The Advocacy Perspective: the financial cost to women of breast cancer treatment and care

Maxine Morand
Chief Executive Officer
Breast Cancer Network Australia
Breast Cancer Network Australia

- Support
- Inform
- Represent
- Connect
Member based consumer advocacy

- 99,000 members
- 300 support groups
- 13,000 online network members
- 2,500 Review & Survey Group members

- 81 Consumer Representatives
- My Journey Kit reached 82% newly diagnosed women this year
Breast Cancer in Australia 2014

• 15,270 diagnosed - 42 today
• At least 160,000 post diagnosis / under treatment / living with secondary breast cancer
• 2,700 deaths
Financial cost of cancer

- Out-of-pocket costs
- Loss/reduction of income
- Lost productivity to society
- In Australia, 78% of women aged 45–54 years participate in the workforce*
  - ~ 50% women aged 55-64 (increasing)

*ABS, Labour Force, Gender Indicators, Australia, 2012
http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by+Subject/4125.0~Jan+2012~Main+Features~Labour+force~
BCNA Member Survey 2013

- Survey focused on needs:
  - Information, psychosocial
- 1340 respondents
- All states and territories
- 87% respondents aged 45–74 years
- 74% diagnosed within the last 5 years
- 86% diagnosed with early breast cancer
Challenges since diagnosis

- Financial pressure
- Obtaining practical help
- Understanding family and friends
- Accessing treatment
- Managing side effects
- Impact on family and children
- Emotional health
- Ongoing wellbeing

Options:
- Unsurprised
- Not at all
- A little
- Quite a bit
- A lot
Women’s experiences

‘The appalling cost of the whole program of treatment, surgery and recon for women with private health cover.’

‘The cost of radiotherapy if you are not a public patient and the fact you cannot claim it on your private health cover.’
BCNA research with women with secondary breast cancer
Demographics

582 participants (32% response rate)

- 66% aged 50-69 years
- 24% under 50 years
- 77% diagnosed with SBC in last 5 years
- 7% living with SBC for 10 years+

Health system
- 49% private system
- 44% public system
- 7% unknown
How often women currently visit a health service for treatment or review

<table>
<thead>
<tr>
<th>Frequency seen by health professional</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daily</td>
<td>&lt;1% (4)</td>
</tr>
<tr>
<td>Weekly</td>
<td>14% (83)</td>
</tr>
<tr>
<td>Fortnightly</td>
<td>5% (28)</td>
</tr>
<tr>
<td>Every 3 weeks</td>
<td>24% (139)</td>
</tr>
<tr>
<td>Monthly</td>
<td>27% (156)</td>
</tr>
<tr>
<td>Every 2 month</td>
<td>7% (39)</td>
</tr>
<tr>
<td>Every 3 months or more</td>
<td>16% (95)</td>
</tr>
<tr>
<td>Sub-total</td>
<td>93% (544)</td>
</tr>
<tr>
<td>Unknown</td>
<td>7% (38)</td>
</tr>
<tr>
<td>Total</td>
<td>100% (582)</td>
</tr>
</tbody>
</table>

- 44% women seen every 3 weeks or more
- 71% seen monthly or more
Financial difficulty

- 25% (133) ‘quite a bit’ or ‘very much’
- 60% (352) experienced some financial difficulty in previous week

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>A little</th>
<th>Quite a bit</th>
<th>Very much</th>
<th>TOTAL respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Private system</td>
<td>36% (101)</td>
<td>42% (119)</td>
<td>12% (34)</td>
<td>10% (30)</td>
<td>284</td>
</tr>
<tr>
<td>Public system</td>
<td>34% (87)</td>
<td>38% (97)</td>
<td>17% (42)</td>
<td>11% (27)</td>
<td>253</td>
</tr>
<tr>
<td>All women</td>
<td>35% (188)</td>
<td>38% (216)</td>
<td>13% (76)</td>
<td>10% (57)</td>
<td>537</td>
</tr>
</tbody>
</table>
Causes of financial difficulty

- Out of Pocket: 126 Public, 70 Private
- Loss of Income: 93 Public, 101 Private
- Loss of Partners Income: 22 Public, 17 Private
- Other: 37 Public, 35 Private
Out-of-pocket costs

- Average out-of-pocket cost previous month: $687
- Previous month range:
  - $0 – $25,000 (private)
  - $0 – $10,500 (public)
Out-of-pocket costs since diagnosis – by treatment type

- Scans
- Surgery
- PBS Drugs
- Non-PBS Drugs
- Radiotherapy

$0.0
$1,000.0
$2,000.0
$3,000.0
$4,000.0
$5,000.0
$6,000.0
Loss of income and work changes

- Less than 10% (57) working full-time
- 16% (93) working part-time
- 32% (180) retired
- 11% (62) home duties
- 31% reported change in role for the worse
- 6% (33) reported workplace discrimination

‘I was not given usual duties on return, and am not given or considered for more responsible / important tasks anymore.’

‘Attitudes towards my ability to do my job have changed and I miss out on certain opportunities.’
Superannuation

- 31% (181) have ‘needed’ to access their super
- Of these, 20 women were unable to

‘Even though I have a limited life span I am not expected to die within 12 months ... shame they don’t take into account my medical bills, and I am not going to make retirement age anyway.

‘I wanted access my superannuation so I could reduce my working hours...it would have been helpful to ease the financial worry.
What is BCNA doing?

- Senate Inquiry into out-of-pocket costs
- Inquiry has recommended:
  - a review of the impact of out-of-pocket costs
  - identification of efficiencies for PBS
  - that consumers be informed about cost of treatments, before treatment
- PBAC advocacy for proven, effective treatments
- Further research with our members in 2015

‘Please keep fighting to have new treatments placed on the PBS.’

‘Medicare rebate on prosthesis was a big win for BCNA.’
What can health professionals do?

- Understand patients’ financial context
- Consider whether your patient can afford treatment in the private system
- Recommend bulk billing when referring
- Provide treatment quotes
- DON’T withhold treatment options because they are costly – women want to know
- Support women to access their superannuation
Thank you