University of South Australia

Issues for regional and rural cancer survivors

Dr Kate Fennell (née Gunn)

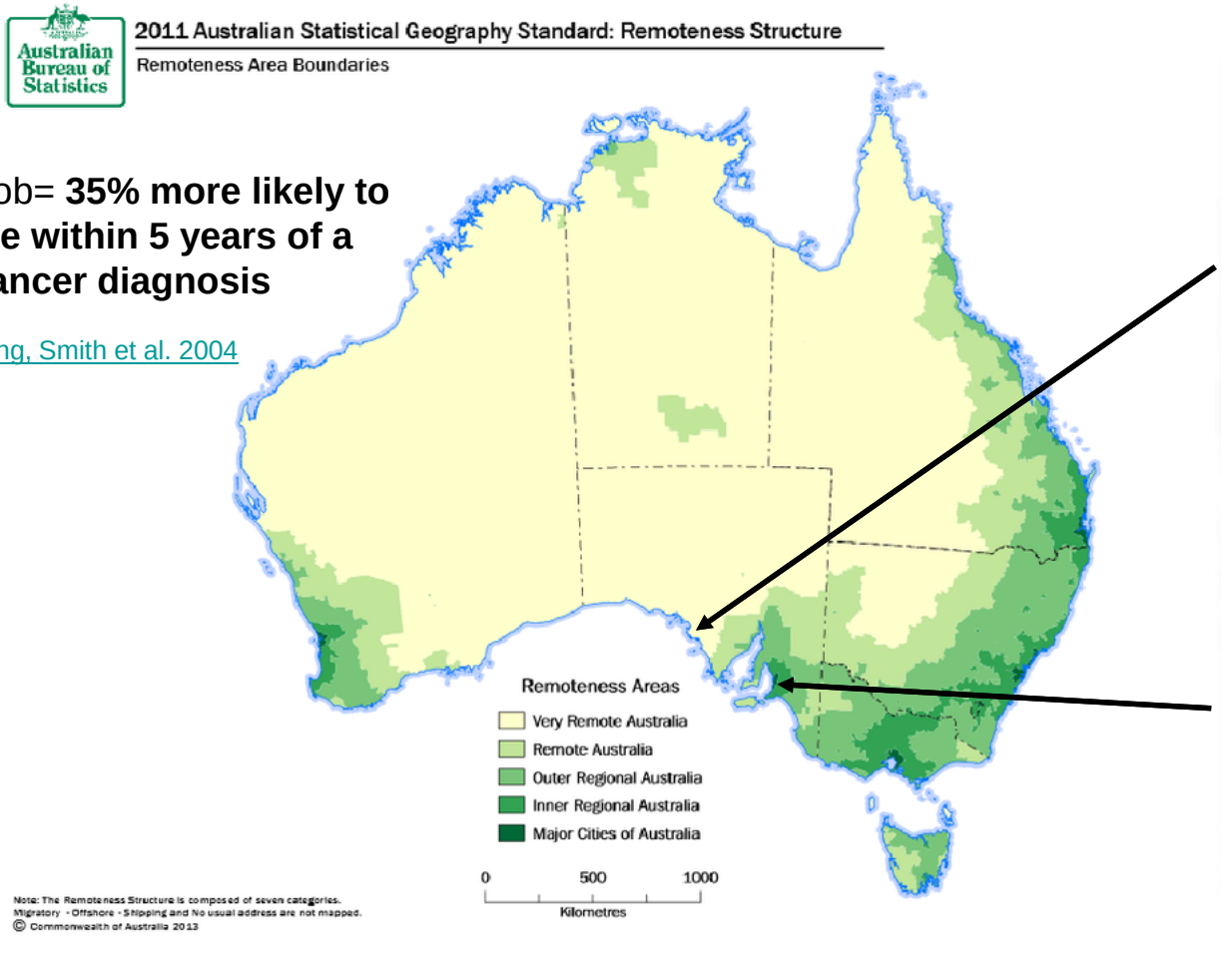
FLINDERS CENTRE for INNOVATION in CANCER

Flinders UNIVERSITY

Cancer Council SA

Bob= **35% more likely to die within 5 years of a cancer diagnosis**

Jong, Smith et al. 2004



Bob

John

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 & Piliouras, 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)
- More unmet psychosocial needs (Beesley, Eakin et al. 2008; Harrison, Young et al. 2009; Butow, Phillips et al. 2012)
- 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.

