Executive Summary

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Prepared for Breast Cancer Network Australia by

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EXECUTIVE SUMMARY

Overview

Breast cancer ‘survivorship’ is a key focus for Breast Cancer Network Australia (BCNA) throughout 2009 and beyond. There is an increasing awareness amongst breast cancer researchers and health professionals of the importance of responding to the needs of women in the extended phases of their breast cancer journey. However, very little is known about what the key survivorship issues are for women with breast cancer from their own perspective.

In April 2009, BCNA commissioned Dr Samantha Thomas and Prof Colette Browning from the School of Primary Health Care, Monash University to conduct a survey of BCNA’s members. This survey aimed to identify the priority ‘survivorship’ research issues from the women’s perspective.

Design

We conducted a random postal survey of 1800 women who had been diagnosed with breast cancer for at least one year. A total of 835 women returned a completed questionnaire over a 5-week period. The survey asked women to identify the key priority areas for research across six key thematic areas:

- Physical Health
- Emotional Health
- Lifestyle Issues
- Family and relationship Issues
- Follow up care
- Practical and day to day issues

We also asked women to provide qualitative information about their key experiences in the extended phase of their breast cancer journey.

Key Findings

The top areas for further research identified in the quantitative responses included ten specific research issues that women identified as ‘Very Important’ research priorities:

1. The physical risk of cancer recurring
2. The long-term impact of medical treatment on physical health
3. Lymphodema
4. The fear of cancer recurring
5. Access to good follow up care
6. Long-term bone health
7. Long-term provision of information and support
8. Long-term care planning
9. Nutrition and Exercise
10. Long term cognitive difficulties

Women were also asked to identify the top five issues that they believe deserve the most research attention or funding.
1. The physical risk of cancer recurring
2. The fear of cancer recurring
3. Lymphoedema
4. Long-term bone health
5. The long-term impact of medical treatment on physical health

The qualitative responses to our survey provided a much greater depth of understanding about the issues that are important to women, and combined with the quantitative results, provided us with a number of clear research priorities and themes.

**Physical health outcomes** were ranked highly by women, in particular the risk of breast cancer recurrence. Women felt that health professionals needed to listen more to their experiences about their physical health, but also that research should incorporate components in which women were able to describe the ways in which their long term physical health needs could be better addressed. Women felt that this was the most beneficial way for them to be involved in improving current interventions for their own physical wellbeing, and the wellbeing of others. In particular women identified the need for improved information, communication with health professionals, and access to care.

**Emotional wellbeing** also featured strongly as an important area for further research attention. Almost all women wrote that they had an underlying fear that their cancer would return. Furthermore, almost all women – from every socio-demographic background – wrote about how this fear of recurrence impacted on their emotional wellbeing, and their ability to ‘get back to normal’.

Women identified that lack of access to adequate information and long term follow up support, had a negative impact on their emotional wellbeing. In particular they were confused about why the physical effects of their cancer may last for some time – when they had perceived that after treatment their physical health would return to normal. Women wrote that this then resulted in poor emotional wellbeing – in particular depression and anxiety. Some groups of women wrote more frequently about their poor emotional health, highlighting the need to understand the role of health inequalities in tailoring interventions to improve emotional wellbeing.

**Access to long term care and support** was ranked highly by women, and was also extensively written about in their qualitative responses. Many women said that they felt that at times their health care professionals dismissed their concerns about their health and wellbeing. Whilst women appreciate the need for medical follow up care, they identified that there was little to meet their daily information and support needs – for them and their families.

Again, particular groups of women had differing experiences and needs when it came to long term care and support. Further research is needed to identify how best to tailor information support for women, and the best ways of providing information based interventions.

The qualitative responses to our survey highlighted the complexities of women’s journeys, and that many parts of their journey were often interlinked. This highlighted the need for some broader pieces of research on the extended phase of women’s journey that focus on:

- adjusting to life after breast cancer
- information and support
- health inequalities
In addition the research findings identify the need for **health service delivery** research to develop strategies and initiatives that will meet the survivorship needs of women.

Finally, methodological considerations were also identified through this research. In particular the depth of understanding that can be gained from **combining quantitative and qualitative research methods**, and the value placed by women on being able to talk about their experiences and have their voices heard within research studies. Connected to this is the benefit of **interdisciplinary approaches to research**, particularly working with consumer groups from the design of research through to evaluation and dissemination of research findings.

**Recommendations**

Listed below are the key research priorities and recommendations from women about future breast cancer ‘survivorship’ research.

**Recommendation 1:** that research on women’s physical health outcomes be undertaken with a particular focus on women’s information, support and access to care needs in relation to the physical risk of breast cancer recurring; lymphoedema; bone health; and the long-term impact of medical treatments on physical health.

**Recommendation 2:** that research is undertaken to identify and tailor information, support, interventions and long-term follow up care to particular groups of women to improve their emotional wellbeing. Particular attention should be paid to issues associated with fear of cancer recurrence and adjusting to life after breast cancer treatment and care.

**Recommendation 3:** that research is undertaken to identify appropriate models of follow up care which are tailored to meet the unique needs of different groups of women, with a particular focus on the day to day information and support needs of women and their families. This research needs to include the development, implementation and evaluation of interventions.

**Recommendation 4:** In-depth research needs to be undertaken into women’s experiences of survivorship with a particular focus on:

- issues associated with adjusting to life after breast cancer;
- the information, support and communication needs of women after the first year of their breast cancer journey; and
- the unique ‘survivorship’ needs of particular groups of women including women with secondary breast cancer, women with young children, women from lower socio-economic groups, rural women, single women, women from culturally and linguistically diverse backgrounds and Aboriginal and Torres Strait Islander women.

**Recommendation 5:** that research be undertaken to develop health care delivery strategies and initiatives that meet the ‘survivorship’ needs of a range of different groups of women.

**Recommendation 6:** that a combination of quantitative and qualitative research methods are used in ‘survivorship’ research, supported by an interdisciplinary approach to research partnerships, to ensure that women’s voices and experiences are central to the research.