

The Women's Health Research Program

Health Bulletin
April 2013

Improving the health and wellbeing of women after breast cancer: The BUPA Health Foundation Health and Wellbeing after Breast Cancer Study

The idea for this study was conceived more than 10 years ago when Susan Davis and Robin Bell put together the ideas for a Centre of Research Excellence in Women's Health. At that time, in consultation with both women with breast cancer and the health care providers who cared for them, it was clear that there was a need for a study which addressed the physical, psychological and socioeconomic consequences of the diagnosis and treatment of breast cancer.

A large prospective cohort study was established with the original NHMRC funding for the Centre of Clinical Research Excellence in Women's Health at Monash University (2003-2007). The participants completed an enrolment questionnaire within 12 months of diagnosis and then annual follow-up questionnaires for the following five years. A critical part of the success of the study was the support it received from the Victorian Cancer Registry both for its recruitment and for the linking of pathology data from the registry with the information provided by the participants directly to the study in the annual questionnaires. Recruitment through the registry was pivotal to ensuring that the participants were representative of all Victorian women with invasive breast cancer.

The conduct of a large study in which women are followed up for several years is expensive, as it requires the tracking of individual participants. This tracking has ensured that questionnaires were sent out and returned in a timely fashion and that women were not lost to follow-up. Maximising retention of women in the study along with the population-based recruitment has been critical in ensuring that our findings apply to all Victorian women diagnosed with breast cancer.

The funding of the study has been challenging as the study ran for 10 years – a lot longer than conventional funding cycles. The funding has come from a range of sources including a number of philanthropic bodies, but particularly Craig and Connie Kimberley, as well as large grants from both the BUPA Health Foundation, Novartis Oncology and from the Victorian Cancer Agency, in the form of a two year fellowship to Robin Bell.

The findings of the study have been published in 16 manuscripts to date with a number of other manuscripts currently under review and further manuscripts in preparation.

The manuscripts have been published in a range of well recognised international and specialist cancer



Professor Robin Bell and Dr Heather Rowe.

and women's health journals, as listed on our website.

Some of the highlights of our study findings are that:

Psychological general wellbeing two years from diagnosis was lower in women with a higher level of education and higher in women who were living with other people so that being well informed may be associated with higher levels of anxiety and women living alone may benefit from extra support.

It was also common for breast cancer survivors to make lifestyle changes in the first two years after diagnosis, particularly changes to their diet and exercise regimens.



MONASH University

M8Alliance

Within two years of diagnosis, about 70 per cent of women reported sexual function problems. Sexual function problems were associated with the presence of vasomotor symptoms, the use of aromatase inhibitors and self-reported issues with body image.

Nearly half of women reported a specific belief about the cause of their breast cancer and of these, more than half considered the cause to be stress. Women reporting this belief had lower psychological wellbeing and were more likely to have made lifestyle changes.

Smoking and alcohol consumption continue to be a problem for women with breast cancer. About 2/3 of women who smoked at diagnosis continued to smoke two years later and about one in six women continued to consume alcohol at levels consistent with long term harm.

Lymphoedema was reported by about 20 per cent of women within two years of diagnosis. The presence of lymphoedema was not well explained by risk factors such as the number of nodes removed from the axilla. Lymphoedema was a dynamic condition with the condition resolving in some women and developing anew in others over the following two years. Some women

reported lymphedema for the first time nearly four years from diagnosis and only 11 per cent of women had consistently reported lymphoedema in each questionnaire within the first four years.

Of women who had a mastectomy, about one in four had reconstructive surgery within two years. Women who had reconstructive surgery were younger, had a higher level of education, were more likely to live in metropolitan Melbourne, more likely to have private health insurance, not to have had radiotherapy and not to have dependent children.

Women were more likely to be treated with adjuvant endocrine therapy if they understood their hormone receptor status. By two years from diagnosis, 87 per cent of women with hormone receptor positive disease were on oral adjuvant endocrine therapy. Cessation of treatment within the following two years was generally due to side effects particularly vasomotor symptoms, bleeding and bone pain. Most women who survived at least five years from diagnosis had persisted with oral adjuvant endocrine therapy despite the side-effects.

The study findings have been presented at a number of both local and international conferences including those of the Australasian Menopause

Society, the Australasian Society for Psychosocial Obstetrics and Gynaecology (ASPOG) and the North American Menopause Society as well as the San Antonio Breast Cancer Meeting in the United States and the International Congress on Hormonal Steroids and Hormones and Cancer, Japan.

