surveillance (van Dooren et al., 2004). As van Dooren has illustrated, women in this category often overestimate their risk status, and a non-significant yet noticeable association has been found between cognitive risk perception and general distress (van Dooren et al., 2004). Our study revealed that statistical prognoses were incomprehensible for many, and information presented by geneticists and oncologists, using different probabilistic tools, was out of kilter with women’s views of personal risk. Women carried risk around with them, as part of an individualized and personal journey through cancer investigation that took into account family history and family members’ views. Women defined the notion intuitively, and wanted professional support with sense-making, requiring concrete facts about life and death scenarios. Other authors have noted that women who undergo genetic investigations for breast cancer often reject risk estimates as inaccurate, and nonsensical in terms of their own personal family histories (Scherer et al., 2013). Collins and Street (2009), as a result of this, have recommended dialogic models for conversations around risk instead of prognostic models, to help coordinate and reign in perceptions, leading to higher-quality decision-making regarding appropriate care (Collins & Street, 2009). Papageorgiou and Salmeron (2012) proposed a Fuzzy Cognitive Map (FMC) method that teaches women about causal weights and risk levels (Papageorgiou & Salmeron,

2012), and Tatari, Akbarzadeh-T, and Sabahi (2012) supported the Fuzzy-Probabilistic Multi Agent System (MAS) to ensure clearer risk assessment and probabilistic computing, and to streamline shared decision-making (Tatari et al., 2012).

As detailed in the introduction, we did not wish to pre-empt women's expressions of risk with definitions from the oncology literature, and we avoided overshadowing women's presentations with clinical prognostic inference. Thus, for a woman who has had a mastectomy, with clinical risk of systemic recurrence, and for whom clinicians were keen to discuss whether chemotherapy was beneficial, she did not necessarily perceive this as her main concern, but rather how the mastectomy would affect her ability to return to work quickly and continue supporting her family.

In our study, women indicated that tests and treatments were an integral part of their chaotic and convoluted journeys. However, once women were ready to leave hospital care, they had to put the impact of tests and treatments behind them. Many found this difficult, and were daunted by the thought of leaving the security of hospital care. The unknown consequences of treatment in the longer-term were still to be fully realized, and this played to their notion of ill-health.

To aid them, our study has highlighted the importance of appropriate information about remission and ongoing care, provided by teams working together. The literature reinforces this view, showing the value of accurate information, consistently presented, particularly around the specificities of risk, such as breast cancer recurrence (Kelly et al., 2013). It has been found that an array of indecipherable statistics, often from more than one source, is less than helpful, and leaves women feeling emotionally fragile. Those who can remain optimistic, may fair better (Recio-Saucedo, Gerty, Foster, Eccles, & Cutress, 2016).

While women aspire to leave hospital cancer-free, the reality of treatments and associated ongoing risk often engenders a strong dependency on a system that holds them captive. Patients talk about fear of moving on, and losing the security that the hospital provides. With foreboding and widely reported stress (Beatty et al., 2008), many women believe that even in remission, there will never be a definitive end to ill-health. Our study reveals women's perceived need for ongoing surveillance, but also the down sides to this; keeping one's illness 'alive' and 'present', and keeping alive the memories of a visceral ill-health experience. This sense of trepidation was very real to women, evidenced by its clear presentation, both through imagery within the Books, and through oral recollections of personal life experiences, from the interviews. Some women will find succor from self-help groups and breast cancer organizations, others from social media, while still others will feel reassured by their religious faith. For some women, this will lead to active involvement in money-raising events, in support of breast cancer charities.

Whatever the outlet, consistency, with ongoing surveillance, from healthcare professionals, is highly rated. But respect and confidence can quickly dissipate, if teams change, or support changes hands. This echoes the findings of Henriksen, Guassora, and Brodersen (2015) who emphasized how women's preconceptions about the services they will receive in hospital and as an ongoing consideration, can strongly influence their perceptions of the services that are provided (Henriksen et al., 2015).