Gunn, K., Turnbull, D., McWha, L., Davies, M., & Olver, I. (2013). *Psychosocial service use: a qualitative exploration from the perspective of rural Australian cancer patients.* Supportive Care in Cancer, 21 (9), 2547-2555. Doi: 10.1007/s00520-013-1812-

Support Care Cancer
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ORIGINAL ARTICLE

Psychosocial service use: a qualitative exploration from the perspective of rural Australian cancer patients

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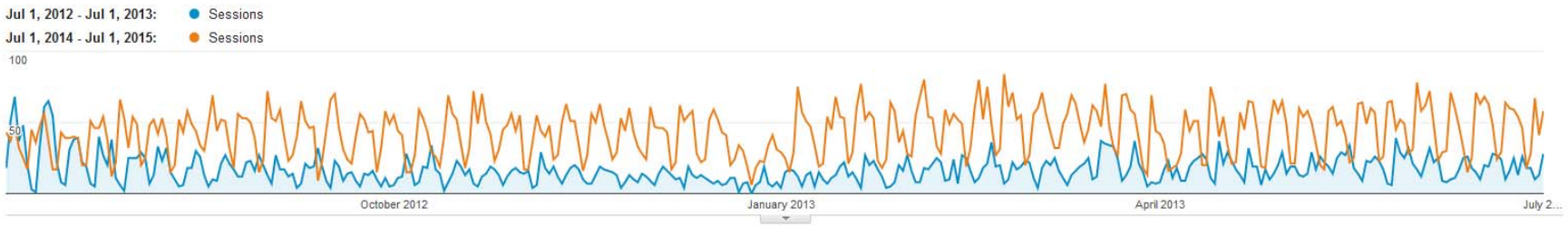
Abstract
Purpose This study aims to identify key issues associated with the provision of psychosocial care from the perspective of rural Australian cancer patients and determine culturally appropriate methods that may reduce barriers to service use. *Method* Seventeen purposively sampled adult South Australians who lived outside metropolitan Adelaide, had a diagnosis of cancer and various demographic and medical histories participated in semi-structured, face-to-face interviews. Participants also completed a demographic questionnaire. Qualitative data were analysed using thematic analysis. *Results* Five key themes were identified: (1) psychosocial communication between health care providers and referral to psychosocial services and (3) making psychosocial services a standard part of care. *Conclusions* Rural cancer patients want their unique needs to be recognised and to be treated differently to their urban counterparts. There is a need for more targeted and rurally relevant information for rural cancer patients, both to inform them of, and change their attitudes towards, psychosocial services. Other practical recommendations are also discussed.

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**?



Fennell, K.M., Turnbull, D., Bidargaddi, N., McWha, L., Davies, M. & Olver, I. (2016) Connecting rural cancer patients and their families, carers and health professionals with psychosocial support; the development and acceptability testing of the Country Cancer Support website, European Journal of Cancer Care, 1-15, Doi: 10.1111/ecc.12533

	Not at all	A little	A moderate amount	A lot	A great deal	% that agree 'A lot' or 'A great deal'	n
Easy to use	4	2	10	34	61	85.6	111
Relevant to needs	3	4	16	54	34	79.3	111
Necessary	1	2	2	28	78	95.5	111
Helpful	2	2	6	38	63	91.0	111
Likelihood of returning to website	0	5	5	42	59	91.0	111
Likelihood of recommending the website to someone else	1	2	4	22	82	93.7	111
Written by people who understand what I'm going through	1	2	8	20	22	79.2	53 *(patients, carers, family and friends only)*

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%)

Fennell, K.M., Berry, N., Meng, R., Wilson, C., Dollman, J., Woodman, R., Clark, R., Koczwara, B. (2016) *Understanding the urban-rural health divide: a comparison of self-reported physical health, mental health and participation in health-promoting behaviors, between rural and urban Australian cancer survivors*, 18th International Society of Psycho Oncology Congress, Dublin.

Rural survivors

Rural or SEIFA?

Greater trust in communities

Travel over 100km to health service in past 6 months

Urban survivors

More endorsed high level of self-reported psychological distress

No differences

- 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?

