Issues for regional and rural cancer survivors

Dr Kate Fennell (née Gunn)
Bob = 35% more likely to die within 5 years of a cancer diagnosis

Jong, Smith et al. 2004
You've got enough running through your mind now. You know… ‘What are the kids going to do? How are the kids going to take it?’ … ‘I have bad days and good. I'm crying a lot, and what are the kids…’ you know.

On top of this, I've got to try and… ‘where am I going to stay? What accomo… I can't drive the bloody car around. The traffic's too much for me in Adelaide. How am I going to get around? I can't afford taxis.’

Rural South Australian male cancer survivor
Key differences

- Poorer treatment outcomes (Jong, Smith et al. 2004; Bydder and Spry 2011)
- Additional stressors (e.g. travel) (Baldwin and Usher 2008; Bettencourt, Talley et al. 2008)
- Later diagnosis (Liff, Chow, & Greenberg, 1991)
- Differences in screening practices (Coory and Baade 2005)
- Differences in treatment types (Craft et al., 2010; Bydder and Spry 2011; Coory and Baade 2005)
- Higher incidence of some cancers (National Rural Health Alliance 2009)
- Low SES, education levels and more disadvantaged groups (National Rural Health Alliance 2010, Jong, Smith et al. 2004)
- Lack of GPs, nurses, allied health professionals, support services, clinical trials and specialist follow-up and knowledge (Sabesan & Pilouras, 2009)
- Cost of health, education and aged care two-ten times greater (National Rural Health Alliance 2010)
- Attitudinal barriers to help-seeking (Koopman et al., 2001)
- In the U.S., poorer mental health (Burris & Andrykowski, 2010) and poorer quality of life (Reid-Arndt & Cox, 2010)
1) What are the key issues associated with the provision of psychosocial care to rural cancer survivors?

- Highly valued by those who have accessed it
- Both lay and professional psychosocial support is important
- Accessing professional support it is difficult
  - Initial beliefs that psychosocial help is unnecessary
  - Feeling overwhelmed and unable to ask questions about services
  - Concerns about dual relationships with service providers
  - Concerns about stigma
  - Lack of rurally-relevant information on psychosocial care

The biggest problem is we don’t know about…um, these places and… what’s available for us.
2) Could a website, designed with rural cancer survivors... be acceptable to other rural cancer survivors and their supporters, and reduce users’ feelings of distress, perceived isolation and make them feel more motivated and confident to access support?

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>A little</th>
<th>A moderate amount</th>
<th>A lot</th>
<th>A great deal</th>
<th>% that agree</th>
<th>A lot or A great deal</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Easy to use</td>
<td>4</td>
<td>2</td>
<td>10</td>
<td>34</td>
<td>61</td>
<td>85.6</td>
<td>91.0</td>
<td>111</td>
</tr>
<tr>
<td>Relevant to needs</td>
<td>3</td>
<td>4</td>
<td>16</td>
<td>54</td>
<td>34</td>
<td>79.3</td>
<td>91.0</td>
<td>111</td>
</tr>
<tr>
<td>Necessary</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>28</td>
<td>78</td>
<td>95.5</td>
<td>91.0</td>
<td>111</td>
</tr>
<tr>
<td>Helpful</td>
<td>2</td>
<td>2</td>
<td>6</td>
<td>38</td>
<td>63</td>
<td>91.0</td>
<td>91.0</td>
<td>111</td>
</tr>
<tr>
<td>Likelihood of returning to website</td>
<td>0</td>
<td>5</td>
<td>5</td>
<td>42</td>
<td>59</td>
<td>91.0</td>
<td>91.0</td>
<td>111</td>
</tr>
<tr>
<td>Likelihood of recommending the website to someone else</td>
<td>1</td>
<td>2</td>
<td>4</td>
<td>22</td>
<td>82</td>
<td>93.7</td>
<td>93.7</td>
<td>111</td>
</tr>
<tr>
<td>Written by people who understand what I’m going through</td>
<td>1</td>
<td>2</td>
<td>8</td>
<td>20</td>
<td>22</td>
<td>79.2</td>
<td>79.2</td>
<td>53</td>
</tr>
</tbody>
</table>

Because of this website I am now feeling less isolated: 73.3%
Because of this website I am now feeling less depressed: 53.6%
Because of this website I am now more motivated and confident to access professional support services at home (in my rural area): 66.7%
Because of this website I am now more motivated and confident to access professional support services in Adelaide: 67.7%
Because of this website I am now more motivated and confident to travel to Adelaide for medical treatment: 75.9%
3) What are the similarities and disparities in mental health, physical health and engagement in health promoting behaviour, between rural and urban South Australians with a history of cancer?

