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Travelling all over the countryside: Travel related burden and financial difficulties reported by cancer patients in NSW and Victoria

# ABSTRACT

**Objective:** To describe travel burden and travel-related financial burden experienced by cancer patients over the first year after diagnosis.

**Design, setting, participants:** Population-based longitudinal cohort of recent adult cancer patients diagnosed with the eight most incident cancers recruited from New South Wales and Victorian Cancer Registries. Self-report survey data were collected at six and 12 months after diagnosis from 1410 participants (city residents: n=890; regional/remote residents: n=520).

**Main outcome measures:** Travel time to cancer treatment (surgery, radiotherapy, chemotherapy), living away from home for treatment, travel-related treatment decisions, extent of financial issues, unmet need for financial help.

**Results:** During the first 12 months after diagnosis, outer regional/remote residents had the greatest travel burden; 61% (n=79) travelled at least 2 hours one-way to receive treatment, and 49% (n=66) lived away from home to receive treatment. The strongest associates of travel burden were living in regional/remote areas (OR=18.9-135.7), having received surgery (OR=6.7) or radiotherapy (OR=3.6). Between 6 and 12 months after diagnosis, 2% (n=24) of patients declined a particular cancer treatment because of the time it would take to get to treatment. Patients who travelled more than two hours or lived away for treatment reported significantly greater financial difficulties (38%; 40%) than those who didn't (12%; 14%), even after adjusting for known or potential covariates (OR=2.7; 2.8).

**Conclusions:** Travel burden is greatest for rural patients, and is associated with greater financial burden. Appropriate and adequate provision of travel and accommodation assistance schemes remains paramount to achieving equitable delivery of cancer services.

**Key words:** Oncology, Service Access, Rural and Remote, Needs assessment, Cost of illness

# WHAT THIS PAPER ADDS

# Box 1: What is already known on this subject

- Travel to cancer treatment is qualitatively described as an 'inconvenient and practical hardship'.
- Travel constitutes one of the largest net out-of-pocket expenses relating to cancer treatment.
- Patient advocates are highly critical of the adequacy of travel and accommodation reimbursement schemes citing low levels of reimbursement and complex administration requirements.

# Box 2: What does this study add

- Travel burden is greatest for rural cancer patients. Compared to 2% of city residents, half of all cancer patients from outer regional or remote areas travelled two or more hours at least once, or lived away from home to receive treatment.
- Very few patients declined a particular cancer treatment because of the time it would take to get to treatment, and geographical location was not associated with declining treatment.
- Greater financial difficulties were reported by patients who travelled or lived away from home, even after accounting for potential confounding factors such as socioeconomic status, co-morbidities, and cancer and treatment characteristics.
- These results emphasise that travel and accommodation assistance schemes are an integral part of providing patient-centred cancer care, especially for rural cancer patients.

#### **INTRODUCTION**

Each year over 100,000 new cases of cancer are diagnosed in Australia.<sup>1</sup> The majority of patients will require surgery,<sup>2-4</sup> half will require radiation therapy,<sup>5</sup> and approximately one-third will require chemotherapy.<sup>1</sup> While city-based Comprehensive Cancer Centres (CCCs) provide one-stop access to many of these services, cancer treatment travel has become a customary part of life for the one third of Australian cancer patients living in rural and regional areas.<sup>6</sup>

Patients describe cancer treatment travel as an 'inconvenient and practical hardship'.<sup>7</sup> They report feeling tired from the travelling itself, which may worsen over time from treatment fatigue;<sup>8</sup> and cite practical and social concerns, including problems managing home responsibilities,<sup>9</sup> concerns about the burden placed on family members<sup>10,11</sup> and disruption to work.<sup>11,12</sup> Travel for treatment constitutes one of the largest net out of pocket cancer treatment expenses for rural patients.<sup>13</sup> Despite this, travel is inadequately reimbursed and the financial assistance available for patients is not well known and difficult to claim.<sup>9,14</sup>

In 2010-2011, \$560 million was allocated to establish new, and upgrade existing, Regional Cancer Centres (RCCs) with the aim of helping improve access and support for cancer patients in regional and remote Australia<sup>15</sup>. The establishment of the RCCs will likely reduce, but not remove travel burden, as patients with complex conditions require specialist and allied health services that exist only in city-based CCCs. Added to this, the funded capacity of RCCs to provide chemotherapy, surgery and in particular radiotherapy is estimated to be insufficient to meet future cancer incidence requirements<sup>16</sup>.