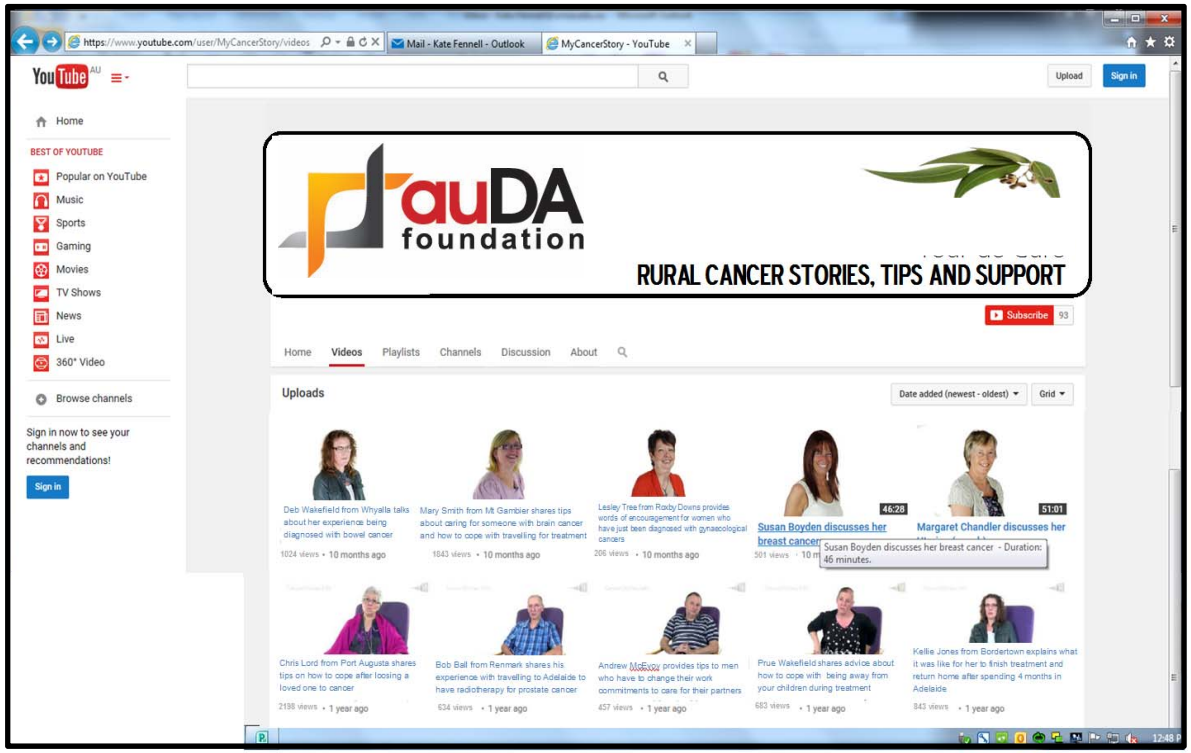
- **When treatment is over, it is not all over**; long term side effects and new health and emotional issues to deal with
  - Post-op issues to manage (e.g. drains, swelling)
  - Comorbidities (e.g. diabetes)
  - Fatigue
  - Fear of recurrence
  - Frustration as things do not return to normal as expected 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

Fennell, K.M., Olver, I., Livingston, P., Meneses, K., Wilson, C. (2016) *The supportive care needs and intervention preferences of rural cancer survivors who have completed active treatment,* 18th International Society of Psycho Oncology Congress, Dublin.



** Rough mock up*

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
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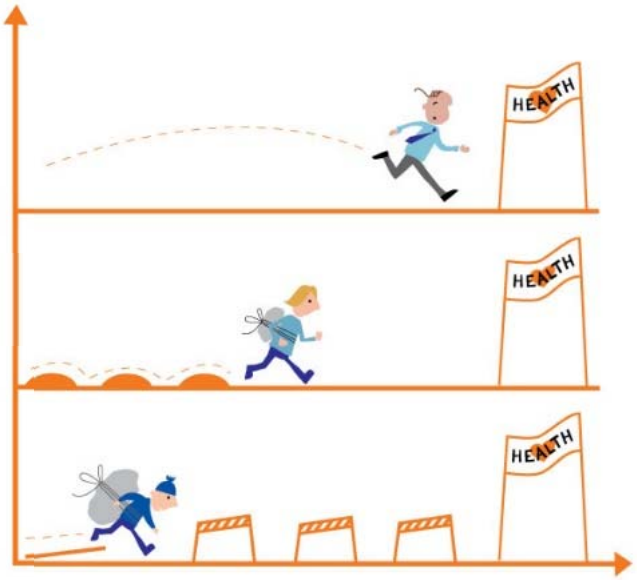
- A/Prof Jim Dollman
- Prof Bogda Koczwara
- Dr Narelle Berry
- Dr Rosie Meng
- Professor Richard Woodman
- Professor Robyn Clark
- Professor Trish Livingston
- Professor Karen Meneses

www.countrycancersupport.com.au

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



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

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Self-reported physical health