This study shows that psycho-social concerns, including heightened distress at assimilating information about clinical treatments and outcomes, is rife. Theoretically and conceptually, we have framed the study in terms of risk as a social phenomenon, while recognizing its impact on not only physical but also mental health and wellbeing, and we

1
2
3 have tried to account for the complex journey which women make as they deal with breast
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5 cancer.
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8 We recommend that the impact of risk status, stemming from formal risk assessment
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10 and probabilistic presentations, needs not only revisiting but rapid review. Information should
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12 be both comprehensible and individualized, so that women can consider how to manage risk
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14 in their lives in a way that makes sense to them. This suggests that healthcare professionals
15
16 should be spending more time in consultations examining women's perceptions of need in
17
18 this domain, and during follow-up on meetings listening to women's concerns, ascertaining
19
20 their personal needs, and attending to their ideas about service delivery. Women should feel
21
22 fully involved and informed, even as they prepare to leave hospital care. For those who have
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24 had cancer, there should be shared, negotiated approaches to care planning as women
25
26 transition from hospital back into the community.
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31 Women are anxious to get support from recognized teams of healthcare professionals,
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33 who can provide factual information in clear formats, but such information must also resonate
34
35 with their personal situation – their family history and their views on what will happen next.
36
37 Their concerns and past experiences should be examined early on, in dialogical, healthcare
38
39 professional relationships, and decisions should be both co-opted and co-defined, with
40
41 ongoing negotiation a key process in that scenario. This will also help women have
42
43 confidence in their clinical team, even as they prepare to loosen their ties with the hospital. It
44
45 may also reduce their sense of foreboding, and help women manage an ongoing health status
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47 that is, for most, ambivalent. We suggest that the greater the service integration, within and
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49 outside the hospital, and the more patients are involved, the greater the chance of a positive
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51 outlook. This advice for healthcare professionals is novel in its ability to extend the clinical
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53 consultation to take account of patient's own, rich personal experiences. Rather than being
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expressed in purely textual terms as is often the case in oncology research, patient experience and patient-reported outcomes have been expressed innovatively, through visual and textual means, derived from patient’s in-depth and very personal self-reflection. This is also novel, having the potential to expand healthcare professional practice beyond a clinical-care provision to an integrated clinical and pastoral care provision. This should not only depend on outcomes from one-to-one, patient-clinician consultation, but involvement of the whole family in decision-making, while ensuring patients are the clear co-definers of healthcare plans, in line with a wider family consultation.



Strengths and Limitations

The strengths of this study lie in the innovative and detailed data collection approaches, the possibility of analyzing women’s Books of Experience during a stage that comes prior to deep reflection, and women’s commitment to the process of creating Books of Experience, to provide honest, thoughtful and thought-provoking presentations. The limitations lie in the small sample, and the single data collection site. In addition, combining the two groups of women in one study and in reporting the findings, while adding to the richness of data delivery, and providing nuanced views, could be seen as for over-complicating matters, or diffusing specific information. In support of this combined approach, the team wish to emphasize the strengths of extending the detailed data delivery and the understandings that can be achieved about the care continuum, across all patient types.

Conclusion

Our study has disclosed women’s extensive concerns about being abandoned. They want continuity of care, and coherent care-planning, and information from teams seamlessly coordinated with others in community care settings. This is vital for this disease group, and

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2
3 may mean revisiting how services are developed and managed and how women transition out
4
5 of hospital care to General Practitioner and community care services. By undertaking careful,
6
7 future-care planning, and by involving women and their families, preparations can begin for
8
9 whatever is to come, including life-after-cancer.
10

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14
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16
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18
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20

21 22 **Declaration of Conflicting Interests**

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25 The Authors declare that there is no conflict of interest.
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Women’s perceptions of journeying towards and unknown future with breast cancer: the “Lives at Risk Study”