The Optimising Cancer Care Australia report<sup>17</sup> recommended a review of matters affecting cancer care access, including an investigation into problems with travel; and Australian cancer consumers have emphasised the importance of transport and accommodation services.<sup>18</sup> However, these issues have been relatively under-researched and investigated qualitatively <sup>10-12, 19</sup> or in convenience samples.<sup>9,14, 20</sup> Population based data are not available, patient travel burden accumulating over time has not yet been reported, and the impact of travel distance on treatment uptake is inconclusive.<sup>7</sup> Although it is known that personal costs are higher for those living greater than 100km from the treatment hospital,<sup>13</sup> any impact of additional costs on overall patient-reported financial difficulties and/or unmet financial needs remains unknown.

In a population based sample of cancer patients in NSW and Victoria, this study reports 1) prevalence of travel burden for treatment (travel time, living away) over the first year after diagnosis by geographic location; 2) proportion of patients who declined cancer treatment due to travel time between 6 and 12 months after diagnosis; 3) characteristics of patients who experienced travel burden for treatment in the first 6 months after diagnosis; 4) characteristics of patients who declined treatment between 6 and 12 months after diagnosis; and 5) impact of travel burden for treatment on the financial experience of patients in the first 6 months after diagnosis.

## **METHODS**

# Participants and procedures

Data were collected as part of the population-based longitudinal Cancer Survival Study described elsewhere<sup>21</sup>. In brief, participants were prospectively selected from NSW and Victorian Cancer Registries. Eligibility criteria included being newly diagnosed with one of the eight most incident cancers in Australia, aged 18-80 years at diagnosis, able to understand English, considered physically and mentally capable of participating by their clinician, and aware of their cancer diagnosis. Of the 3315 eligible individuals approached, 1453 consented (44% response rate) to participate. Patients who returned the T1 questionnaire later than 9 months after diagnosis (n=37), and the T2 questionnaire later than 15 months after diagnosis (n=29) were excluded from analysis. Overall, 1410 patients who completed either T1 (n=1323) or T2 (n=1241) questionnaire were included in the analysis. Ethics approval was obtained.

#### Measures

Data were obtained by self-report survey and from the Cancer Registries.

#### **Outcomes**

*Travel burden and declining cancer treatment:* At T1 and T2, four items assessed travel time to surgery, radiotherapy and chemotherapy in the preceding 6 months; and whether or not the patient lived away from home for cancer treatment in the preceding 6 months. At T2, one item assessed the impact of travel time on treatment decision-making in the preceding 6 months. These items were adapted from study-specific items administered elsewhere.<sup>22</sup>

*Financial difficulties:* The European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30 v3), single item financial difficulties subscale was used to measure the extent to which respondents' physical condition or medical treatment caused financial difficulties at T1.<sup>23</sup> Level of unmet need for monetary allowance for travel, treatment and equipment expenses was assessed by a single item from Supportive Care Needs Survey (SCNS) Access to Services Module at T1.<sup>24</sup>

## Associate variables

*Patient, disease and treatment characteristics:* Age, sex, postcode, country of birth, aboriginality, cancer type and disease severity at diagnosis were obtained from the Cancer Registry. Marital status, education, health insurance status, gross family income, number of adults residing with, number of children residing with, pre-cancer and current employment status, current remission status, comorbidities and cancer treatments ever received were obtained by self-report survey items at T1 and T2.

