SECONDARY BREAST CANCER
TELEPHONE COUNSELLING SERVICE
PILOT PROJECT

EXECUTIVE SUMMARY

‘I would recommend the counselling service because I felt
listened to, and understood. The Counsellor gave me time and
never rushed our conversations, she was totally available to my needs.’
Executive Summary

I was very pleased to be able to talk to someone outside my family without fear of burdening them about my fears. – Participant

In 2014 BCNA surveyed women with secondary breast cancer to identify their unmet supportive care, financial, practical and information needs. Results indicated that almost one third of the 582 women surveyed felt they needed greater emotional support from their treating team, had limited access to information and support programs, and minimal contact with health professionals who could advise on strategies to live well.

In response to these findings, BCNA identified several key recommendations and research priorities to help support women and men diagnosed with secondary breast cancer and their families. This included increased referral to counselling services that are free and easily accessible to all Australians regardless of where they live or where they are being treated. BCNA believed that a telephone service would be the most appropriate way of delivering equitable access to professional counselling services.

In order to test feasibility of this concept, in October 2015 we piloted a telephone counselling service for Australians living with secondary breast cancer and their family members. Two counsellors, both with over 20 years' experience in cancer social work and psychotherapy, delivered the counselling sessions over a three month period.

The evaluation data indicated that the secondary breast cancer telephone counselling service pilot achieved all project objectives, including assisting participants with:

- adjustment to illness
- information provision
- mental health assessment
- referral to appropriate services.

Primary achievements
Fifty women received counselling during the pilot, indicating that BCNA’s aim to recruit 30 to 50 participants was achieved.

BCNA’s counsellors delivered 98 counselling sessions during the pilot. Forty four per cent of participants required one session only, and 56 per cent had two or more sessions.

Overall findings

- Efficient reach to 50 participants
- A high level of satisfaction among participants and counsellors
- A positive impact on adjustment to life with secondary breast cancer and improvement in wellbeing for the majority of participants
- The telephone counselling method worked well, especially for those living in rural and regional area and for people with limited mobility
- An appreciation for highly experienced expert counsellors with an understanding of breast cancer treatment and care
- Satisfaction among BCNA staff that the organisation can offer a support service to individuals and families affected by secondary breast cancer
Participant profile
Forty eight participants were women living with secondary breast cancer and two were family members.

Participants represented all states and territories except the NT (where no sessions were delivered). The majority lived in Victoria (55 per cent) and NSW (17 per cent). Fifty eight per cent lived in a metropolitan location and 40 per cent lived in a regional or rural location. One woman did not provide her address.

Thirty one of the 50 participants completed the online evaluation survey, indicating a 63 per cent response rate. Most of the survey respondents were aged 50 to 69 years, and none were younger than 40 years of age.

Issues of concern
Ninety per cent of participants rated emotional concerns as their most important issue prior to counselling. Consistent themes addressed included living with uncertainty, anxiety, fear, loneliness, grief and facing the end of life. In addition, an emerging theme from those living longer than they or their oncologist predicted was how to manage this ‘new world’, not knowing which direction their future would take.

Women rated their other concerns as relationship issues, dealing with physical symptoms such as chronic pain, communication and financial issues, in order of priority.

Formulating plans for the future was a fundamental feature of the project. One counsellor described an overwhelming sense of relief expressed by women as they worked together on plans for accessing community based support, enhancing wellbeing, letter writing and communication skills.

*I think developing a plan... was met with relief, as these women had felt they were floundering without direction or guidance about how to manage now.* – Counsellor

Satisfaction
Overall, responses indicated that satisfaction levels were high and the counselling service addressed most of the participants’ needs and expectations.

Ninety per cent of survey respondents indicated they either fully or partially received what they needed and 73 per cent reported that the service met or exceeded their expectations. Eighty per cent indicated that they received assistance with their emotional concerns.

Almost all women indicated that the counsellors understood them and responded appropriately. Eighty per cent were able to speak to the same counsellor for all appointments. Comments reflected participants’ appreciation for the counsellors’ skills and expertise in supporting people with cancer and the high quality of the service.