- South Australian Monitoring and Surveillance System
- 1 January 2010 and 1 June 2015
- Only those (n = 4,295) with self-reported history of cancer other than non-melanoma skin cancer (11.8%)
Rural survivors vs. Urban survivors

Rural or SEIFA?

Greater trust in communities

Travel over 100km to health service in past 6 months

More endorsed high level of self-reported psychological distress
Problems with travel to access health services
Self-rated health status
Inability to perform normal duties
COPD
CVD
Arthritis
Osteoporosis
Current high blood pressure
Current high cholesterol

Sufficient levels of activity
Enough fruit
Enough vegetables
Current smoker
Reporting a mental health condition
4) What do rural cancer survivors and their carers perceive as their key challenges post-treatment?

- **When treatment is over, it is not all over;** long term side effects and new health and emotional issues to deal with
  - Post-op issues to manage (e.g. drains, swelling)
  - Comorbidities (e.g. diabetes)
  - Fatigue
  - Fear of recurrence
  - Frustration as things do not return to normal as expected and others don’t recognise this
  - Sexual and fertility issues
  - Feeling isolated from family, friends and treating teams

- **Lack of faith in local medical care** to help them address post-treatment and general health issues

- **Frustration with returning to Adelaide/ metropolitan centres for ongoing cancer surveillance and follow-up care**
5) How would rural survivors like these post-treatment issues to be addressed?

• Open to new forms of support via **telephone or face-to-face**

• **Internet**-based interventions would **only benefit some**

• **Nurses** are an appropriate profession to deliver support

• Preference to **receive** supportive calls, not have to phone themselves

• May need to be ‘**pushed** into/ encouraged to discuss emotional issues’

• **Continuity** of care highly valued (must be the same person they speak to each time)

• **Tele-health** a popular alternative to travelling for face to face specialist appointments

• **Peer-support videos** would be useful

---

6) Does a set of videos, delivered via a YouTube channel help?

7) What models of support have been effective at addressing post-treatment psychosocial and tertiary prevention issues in other rural settings around the world?
Acknowledgments

• Participants
  • Prof Ian Olver
  • Prof Carlene Wilson
  • Prof Deb Turnbull
  • Ms Lindsay McWha
  • Dr Matt Davies
  • A/Prof Niranjan Bidargaddi
  • A/Prof Jim Dollman
  • Prof Bogda Koczwara
  • Dr Narelle Berry
  • Dr Rosie Meng
  • Professor Richard Woodman
  • Professor Robyn Clark
  • Professor Trish Livingston
  • Professor Karen Meneses

www.countrycancersupport.com.au
The rules are made in the city and then they try to, ah, ah, stamp them on you in the country and they just don't work and they make things worse and they make things harder.

Rural female, bones/breast, long-term survivor and carer of lung/ melanoma short-term survivor

I do feel that rural people do get left out a lot in a lot of ways. I'm surprised that you're actually going into the rural areas which is good.

