



Original article

A qualitative study of women's experiences of healthcare, treatment and support for metastatic breast cancer



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ARTICLE INFO

Article history:

Received 19 October 2014

Accepted 13 February 2015

Available online 7 March 2015

Keywords:

Breast cancer

Metastatic

Healthcare

Social support

Qualitative research

ABSTRACT

Objective: The purpose of this qualitative research was to identify the healthcare, information and support needs of women living with metastatic breast cancer.

Materials and methods: Semi-structured qualitative interviews were conducted with 18 women. Women were asked about their experiences of living with metastatic breast cancer and their information and support needs.

Results: Women valued relationships with their healthcare professionals, particularly their oncologists. They wanted more attention paid to side-effects of ongoing treatments, which had a negative impact on their health. While oncologists were a primary source of information, women also drew on other sources. There were mixed findings about the value of support groups, with women preferring to seek alternative sources of social support.

Conclusion: A diagnosis of metastatic breast cancer brings heightened reliance on healthcare professionals to respond to women's needs in a way that is different to that required with a diagnosis of early breast cancer.

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Introduction

Metastatic breast cancer (MBC), also referred to as advanced or stage IV, occurs when breast cancer cells spread beyond the lymph nodes of the axilla to distant sites [1]. While incurable, treatment advances have resulted in an increasingly long period of time between diagnosis and end of life [2,3]. Despite this we have limited knowledge about women's experiences of living with MBC.

To date, most research has comprised intervention studies examining treatment efficacy [4–6] or studies showing the negative health consequences of a diagnosis of MBC [7]. Women with MBC are vulnerable to physical and psychosocial health issues, associated with ongoing treatment and symptoms and the uncertainty of living in 'contracted time' [8,9]. Although social support is important in improving psychosocial wellbeing [7,10], it decreases

over time, and women may feel isolated [9,11–13]. Vilhauer [12] found women with metastases may not receive adequate support from their partners, other family members and friends. They perceive other people as being uncomfortable, fearful or disinterested in talking about their experiences and concerns. As a result they may seek out support from other sources, particularly other women with MBC, because of their shared experiences [7,11].

The relationship between patients and healthcare providers has changed over time with patients now taking a more active role in their own healthcare, and the healthcare resources they choose to access [14,15]. While they depend on information and follow up care from their treating clinicians [16], they also draw on other information sources such as social networks or online sources [17]. At the same time women with metastases need to trust their healthcare providers because of vulnerabilities of living with a chronic, incurable condition [18,19] and the need for ongoing medical intervention. Quantitative research examining experiences with their healthcare providers, has found that women with recurrent MBC feel less supported and more dissatisfied with medical care and information after being diagnosed with a recurrence than when they were diagnosed with early breast

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cancer [20]. This may be because healthcare providers feel ill-equipped to provide care for women with MBC. Butow et al. [14] suggest there could be a disconnect between the information provided by clinicians and the information that patients want, with clinicians relying on statistics and patients wanting advice about the impacts of symptoms and treatments on daily living. For example, women have indicated a need for greater coordination of care and communication between healthcare team members, along with more information and support for psychological health issues [16].

Materials and method

A qualitative approach was used to explore women's experiences of living with MBC, the healthcare and treatment they receive, and their information and support needs. Women were recruited from a cross-sectional research project which investigated physical activity and physical fitness levels in women with MBC. All women participated in an exit interview at the conclusion of the study to talk about their experiences of the program within one week after completing the physical activity component of the study. Following the exit interview questions, women were asked if they would be happy to answer some additional questions about their health, and all women agreed to this. Ethical approval was granted by a Local Health District Human Research Ethics Committee.

Semi-structured telephone or face-to-face interviews were conducted by an experienced qualitative researcher (see list of questions in Table 1). Prompts were used to elicit in-depth information about women's experiences. The interviews allowed participants to talk about aspects of their experience that were important to them and for both participants and interviewer to introduce new topics. Interviews were audio-recorded, and transcribed in full. A thematic analysis was conducted to identify the key ideas within the data [21]. Transcripts were read closely and codes developed for the ideas expressed throughout. Codes were compared across and within transcripts and broader categories developed, before deriving broader themes that encapsulated women's perceptions of their experience of living with MBC.

