Impact of rural community information forums on people affected by breast cancer

Authors
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Background
Compared to metropolitan women, non-metropolitan (‘rural’) women with breast cancer have poorer survival outcomes and unmet psychosocial needs. Accessing breast care nurses, allied health services, and practical and psychosocial supports can also be difficult.

About BCNA information forums
The Australian Government funds BCNA to deliver community information forums (forums), which have reached more than 5,000 women in rural areas around Australia since 2008. The forums provide the opportunity for rural women to hear from a range of speakers on the latest in breast cancer treatment, care and emotional wellbeing. There is also a strong focus on local services and community support.

Project rationale
While internal evaluations of the forum sessions have been consistently positive, little is currently known about whether there is any ongoing local impact of the forums on rural communities as a result.

Aims
1. Profile and describe the attendees of BCNA’s rural forums.
2. Evaluate the short-term social impacts of the forums including:
   • the extent to which breast cancer-related challenges were addressed
   • improved knowledge, support and lifestyle behaviours (e.g. healthy eating, exercise)
   • access to local support services following attendance at a forum (e.g. community supports, breast care nurses).
3. Assess the educational and social impact of community information forums

Methods
Women attending a BCNA one-day rural community information forum at one of three locations (Port Macquarie, Nambour and Bums) completed a post-forum paper-based survey (baseline) and an online survey 4-6 weeks post-forum, with some women also participating in follow-up interviews. In addition, 4) supporters (family/friends who attended the forum with the women) also completed a survey at these time points.

Surveys were analysed using descriptive statistics. Cross-tabulation analysis was performed by age, education level, socio-economic status (SES, based on SEIFA quintiles), time since diagnosis, diagnosis stage (early/EBC vs. secondary/SBC) or Aboriginal/Torres Strait Islander background.

Findings
Characteristics of forum attendees
A total of 253 women diagnosed with breast cancer attended the three forums with 170 completing the baseline and 92 completing the follow-up surveys (54% response rate). Generally, attendees were Australian-born, well-educated and resided in areas classified as lower socio-economic disadvantaged. Their mean age was 62.7 years with most women receiving their most recent diagnosis within the past 12 months. The majority (84.1%) had a diagnosis of EBC (see Tables 1 and 2).

Table 1 Demographic variables of women who attended BCNA rural forums

<table>
<thead>
<tr>
<th>Demographic Variables</th>
<th>Baseline N (%)</th>
<th>Baseline (n=170)</th>
<th>Follow-up (n=92)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≥ 70</td>
<td>25 (14.7)</td>
<td>17 (18.5)</td>
<td></td>
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<tr>
<td>60-69</td>
<td>55 (32.4)</td>
<td>48 (52.6)</td>
<td></td>
</tr>
<tr>
<td>50-59</td>
<td>70 (41.2)</td>
<td>44 (48.7)</td>
<td></td>
</tr>
<tr>
<td>45-49</td>
<td>20 (11.8)</td>
<td>14 (15.2)</td>
<td></td>
</tr>
<tr>
<td>15 years previously</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤ 5 years previously</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aboriginal</td>
<td>4 (2.4)</td>
<td>1 (1.2)</td>
<td></td>
</tr>
<tr>
<td>Torres Strait Islander</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>English only</td>
<td>163 (97.6)</td>
<td>89 (97.8)</td>
<td></td>
</tr>
<tr>
<td>English plus another language</td>
<td>4 (2.4)</td>
<td>2 (2.2)</td>
<td></td>
</tr>
<tr>
<td>Highest level of education completed</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No formal education</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Primary School</td>
<td>52 (5.9)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>High School</td>
<td>68 (40.5)</td>
<td>40 (44.4)</td>
<td></td>
</tr>
<tr>
<td>Certificate or Diploma</td>
<td>68 (40.5)</td>
<td>35 (38.9)</td>
<td></td>
</tr>
<tr>
<td>University Degree or higher</td>
<td>27 (16.1)</td>
<td>15 (16.7)</td>
<td></td>
</tr>
<tr>
<td>Socio-economic status indicator (SEIFA), based on residential postcode</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1st quintile (most disadvantaged)</td>
<td>57 (34.4)</td>
<td>31 (34.4)</td>
<td></td>
</tr>
<tr>
<td>2nd quintile</td>
<td>52 (31.8)</td>
<td>31 (34.7)</td>
<td></td>
</tr>
<tr>
<td>3rd quintile</td>
<td>25 (15.0)</td>
<td>17 (18.8)</td>
<td></td>
</tr>
<tr>
<td>4th quintile</td>
<td>17 (10.4)</td>
<td>9 (10.0)</td>
<td></td>
</tr>
<tr>
<td>5th quintile (least disadvantaged)</td>
<td>2 (1.2)</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