Counselling via telephone seemed to work very well for counsellors and for almost all of the participants, especially those living in rural and regional locations, and those with limited mobility. Almost all respondents indicated that they would recommend the service to others, including family members, with some reporting that they had already done so.
Wellbeing and self-management
The counselling sessions seem to have made a significant impact on most participants' wellbeing and capacity for self-care. Almost half of the respondents indicated that they received ideas for self-management activities and 67 per cent noted an improvement in their wellbeing since counselling. Eighty per cent indicated that the activities helped them adjust to life with secondary breast cancer, which demonstrates a significant achievement.

Fifty three per cent reported that they felt confident that their relationships with others would benefit from the counselling sessions. One counsellor reported that many women indicated that they did not feel confident speaking to their oncologist about how they were feeling.

So I worked with women to articulate their feelings and encouraged them to realise their rights. - Counsellor

Sixty per cent of respondents indicated that they had a discussion with the counsellor about plans for accessing local support, however only 43 per cent reported feeling confident about accessing ongoing community-based support. It was not clear whether these women require additional support to gain personal confidence, or whether local support services may not be accessible, regardless of individuals’ confidence.

Enablers and Barriers
The primary project enablers drawn from the evaluation were:
- promotion via emails to women with secondary breast cancer and articles in The Inside Story (BCNA’s magazine for women with secondary breast cancer)
- no cost to participants
- service delivery via telephone method
- highly skilled counsellors with expertise in secondary breast cancer
- focus on building participants’ capacity for wellbeing and self-care
- satisfactory systems and processes that require minor improvements
- support from the BCNA CEO and Board.

The primary project barriers were:
- some internal administrative challenges
- increased workload for BCNA’s Member Services team, requiring greater than expected resources
- four back-to-back sessions in a counselling block which were found to be too arduous for counsellors
- promotional strategies for recruitment to the pilot did not encourage many family members to take up the offer of counselling.
Recommendations

Program promotion and participant recruitment
Develop and implement a promotional strategy that aims to garner greater external support from key stakeholders in order to increase service demand for family members as well as women and men diagnosed with secondary breast cancer.

Consider methods that:
- promote the project’s outcomes externally to engage oncology health professionals, policy makers and the wider cancer sector
- work closely with medical oncologists, as a key point of contact with women with secondary breast cancer
- engage health professional ‘practice champions’ to promote the service to colleagues and professional bodies
- explore collaborative opportunities with relevant organisations to reach people diagnosed with secondary breast cancer and family members (e.g. Cancer Councils, carer organisations, local government, Canteen, BreaCan, Men’s Shed, Rotary)
- explore the value of social media as a promotional vehicle.

Service quality
- Build in succession planning to ensure BCNA continues to deliver a high quality service with experienced oncology counsellors and consider introducing additional counsellors as the program expands.
- Formalise debriefing and support processes for counsellors and regularly monitor the impact of the service on the counsellors’ capacity and wellbeing.
- Consider the possibility of introducing more flexible times for counselling sessions, particularly to accommodate time zones for people living in Western Australia.
- Explore opportunities for women to return to the service during high risk situations, such as impending test results or when their cancer progresses.
- Implement measures to help ensure people return to the service when they need to; consider a role for counsellors to prompt this, after determining whether this approach would be acceptable to participants.
- Consult with stakeholders to inform development of promotional plans for reaching family members in the future.
- Ensure future service evaluation includes the option for a follow up phone call to those who express negative experiences with the counselling service.

Sustainability
- Align future promotional activity with service capacity and monitor regularly to ensure that demand for counselling services can be sustained.
- Establish counsellors’ capacity to support an ongoing service in the short and long term.
- Implement the program for the remainder of 2016 and evaluate it again.
- Seek opportunities for future program funding from government, philanthropic and corporate partners.
Program administration and logistics

- Improve automation of administration functions and introduce a more interactive booking process.
- Consider appointing one Member Services Team member or appointing a new staff member with a health professional background, such as a breast care nurse, to coordinate the service and triage complex calls.
- Implement appropriate training and support for BCNA Member Services Team staff to enable them to confidently manage all relevant aspects of the service.

*The service met my needs at the time and got me back on track… I had a stressful time which resulted in me needing help to offload and get back to my positive self.* – Participant

*The unmet needs of this patient group are as we expected – large – and this (service) fills a very important gap.* – Counsellor