Rural male, prostate, long-term survivor
## Self-reported physical health

<table>
<thead>
<tr>
<th>Condition</th>
<th>% urban cancer survivors [CI]</th>
<th>% rural cancer survivors [CI]</th>
<th>Chi-squared</th>
<th>Model 1 – no adjustment</th>
<th>Model 2 – full adjustment except SEIFA</th>
<th>Model 3 – full adjustment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Poor self-rated physical health</td>
<td>10.8 [9.5,12.2]</td>
<td>13.2 [10.6,16.3]</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Comorbid diabetes</td>
<td>14.7 [13.4,16.1]</td>
<td>19.0 [15.5,23.0]</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>X</td>
</tr>
<tr>
<td>Comorbid COPD</td>
<td>6.6 [5.6,7.6]</td>
<td>8.7 [6.8,10.9]</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Comorbid CVD</td>
<td>18.3 [16.9,19.8]</td>
<td>21.5 [17.8,25.6]</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Comorbid arthritis</td>
<td>42.2 [40.1,44.3]</td>
<td>41.9 [37.5,46.3]</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Comorbid osteoporosis</td>
<td>10.8 [9.6,12.1]</td>
<td>10.8 [8.7,13.3]</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Current high blood pressure</td>
<td>41.7 [39.6,43.8]</td>
<td>42.9 [38.5,47.5]</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Current high cholesterol</td>
<td>32.3 [30.5,34.2]</td>
<td>35.1 [30.9,39.6]</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Obese (BMI)</td>
<td>24.1 [22.3,26.1]</td>
<td>32.5 [28.1,37.3]</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>X</td>
</tr>
<tr>
<td>Totally unable to work or carry out normal duties due to health in the past 4 weeks at least one day</td>
<td>17.4 [15.8,19.1]</td>
<td>21 [17.0,25.7]</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Cut down activities, or did not get as much done as usual due to health in the past 4 weeks at least one day</td>
<td>29.5 [27.5,31.5]</td>
<td>32.8 [28.5,37.5]</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>

N=4295 unless indicated otherwise
## Health promoting behaviour

<table>
<thead>
<tr>
<th>% urban cancer survivors [CI]</th>
<th>% rural cancer survivors [CI]</th>
<th>Significant difference?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Chi-squared</td>
</tr>
<tr>
<td><strong>At lifetime risk of harm from alcohol</strong> (n=4,267)</td>
<td>17.6 [15.9,19.5]</td>
<td>22.3 [18.1,27.1]</td>
</tr>
<tr>
<td><strong>Current smoker</strong> (n=4,193)</td>
<td>8.7 [7.4,10.1]</td>
<td>7.7 [5.9,10.0]</td>
</tr>
<tr>
<td><strong>No physical activity</strong> (n=4,193)</td>
<td>26.2 [24.4,28.1]</td>
<td>32.9 [28.9,37.1]</td>
</tr>
<tr>
<td><strong>Insufficient vegetable intake (&lt; 5 serves per day)</strong> (n=4,242)</td>
<td>87 [85.4,88.4]</td>
<td>85.4 [82.3,88.0]</td>
</tr>
<tr>
<td><strong>Insufficient fruit intake (&lt; 2 serves per day)</strong> (n=4,286)</td>
<td>51.1 [48.9,53.3]</td>
<td>54.5 [49.8,59.1]</td>
</tr>
</tbody>
</table>

N=4295 unless indicated otherwise
## Self-reported mental health

<table>
<thead>
<tr>
<th>Current mental health condition</th>
<th>% urban cancer survivors [CI]</th>
<th>% rural cancer survivors [CI]</th>
<th>Significant difference?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suicidal ideation</td>
<td>5.3 [4.4,6.3]</td>
<td>4.1 [2.8,5.9]</td>
<td>X</td>
</tr>
<tr>
<td>High/very high levels of psychological distress (K10) (n=4,261)</td>
<td>9.6 [8.2,11.2]</td>
<td>7.0 [5.4,9.0]</td>
<td>✓</td>
</tr>
<tr>
<td>Neighbours trust each other</td>
<td>79.8 [78.1,81.4]</td>
<td>88.7 [86.1,90.9]</td>
<td>✓</td>
</tr>
<tr>
<td>Control over the decision that affect my life - strongly agree/agree</td>
<td>91.8 [90.4,93.1]</td>
<td>93.7 [91.6,95.3]</td>
<td>✓</td>
</tr>
</tbody>
</table>

N=4295 unless indicated otherwise
### Results: Access to health services

<table>
<thead>
<tr>
<th>Travel over 100km to access a health service in the last 6 months – yes (n=975)</th>
<th>% urban cancer survivors [CI]</th>
<th>% rural cancer survivors [CI]</th>
<th>Significant difference?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>15.7 [11.6,21.1]</td>
<td>47.7 [42.1,53.4]</td>
<td>✔</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>✔</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Problem with transport – all the time</th>
<th>% urban cancer survivors [CI]</th>
<th>% rural cancer survivors [CI]</th>
<th>Significant difference?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1.6 [1.2,2.0]</td>
<td>2.3 [1.5,3.6]</td>
<td>X</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>

N=4295 unless indicated otherwise