Table with systematic response to Editor and Reviewers’ comments

REVIEWER COMMENTS	RESPONSE
Editor’s General Comments	
1. Please include links (references) to relevant QHR literature.	Done as requested. We have added Grinter & Braun (2016) and Chalmer & Thomson (1996) from QHR as additional references in the literature (see p.3)
2. Upload Table 2 as a Supplemental File	Done as requested. Removed all tables and figures into supplementary files; indicated where relevant in text to insert tables or figures.
3. Remove participant numbers from results	Done as requested. We have replaced them with either (Group A Participant) or (Group B Participant)
4. Guide needs a list number	Done as requested. Now listed as Appendix 1 and uploaded as supplementary file.
REVIEWER 1:	
Reviewer Comment 1.8 Breast cancer survivorship: recommend reading Kirshbaum M, Dent J, et al, 2016. This article should be considered for integration of a support-based, post-diagnosis, psycho-educational approach into the discussion.	We would like to thank the reviewer for identifying this new paper, and have included comments and a reference to it in the discussion section (see p.26).
Reviewer Comment 1.9 P3. of the pdf under Prognostic estimate: NICE ... change the word guidelines to guidance, and remove the word improving for “recommending treatments and services in relation to cost effectiveness”	Done.
Reviewer: 2	
Reviewer Comment 2.1 More of the women’s actual data could be included in this section, where they illustrate the quotes that are presented with examples. Sub themes in the analysis section would break up the text more appropriately for smaller chunks of information.	We have included more data to meet the requirements of Reviewer 2. Additional quotes are included with examples throughout the findings section. We have used sub thematic headings in the analysis section to break up the text into smaller sections.
Reviewer Comment 2.2 Check your use of colons and semi-colons Typos P4 L36 ‘talk’ should be ‘talks’	We have returned to the text and made some changes to the use of colons and semi-colons. Amended to ‘talks’.
Reviewer Comment 2.3 P3 NICE as this comment relates to a previous iteration of the body then this should be noted.	This has now been noted as a previous iteration of the work of NICE.

In reference to NICE there is some discrepancy between the reference and the work of Jain – this part of the discussion needs some clarification to indicate that the estimates of risk from NICE have perhaps changed since Jain was writing.	We have returned to the two references and clarified this point (see p4).
Reviewer Comment 2.4 P9-11 of the three stages outlined, only two are mentioned in the abstract	The abstract has now been amended to include all three stages outlined between p9-11.
Reviewer Comment 2.5 P9 although it is interesting to include women from a number of different parts of the 'cancer journey' I wonder if the focus of analysis should be tightened to include only one group?	We are keen to stick with our original inclusion of all group findings in the descriptions that women provided of their 'cancer journey' as: a) this is in keeping with the study aims and objectives, b) this links more coherently to the recruitment and sampling strategy and c) this is more consistent with the way data were collected across groups, including our handling and analysis of the data.
Reviewer Comment 2.6 P10 are bio-photographic elicitation interviews related to photovoice? Similarities/differences might be useful with references?	No this is a method that concentrates on health behaviours, interactions and expectations, not cultural-driven or community-directed issues underpinned by ethnographic methodology. It is a method that members of the team have developed, refined and presented extensively in other publications (see for example additional references added: Olaug and Rapport 2016, Rapport et al. 2009). Bio-photographic elicitation methods have been adapted from the early work of Radley et al. (2003), and we have added some sentences into the methods section alluding to differences between this and photovoice, with refs.
Reviewer: 3	
Reviewer Comment 3.1 Recommendations to clinicians, what makes them unique and how do the methods provide new answers to old questions?	Uniqueness is based to a large degree on the kinds of methods we used, the insights they provided about patients' expectations, and how to enable patients and family members to express themselves more clearly, which was underpinned by these novel techniques. There is also a comment that has been included on the opportunities this offers to be reflective without undue researcher influence, and we have added a section into the discussion to this effect.
Reviewer Comment 3.2 Theoretical orientation / epistemological frameworks/assumptions? Is it possible to eliminate researcher bias and how did the authorship deal with reflexivity?	See epistemological paragraph added before Aims, laying out theoretical orientation. We have also added in a few sentences linking to this in the discussion section. The study researcher kept a research journal, but most importantly, the methods used encouraged patients' self-reflection and extensive consideration of the information they wished to put across to the researcher as