# Statistical analyses

Frequency data were used to calculate the prevalence of travel burden over the first year after diagnosis, and the proportion of patients declining cancer treatment 6-12 months after diagnosis. Potential associates (T1 patient characteristics) of travel burden up to 6 months after diagnosis (ie. at greatest travel burden) were assessed with backward stepwise logistic regression. Travel burden was defined as 1) ever travelled two or more hours one way for surgery, radiotherapy, chemotherapy; and 2) ever lived away from home for surgery, radiotherapy, chemotherapy in the first 6 months after diagnosis. The cut point for travel burden as two or more hours one way approximates travel assistance schemes available in NSW and Victoria and is roughly equivalent to regional and remote areas based on ARIA+ index. Variables significant at 0.05 levels were retained in the model. Next, potential associates (T2 patient characteristics ) of declining treatment because of travel time (versus didn't refuse treatment) between 6 and 12 months after diagnosis were assessed using chisquare analyses only, due to small numbers. Finally, the impact of travel burden on financial difficulties at 6 months after diagnosis was assessed using logistic regression analysis, adjusting for potential covariates at the 0.2 level. Patients were classified as either a) experiencing moderate/high unmet need or financial difficulties quite a bit or very much *versus* b) no or low unmet need for monetary allowance for travel, treatment and equipment

expenses *and* not at all or a little financial difficulties. Living away from home and travelling for treatment in the first 6 months were dependent variables.

# RESULTS

Table 1 summarises participant characteristics compared with all cancer patients diagnosed in Australia during 2005.

#### Prevalence of travel burden by geographic location

Overall, 12.1% (95% CI: 10.2%-13.8%; n=150) of patients travelled two or more hours one-way to receive treatment (surgery, radiotherapy or chemotherapy) at least once during the first year after diagnosis. Almost two-thirds (60.8%; 95% CI: 52.4%-69.2%; n=79) of patients residing in outer regional/remote areas, 18.3% (95% CI: 14.0%-22.6%; n=58) of inner regional residents, and 1.6% (95% CI: 0.7%-2.5%; n=13) of city residents travelled two or more hours at least once for treatment. As shown in Figure 1, the highest proportion of patients travelling two or more hours one-way were those who resided in outer regional or remote areas and received radiotherapy (73.6%; 95% CI: 61.6%-85.6%; n=39). One in ten (10.4%; 95% CI: 8.4%-11.6%; n=135) of all patients who received treatment temporarily lived away from home in another town or city to receive treatment. A total of 49.3% (95% CI: 40.8%-57.8%; n=66) of patients from outer regional/remote areas, 15.1% (95% CI: 11.3%-18.9%; n=51) of inner regional residents, and 2.2% (95% CI: 1.2%-3.2%; n=18) of city residents lived away from home for treatment.

#### Factors associated with travelling more than 2 hours for treatment

As shown in Table 2, place of residence was the strongest associate of travel burden. Compared to those who lived in major cities, those from inner regional (OR=18.9) or outer regional/remote areas (OR=135.7) had greater odds of travelling two or more hours to receive treatment. Compared to patients with stable disease, patients in remission had lower odds (OR=0.43) of travelling for treatment; and compared to patients with prostate cancer, those diagnosed with melanoma (OR=0.33) or breast cancer (OR=0.28) had lower odds of travelling two or more hours. Patients who received surgery had 6.7 times the odds of travelling two or more hours compared to those who did not. Finally, patients who received radiotherapy had over 3.6 times the odds of travelling two or more hours compared to patients who did not.

#### Factors associated with living away from home for treatment

As shown in Table 3, current employment status, having received radiotherapy and place of residence were significantly associated with living away for home for treatment. Compared to those who were retired or aged pensioners, those in paid work had fewer odds (OR=0.48), and those not working had greater odds (OR=1.55) of living away for treatment. A significant interaction was identified between place of residence and having received radiotherapy; of those who had received radiotherapy, patients living in inner regional (OR=11.4) or outer regional/remote (OR=348.9) areas had significantly greater odds of living away from home than those that did not receive radiotherapy and who lived in inner regional (OR=4.9) or outer regional/remote areas (OR=16.2).