	% urban cancer survivors [CI] [CI]	% rural cancer survivors [CI]	Significant difference?			
			Chi-squared	Model 1 – no adjustment	Model 2 – full adjustment except SEIFA	Model 3 – full adjustment
Poor self-rated physical health	10.8 [9.5,12.2]	13.2 [10.6,16.3]	X	X	X	X
Comorbid diabetes	14.7 [13.4,16.1]	19.0 [15.5,23.0]	✔	✔	✔	X
Comorbid COPD	6.6 [5.8,7.6]	8.7 [6.8,10.9]	X	X	X	X
Comorbid CVD	18.3 [16.9,19.8]	21.5 [17.8,25.6]		X	X	X
Comorbid arthritis	42.2 [40.1,44.3]	41.9 [37.5,46.3]	X	X	X	X
Comorbid osteoporosis	10.8 [9.6,12.1]	10.8 [8.7,13.3]	X	X	X	X
Current high blood pressure	41.7 [39.6,43.8]	42.9 [38.5,47.5]	X	X	X	X
Current high cholesterol	32.3 [30.5,34.2]	35.1 [30.9,39.6]	X	X	X	X
Obese (BMI)	24.1 [22.3,26.1]	32.5 [28.1,37.3]	✔	✔	✔	X
Totally unable to work or carry out normal duties due to health in the past 4 weeks at least one day	17.4 [15.8,19.1]	21 [17.0,25.7]	X	X	X	X
Cut down activities, or did not get as much done as usual due to health in the past 4 weeks at least one day	29.5 [27.5,31.5]	32.8 [28.5,37.5]	X	X	X	X

N=4295 unless indicated otherwise

Health promoting behaviour

	% urban cancer survivors [CI] [CI]	% rural cancer survivors [CI]	Significant difference?			
			Chi-squared	Model 1 – no adjustment	Model 2 – full adjustment except SEIFA	Model 3 – full adjustment
At lifetime risk of harm from alcohol (n=4,267)	17.6 [15.9,19.5]	22.3 [18.1,27.1]	✔	X	X	X
Current smoker	8.7 [7.4,10.1]	7.7 [5.9,10.0]	X	X	X	X
No physical activity (n=4,193)	26.2 [24.4,28.1]	32.9 [28.9,37.1]	✔	✔	✔	X
Insufficient vegetable intake (< 5 serves per day) (n=4,242)	87 [85.4,88.4]	85.4 [82.3,88.0]	X	X	X	X
Insufficient fruit intake (< 2 serves per day) (n=4,286)	51.1 [48.9,53.3]	54.5 [49.8,59.1]	X	X	X	X

N=4295 unless indicated otherwise

Self-reported mental health

	% urban cancer survivors [CI] [CI]	% rural cancer survivors [CI]	Significant difference?			
			Chi-squared	Model 1 – no adjustment	Model 2 – full adjustment except SEIFA	Model 3 – full adjustment
Current mental health condition	19.4 [17.7,21.3]	18.5 [15.5,21.9]	X	X	X	X
Suicidal ideation	5.3 [4.4,6.3]	4.1 [2.8,5.9]	X	X	X	✔
High/very high levels of psychological distress (K10) (n=4,261)	9.6 [8.2,11.2	7.0 [5.4,9.0]	✔	✔	✔	✔
Neighbours trust each other	79.8 [78.1,81.4]	88.7 [86.1,90.9]	✔	✔	✔	✔
Control over the decision that affect my life - strongly agree/agree	91.8 [90.4,93.1]	93.7 [91.6,95.3]	X	X	✔	✔

N=4295 unless indicated otherwise

Results: *Access to health services*

	% urban cancer survivors [CI] [CI]	% rural cancer survivors [CI]	Significant difference?			
			Chi-squared	Model 1 – no adjustment	Model 2 – full adjustment except SEIFA	Model 3 – full adjustment
Travel over 100km to access a health service in the last 6 months – yes (n=975)	15.7 [11.6,21.1]	47.7 [42.1,53.4]	✔	✔	✔	✔
Problem with transport – all the time	1.6 [1.2,2.0]	2.3 [1.5,3.6]	X	X	X	X

N=4295 unless indicated otherwise