<p>Focus: Conclusions emphasise concerns of abandonment, yet findings revolve around psychological and emotional experience, while other sections summarize probability and risk?</p>	<p>they worked with the Books of Experience, and this has been added to the methods section. This supported an honest, subjective patient narrative, while helping the researcher to remind herself of her responsibilities to a style of questioning that concentrated on clarification rather than deep probing of views.</p> <p>The focus of the paper is clearly outlined in the aims. There, we indicate that the focus of this study was the meaning patients brought to the concept of risk, from the two cohorts under study, and the journeys women underwent as part of the care continuum. However, we have added a few sentences now to emphasise the importance of the emergent themes that came to light as a result of patient-driven reflections. In the case of this study that led to revelations about views on probability, and women’s psychological and emotional experiences.</p>
<p>Reviewer Comment 3.3 Articulate your epistemological assumptions and how they are linked to the methodological approach.</p> <p>Methods: Referring to the Books p7. and the Bio-photographic elicitation interviews p7. – not cited to credit their development?</p> <p>Provide more explanation of how the Clinical Liaison Officer reduced the likelihood of coercion.</p> <p>Stakeholder Forum p11. – clarify what “the events led to extensive cross-fertilization of ideas and findings” means.</p> <p>What does “multiple, extended, multidisciplinary analysis workshops supported a rich analytic framework” mean?</p> <p>Explain the use of ‘workshops’ and provide citations to any guidelines consulted for their use in the data analysis.</p>	<p>Please see responses to 3.2, embedded now, as a new paragraph before Aims and in the discussion section.</p> <p>The Books of Experience, and bio-photographic elicitation interviews derive from our own research work with these methods, which we have now referenced more extensively in this article (see Rapport et al 2008, 2009b), and in the methods section (see response to Reviewer 2 above), we have credited the work of Alan Radley (2003), (reference added) regarding his approach to data capture and analysis.</p> <p>Query addressed in the text where the Clinical Liaison Officer’s role is mentioned.</p> <p>See text, p11 on the Forum events.</p> <p>See additions in the text on workshops.</p> <p>See elaboration in the text on the workshops.</p>
<p>Reviewer Comment 3.4 No ethical concerns noted</p>	<p>No changes needed</p>
<p>Reviewer Comment 3.5 Data Analysis and Findings: Findings would be improved if description was more interpretive rather than leaving that to the discussion.</p>	<p>With respect, we would normally expect to present data findings first before interpreting those findings.</p>
<p>Reviewer Comment 3.6 Psychological and emotional experience: no specific psychological theories or constructs included to make</p>	<p>See inclusion of details of our constructivist approach (embracing physical and mental</p>

<p>sense of participants' narratives. Interpretation of data linked to existing theories is needed.</p> <p>Expand examination of temporality in participants' narratives.</p>	<p>health and wellbeing) to data capture and interpretation.</p> <p>Unfortunately, as with many of the fascinating threads from these data, we do not have the space in this paper to expand further on temporality.</p>
<p>Reviewer Comment 3.7 -Style, Clarity and Formatting queries.</p> <p>Manuscript Style and Formatting: review punctuation, remove some unnecessary commas.</p> <p>Abstract: Use more straightforward language, naming themes as identified doesn't communicate the findings in a way useful for the reader.</p> <p>P2. Use of future tense verbs is confusing, e.g. "More extensive treatment planning for this group will only be discussed if cancer is subsequently identified".</p> <p>P2. Explain how/whether increased survival rates relate to risk detection technologies.</p> <p>"Classifying Risk" section, P2. How are risk classifications applied and used?</p> <p>"Impact of risk assessment and risk classification" section, P3. Cite research addressing perceptions of risk.</p> <p>P3. Clarify the meaning of "differences in psychological distress have been put down to age, gender and lifestyle"</p> <p>Be specific about country of origin (United States rather than American, P3.)</p> <p>This study or the Khanom et al. study? Clarify the study that the statement on P14. relates to.</p> <p>Reconsider the use of the word 'shunned' P17.</p> <p>P23. 'Barely registered' reconsider the wording.</p>	<p>Extra commas have been removed.</p> <p>While the abstract, by its very nature, is brief, we mention the thematic headings in the abstract, while expanding on them in detail in the body-text.</p> <p>This has been changed.</p> <p>See text.</p> <p>Added to text.</p> <p>The quote on age, gender and lifestyle comes straight from the literature, where it is stated but with no further detail provided.</p> <p>This now reads United States.</p> <p>This is one and the same study. Now clarified.</p> <p>The word 'shunned' has now been changed.</p> <p>'Barely registered' has been reworded to 'was difficult to conceive'.</p>
<p>Reviewer Comment 3.9</p> <p>Participant demographic features are missing e.g. Sexual orientation and ethnic identity.</p>	<p>We did not collect data on either sexual orientation nor ethnic identity so this cannot be reported in this study.</p>