#### **Declining cancer treatment**

At T2, 2% (95% CI: 1.2%-2.8%; n=24) of patients had declined a particular cancer treatment because of the time it would take to get to treatment. Declining treatment because of travel time was significantly associated with pre-cancer employment status ( $\chi 2(2)=12.4528$ , p=0.002); patients who were unemployed or in unpaid work were significantly more likely (n=8, 5.16%) to decline treatment because of travel time than those in paid work (n=10, 1.8%) or retired or aged pensioners (n=3; 0.71%). Declining treatment was not associated with other patient, disease and treatment characteristics, including geographical location ( $\chi 2(2)=0.161$ , p=0.923) and income ( $\chi 2(2)=1.358$ , p=0.507).

#### **Travel-related financial burden**

Table 4 shows that financial difficulties were reported by 38.4% (n=48) of patients who travelled two or more hours, and 39.6% (n=42) of patients who lived away from home for treatment. Logistic regression results indicate travelling two or more hours and living away from home for treatment were significantly associated with greater patient-reported financial difficulties, even after adjusting for known or potential covariates.

#### DISCUSSION

This is the first large-scale population-based study documenting cancer treatment related travel and associated financial burden over the first year after diagnosis for the eight

most incident cancers in Australia. The use of the two largest state-based cancer registries in Australia as the sampling frame, which account for 60% of all Australian cancer patients, is one of the major strengths of this study. Our results are based on self-report and may underestimate the prevalence of travel burden, as we did not survey patients with rarer cancers (eg pancreatic) who often require more specialised treatment available only at large tertiary hospitals. Our results emphasise the considerably disproportionate level of travel burden experienced by rural patients.

Despite travel and accommodation assistance schemes being available to cancer patients in Australia, at least one-third of patients who travelled two or more hours for treatment or who lived away from home for treatment reported financial difficulties. However a limitation of the study was that we did not assess access to or use of travel assistance schemes. Our study highlights that travel for treatment is indeed a rural issue with the strongest associate of travel burden being place of residence; these results support a recent Australian study<sup>13</sup> which quantified greater out-of-pocket costs for those living over 100km away from treatment centres. Travel time influenced the decision to decline a particular cancer treatment only for a minority of study participants, which is consistent with previous literature.<sup>20</sup> Our finding that patients who were unemployed or in unpaid work perceived travelling for cancer treatment to be a greater barrier is consistent with the growing body of evidence that patients with fewer financial resources experience greater overall burden. However, caution should be exercised when interpreting these associations given the small numbers of patients who self-reported declining treatment.

#### Conclusion

Travel burden is a particularly pertinent issue for rural cancer patients, with half of all cancer patients residing in outer regional or remote areas reporting a need to travel or live away from home to receive treatment in the first year after diagnosis. Furthermore, cancer patients who experienced travel burden reported higher rates of financial difficulty than those who did not. While RCCs may contribute to improved access to cancer care for regional and rural patients, many patients will still need to travel long distances or relocate to attend RCCs or city-based CCCs. Well resourced travel and accommodation assistance schemes that allow for the complexity of health services delivery and the tyranny of distance have an important role in the provision of patient-centred cancer care.

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	Sample		2005	
			Australian	
			data^	
	N=1410		N=58665	
	n	(%)	(%)	
Gender				
Female	567	(40)	(42)	
Male	843	(60)	(58)	
Age at diagnosis (years)				
<50	210	(15)	(15)	
50-59	339	(24)	(22)	
60-69	512	(36)	(31)	
70 or more	349	(25)	(31)	
Primary cancer location				
Prostate	374	(27)	(24)	
Melanoma	217	(15)	(16)	
Breast	216	(15)	(19)	
Bowel	167	(12)	(17)	
Haematological (NHL, Leukaemia)	198	(14)	(8)	
Lung	137	(10)	(12)	
Head and neck	101	(7)	(4)	
Geographical location				
Major cities	890	(63)		
Inner regional	373	(26)		
Outer regional	136	(10)		
Remote	11	(1)		
Aboriginal or Torres strait Islander				
Yes	7	(0.5)		
No	750	(53)		
Not stated	653	(46)		
Country of birth				
Australian born	616	(44)		
Not Australian born	169	(12)		
Not stated	625	(44)		