The BUPA Health Foundation Health and Wellbeing After Breast Cancer Study has received recognition in the form of awards for presentations by Professor Bell from the Australasian Menopause Society in 2011 and the ASPOG meeting in 2012. The work is covered extensively on our website to ensure that both women and health care providers are able to access the study findings. The work has also received extensive coverage in the general media when new publications have been released, again ensuring that the findings from the work are widely accessible.

Women's Health Research Program

womenshealth.med.monash.edu.au

womens.health@monash.edu

Tel: 03 9903 0827

Fax: 03 9903 0828

Bell RJ, Lijovic M, Fradkin P, Davis SR. A pragmatic approach to the classification of menopausal status for community-based research *Menopause* 2008;15(5): 978-983

Lijovic M, Davis SR, Fradkin P, La China M, Farrugia H, Bagnato M, de Crespigny J, Wolfe R, Bell RJ. Use of a cancer registry is preferable to a direct-to-community approach for recruitment to a cohort study of wellbeing in women newly diagnosed with invasive breast cancer *Biomed Central Cancer* 2008; 8(1):126

Lijovic M, Davis SR, Fradkin P, Bradbury J, LaChina M, Schwarz M, Wolfe R, Farrugia H, Bell RJ. The relationship between knowledge of family history and cancer characteristics at diagnosis in women newly-diagnosed with invasive breast cancer *Familial Cancer* 2009;8:299-305

Bell RJ, Lijovic M, Fradkin P, Bradbury J, La China M, Schwarz M, Wolfe R, Farrugia H and Davis SR Lack of knowledge of hormone receptor status is associated with lower prevalence of use of endocrine therapy in women with invasive breast cancer *J Women's Health* 2009 Dec;18(12):1975-80

Bell RJ, Lijovic M, La China M, Schwarz M, Fradkin P, Bradbury J and Davis SR Psychological well being in a cohort of women with invasive breast cancer nearly 2 years after diagnosis *Supportive Care in Cancer* 2010 Aug;18(8):921-9

Davis SR, Lijovic M, Fradkin P, Bradbury J, La China M, Schwarz M and Bell RJ Use of complementary and alternative therapy by women in the first two years following diagnosis and treatment of invasive breast cancer. *Menopause* 2010 Sep-Oct; (5):1004-9

Panjari M, Bell RJ, Lijovic M, La China M, Schwarz M, Fradkin P, Bradbury J, Farrugia H, Davis SR The relationship between hormone therapy use at the time of diagnosis of breast cancer and tumor characteristics: a cohort study *Hormones and Cancer* 1:93-99 2010

Panjari, M, Bell RJ and Davis SR Sexual function after breast cancer *J Sexual Medicine* 8:294-302, (2011)

Mary Panjari, Susan R Davis, Pamela Fradkin, Robin J Bell *Breast Cancer Survivors' Beliefs about the Causes of Breast Cancer Psycho-oncology* 2012 Jul; 21(7):724-9

Robin J Bell, Marijana Lijovic, Pamela Fradkin, Max Schwarz and Susan R Davis *Changes in patterns of use of cigarettes and alcohol in women after a first diagnosis of invasive breast cancer: a cohort study of women from Victoria, Australia. Supportive Care in Cancer.* 2012; 20(4):783-789

Mary Panjari, Robin J Bell, Pam Fradkin, Susan R Davis *Cosmetic surgery prior to diagnosis of breast cancer Climacteric* 2012 Apr;15(2):195-9

R J Bell, P J Robinson, P Fradkin, M Schwarz and S R Davis *Breast reconstruction following mastectomy for invasive breast cancer; is strongly influenced by demographic factors in women in Victoria, Australia Breast.* 2012 Jun;21 (3):394-400

R J Bell, P Fradkin, M Schwarz and S R Davis *Understanding discontinuation of oral adjuvant endocrine therapy by women with hormone receptor positive invasive breast cancer nearly 4 years from diagnosis Menopause* 20(1):15-21, January 2013

R J Bell, M Schwarz, P Fradkin, and S R Davis *Use of imaging in surveillance of women with early stage breast cancer ANZJ Surg* 2013;83 (3): 129

Robin J Bell, Max Schwarz, Pamela Fradkin, Penelope J Robinson, Susan R Davis *Patterns of use of oral adjuvant endocrine therapy in Australian breast cancer survivors five years from diagnosis (Menopause in press November 2012)*

Robin J Bell, Penelope J Robinson, Raychel Barallon, Pamela Fradkin, Max Schwarz, Susan R Davis *Lymphedema: experience of a cohort of women with breast cancer followed for four years after diagnosis in Victoria Australia. Supportive Care in Cancer in press February 2013*