Table 1: Risk level assigned to patients according to group and location

Location	Risk level assigned to patients		
	Low	Moderate	High
Group A: Cancer Care Unit (n=14)			
Cancer care unit	3	3	4
Cancer genetics		2	
Cancer support service	1		
Other	1		
Group B: Genetics Department (n=11)			
Cancer Genetics	1	6	1
Burns and Plastics Unit			1
Other	2		

Table 2: Patient characteristics

Demographic details	Group A	Group B
Age ≥ 45	4	8
Age ≤ 45	10	3
Marital status		
Married	7	6
Single	4	2
Living with partner	1	3
Widow	2	
Education		
Higher degree	1	0
First degree	3	4
Further education	4	6
School education	6	1
Breast cancer family status		
Breast cancer diagnosis (own)	14	0
Mother with cancer diagnosis	2	10
Sister with cancer diagnosis	1	2
Other family with cancer diagnosis	2	1
No family history of cancer	10	0



Figure 1. Books of experience

168x125mm (150 x 150 DPI)

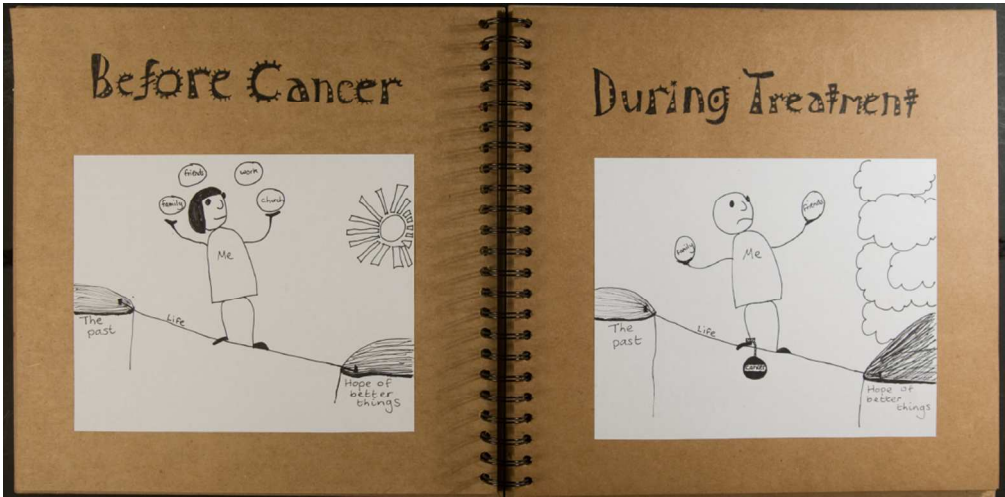


Figure 2. Cartoon from a book of experience

305x150mm (96 x 96 DPI)

Appendix 1. Guide for completing the 'Book of Experience'

Guide for completing your 'Book of Experience'

Please use this page as a guide to help you with your Book of Experience, with suggestions of the kinds of things we are interested in. Please describe/present/show, using imagery and text, your views and experiences on the following:

1. Impact on your life

The impact of being given a risk classification on your life, and the lives of family members.

2. Support and care

Your views or the views of family members about the support and care you currently receive from either healthcare professionals (oncology specialists, clinical nurses, genetic counsellors) or family members and friends.

3. Future expectations

Your expectations or the expectations of others for the future, and your future healthcare support needs.

4. Tests, treatments, drugs

Your views or the views of family members of the tests and treatments you have been through, the drugs you have been taking, or any other assessments following your risk classification (you may include test results or notes from the hospital if you wish).

5. Risk classification as a label

What does the risk classification label mean to you?

6. What happened during the following time periods?

[While completing the Book of Experience please let us know which of the following time periods your Book refers to:

- a) When your risk status was originally classified/you were waiting for a risk classification.
- b) When you were told you had to complete a questionnaire for the Genetics Unit

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to classify your risk or seeing a consultant in the Cancer Care Unit.

- c) When you were waiting for the results of the risk classification.
- d) When you first had your risk classification discussed with a healthcare professional.
- e) When you discussed the results with family members/carers/friends.
- f) Now, at this moment in time, when you think about the implications of risk on your life/the lives of others.]

7. Anything else?

Any additional information you think is needed that would help you and your family or friends understand more about risk classification.