# Table 1: Patient and disease characteristics of study sample

Cancer category at diagnosis		
Early	736	(52)
Late	269	(19)
Not applicable	198	(14)
Unknown	207	(15)
Received any cancer treatment		
Time 1	1272	(96)
Time 2	508	(41)
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^AIHW &AACR 2008, limited to 20-79 years



Figure 1: Time travelled (one way) to surgery, radiotherapy, chemotherapy in first year after diagnosis by place of residence (major city, inner regional, outer regional or remote)

Table 2. Individual characteristics significantly associated with travelling more than 2 hours to treatment in the first 6 months after diagnosis  $^{\#}$ 

	N 1002	Odds Ratio (95% CI)	P-value
Place of residence		· · · · · · · · · · · · · · · · · · ·	< 0.001
Inner regional	243	18.91 (8.41-42.52)	
Outer regional or remote	103	135.65 (56.96-323.05)	
Major cities	656		
Ever received surgery			< 0.001
Yes	811	6.71 (2.67-16.95)	
No/Don't know	191		
Ever received radiotherapy			< 0.001
Yes	302	3.62 (1.78-7.41)	
No/Don't know	700		
Cancer status			0.006
Metastatic	46	0.26 (0.06-1.22)	
Recurrent only	62	1.60 (0.59-4.38)	
Remission	689	0.43 (0.23-0.80)	
Stable disease	205		
Cancer type			0.005
Colorectal	127	0.41 (0.16-1.03)	
Breast	168	0.28 (0.10-0.75)	
Haematological	132	0.72 (0.26-2.03)	
Head and neck	74	1.15 (0.41-3.26)	
Lung	105	1.69 (0.68-4.21)	
Melanoma	180	0.33 (0.13-0.87)	
Prostate	216		
Hosmer and Lemeshow Goodness-of-fit test			p=0.2108

Hosmer and Lemeshow Goodness-of-fit testp=0.2108#variables significant at 0.05 level were retained in the modelNS=not significant at the 0.05 level

Table 3. Individual characteristics significantly associated with living away from home to receive treatment in the first 6 months after diagnosis<sup>#</sup> \*

	Ν	Odds Ratio	P-value
	1179	(95% CI)	
Current employment status			0.008
Paid work	422	0.48 (0.23-0.98)	
Unpaid work or not working	293	1.55 (0.84-2.85)	
Retired or aged pensioner	464		
Interaction			<0.001
Received radiotherapy			
Geographical location			
Inner regional	83	11.41 (4.60-28.31)	
Outer regional or remote	51	348.91 (103.78-1173.03)	
Major cities	247		
Did not receive radiotherapy			
Geographical location			
Inner regional	209	4.97 (1.83-13.47)	
Outer regional or remote	75	16.20 (5.83-45.00)	
Major cities	514		
Hosmer and Lemeshow Goodness-of-fit test			p=0.7179

#variables significant at 0.05 level were retained in the model

NS=not significant at the 0.05 level

\*geographical location (p<0.001) and Ever received radiotherapy (0.127) formed part of the final regression model. However, as a significant interaction was identified between these variables, the odds ratios are presented above in the interaction term.

Table 4. Impact of living away from home and travelling for treatment on financial difficulties in the first 6 months after diagnosis

	Financial Difficulties Reported	Odds Ratio (95% CI)		
	(%)	Crude	Adjusted#	P-value*
Travel for cancer treatment				
More than 2 hours	38.4 %	3.92 (2.63-5.86)	2.65 (1.86-6.04)	0.0178
Less than 2 hours	12.3 %			
Lived away from home for treatment				
Lived away	39.6%	4.09 (2.68-6.26)	2.79 (1.22-6.39)	0.0152
Did not live away	13.8%			

#Adjusted for significant confounders: travelled for treatment, lived away from home, pre-cancer employment status, 6-month employment status, marital status, education, health insurance status, gross family income, number adults residing with, number children residing with, geographical location, cancer treatment ever received (surgery, chemotherapy, radiotherapy), presence of comorbidities.