Results

Eighteen women, aged 42–78 years old, participated in the study. Twelve were married with children, three were married without children, two women were separated or divorced with children and one was single with no children. Two women identified as Asian, one as Middle Eastern, one as South American and one as Pacific Islander. Women had been diagnosed with MBC between one and 11 years prior to the study. Fifteen women had been diagnosed with a recurrence of breast cancer (one to six years prior) following an initial diagnosis of early breast cancer. Three women were diagnosed with MBC as their primary diagnosis (in 2001, 2009 and 2012). Table 2 provides demographic information about participants.

Table 1
Interview questions.

The following questions were asked, with prompts to elicit further information as needed:

1. Can you tell me, how you are feeling?
2. Can you tell me about your diagnosis and treatment of breast cancer?
3. What strategies do you use to stay as healthy as possible?
4. What advice would you give a friend who was in a similar situation to you?
5. Have you participated in any support groups for women with breast cancer?

The main themes identified about participants' perspectives on support, information and healthcare were (1) the paradox of care, (2) communication and information needs, and (3) the good and bad of social support groups.

Theme one: the paradox of care

The paradoxical nature of women's experience can be seen in the sub-themes (see Table 3): the side-effects of treatment; expressions of hope and trust; and the use of complementary and alternative therapies.

While on the one hand, women acknowledged the need, and continued to hope, for life-saving interventions, on the other, their quality of life was impacted by the side-effects of their cancer treatment. Side-effects such as pain, fatigue, lack of energy, muscle weakness, nausea, infections and lymphoedema had the greatest negative impacts on women's health and placed limitations on their level of functioning and participation in daily life. While women were very positive about their medical care and support and reported being confident in their healthcare providers' ability to manage their disease, many were dissatisfied or frustrated with the support that their healthcare providers gave to alleviate side-effects of treatment. Some said they were not told about the potential side-effects of particular treatments and perceived that oncologists expected their patients to "put up with" side-effects even when they were having a serious impact on their quality of life. There may be differences between what clinicians and patients perceive is most important in caring for women with MBC, with healthcare providers focusing on survival and women focusing on living with good overall quality of life. Importantly, for women who had experienced a recurrence of cancer, their perspective was also shaped by the differences between their experience of primary cancer and their recurrence. The following quote illustrates this difference; as well as the perceived difference between women and their healthcare providers: "I guess when you get diagnosed the second time, [it] is a different type of thing, but they [healthcare professionals] probably don't see it that way, they just say well here's the next lot of treatment I guess." (Donna).

This paradoxical relationship between treatment needs and wellbeing was illustrated in the continued hope women had about the capacity of treatment to keep them alive (and healthy) for a long time. Hope was sustained by the development and advancement of new treatments for metastases. Most women discussed having high trust in their healthcare professionals, and this played a vital role in their experiences of MBC and of undergoing cancer treatment. Women discussed having complete trust in their oncologist's ability to manage their cancer, including that oncologists would find alternatives when treatment became ineffective. This trust was important in sustaining their hopeful outlook.

Women were unlikely to use complementary or alternative therapies (CAM) to manage cancer symptoms. Only four women currently used CAM to manage symptoms or side-effects. This may be another sign of women's high trust in conventional medicine but also an indication of low trust in CAM. Two women, who had used CAM after their diagnosis with early breast cancer, chose not to after their secondary diagnosis, stating either that treating oncologists did not encourage it because of concerns that CAM use may have been a contributing factor in their recurrence.

Theme two: information and communication needs

Healthcare professionals emerged as integral to women's support and information needs. Healthcare professionals, particularly clinicians, were described as the most dependable source of information, with four women relying exclusively on their oncologist for

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