Impact of attending the forum on breast cancer challenges
At baseline (see Figure 1), the top breast cancer related challenges were:
• financial concerns (women 56.6%, supporters 20.0%)
• emotional issues (women 53.8%, supporters 70.0%)
• being active and well (women 53.2%, supporters 35.0%)
• side effects from treatment (women 56.6%, supporters 50.0%)

At 4-6 week follow-up (see Figure 1), the majority of women agreed that attending the forum helped them address their top challenges identified at baseline including:
• emotional challenges (64.4%)
• side effects from treatment (54.6%)
• access to treatment (48.2%)
• relationship issues (45.3%)
• financial concerns (40.6%)

Women’s age (p=0.0448) and SES (p=0.039) were both significantly associated with the forum helping with side effect challenges from treatment; those aged >50 years and those living in the most disadvantaged areas more likely to report the forums helping. No other disease or demographic variables were associated with challenges.

Table 2 Breast cancer characteristics of women who attended BCNA rural forums

<table>
<thead>
<tr>
<th>Disease Variables</th>
<th>Baseline N (%)</th>
<th>Baseline (n=170)</th>
<th>Follow-up (n=92)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Years since diagnosis (range 1-71)</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>≤ 12 months</td>
<td>37 (21.2)</td>
<td>14 (15.6)</td>
<td></td>
</tr>
<tr>
<td>1.5 years previously</td>
<td>73 (43.5)</td>
<td>52 (57.8)</td>
<td></td>
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<tr>
<td>5 years previously</td>
<td>56 (33.5)</td>
<td>24 (26.7)</td>
<td></td>
</tr>
</tbody>
</table>

Stage of breast cancer
EBC 144 (84.1) 80 (88.9)
SBC 27 (15.9) 10 (11.1)

Forum’s impact on knowledge, support and lifestyle behaviours (4-6 weeks post-forum)
At 4-6 week follow-up, the majority of respondents (55%-67%) agreed that attending a BCNA forum resulted in:
• improved knowledge of community services, treatment and managing side effects
• feeling more emotionally able to cope
• connectedness with others going through a similar experience

Women’s age was significantly associated with self-reported increases in knowledge about breast cancer (p=0.0196), breast cancer treatment (p<0.0001), and managing the side effects of breast cancer (p=0.0009). In each case, older women (50+) were more likely to report improved knowledge than younger women (<50 years).

Education level was also significantly associated with self-reported increases in knowledge about breast cancer (p=0.0196) and breast cancer treatment (p=0.0495). Women with high school certificates or lower reported greater increases in knowledge than those with graduate diplomas/certificates or a higher qualification.

Behaviour changes following the forum included (See Figure 2):
• 35.7% made positive changes to physical activity (11.9% intend to)
• 32.9% developed new relationships with other women with breast cancer (4.7% intend to)
• 26.2% became involved in their community (e.g. raising funds for breast cancer, supporting others affected by breast cancer) (37.7% intend to)
• 26.2% made positive changes to eating behaviours (9.5% intend to)

Women living in the most disadvantaged areas (1st SEIFA quintile) were more likely to report feeling more emotionally able to cope with their breast cancer than those who were more advantaged (2nd to 5th SEIFA quintiles) (p=0.046).

Access to support services following attendance at forum
The survey explored the extent to which women utilised services and providers in their community. Following the forum:
• 10%-27% of women indicated they had accessed local services they had not previously used
• a further 6%-19% indicated they intended to use these services in the future
• the services most accessed were not-for-profit organisations (e.g. Cancer Council, CanTeen) and allied health services.

Older women (>70 years) were more likely than younger women (<70 years) to report either already utilising or intending to utilise a nurse since attending the forum (p = 0.0207).

Limitations
As this study was conducted with a small sample of rural Australian women with breast cancer, results may not be widely applicable. Nonetheless, this is the first known research of its kind, which provides evidence of the value of community information forums in addressing unmet needs of rural Australians affected by breast cancer.

Conclusions/Recommendations
BCNA’s rural information forums clearly address many breast cancer challenges, which are often exacerbated by living in a rural setting.

More targeted approaches by BCNA and local services, particularly for older women, women with SBC and those from particularly disadvantaged areas may have significant impact on these women’s ability to manage these challenges.

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For more information email beacon@bcna.org.au or visit www.bcna.org.au

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