

FUEL, BEDS, MEALS AND MEDS: OUT-OF-POCKET EXPENSES FOR PATIENTS WITH CANCER IN RURAL QUEENSLAND

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Abstract

Objective: Cancer patients who travel long distances to access medical services face considerable disruption and personal financial cost. This study quantified the financial cost of receiving cancer treatment for individuals residing in regional, rural and remote locations.

Method: Adults diagnosed or treated for cancer at the Townsville Hospital Cancer Centre within the last 30 months who most recently presented to the cancer centre within the previous six months were recruited to this cross-sectional study (n=439). Direct out-of-pocket expenses relating to travel, accommodation and other expenses were estimated together with financial support received. Bootstrapping statistics assessed significant subgroup differences in costs with 95% confidence intervals.

Results: Over an average period of 16 months since diagnosis, net out-of-pocket expenses of \$1.8 million were reported for 410 regional men and women relating to their cancer treatment (mean \$4311, median \$2263, inter quartile range \$563-\$6231). Personal costs were significantly higher for participants who lived more than 100km from Townsville Hospital (\$7752) and for those treated with radiation (\$5135).

Conclusion: Financial costs for rural cancer sufferers vary widely and may be extensive. Consideration of adequate financial support from governments and other organisations is essential if rural Australians are to continue accessing standard cancer treatment.

Each year in Australia doctors tell more than 100,000 people that they have cancer (excluding squamous and basal cell skin cancers).¹ Thirty-six per cent of new cancers are diagnosed among people living in regional, rural and remote areas,² while the proportion of the Australian population living in regional, rural and remote areas is 32%.³ As new cancer diagnoses are over-represented in rural Australians, this has important implications for cancer stage at diagnosis, treatment processes, and impact on families, as well as additional personal expenses associated with treatment and follow-up care. Despite improvements in screening and treatment that have extended the five-year survival rates during the last two decades for many common cancers,² rural cancer patients have not shared these survival benefits equally with their city counterparts.⁴⁻⁶

Access to effective healthcare is particularly difficult for patients living in rural and remote areas when the

majority of medical specialists are located in urban centres. Individuals with cancer who require radiation treatment, normally given daily for six weeks, have substantial relocation needs and role disruption. These treatment demands and the associated financial pressure for many patients and families, already struggling to cope with a life-threatening condition, can be very stressful and especially concerning for low-income patients or those already experiencing economic hardship.⁷ Although medical concerns are of primary importance to doctors and patients, financial distress contributes to the context in which patients make decisions about treatment and recovery.⁸ Therefore, high perceived out-of-pocket costs may potentially cause treatment delays or non-compliance for those living in areas remote from treatment centres.^{8,9} Furthermore, financial concerns may also lead patients to entirely opt out of recommended treatments, potentially

contributing to and partially explaining the poorer survival outcomes for rural cancer patients.²

In an attempt to contain costs, hospital systems are shifting the management of many diseases on to patients and families. Early discharge programs and outpatient care are successful only if individuals are adequately supported in their physical, psychosocial and financial needs.¹⁰ In the future, the need for financial and other assistance for patients with cancer is likely to increase substantially due to: an ageing population and the associated increased numbers of cancers expected; increases in complex health needs due to multidisciplinary cancer care and promotion of national screening services; advances in oncology pharmaceuticals and the potential for prolonged treatment regimes caused by multiple courses of chemotherapy; highly specialised and expensive equipment being limited to hospitals/specialist centres, requiring patients to travel for treatment; possible rationalisation and centralisation of health services by state and territory governments; and increased needs accompanying ongoing surveillance for detection of tumour recurrences and follow-up visits by doctors as a result of improvements in survival rates.^{11,12}

To improve patient access to medical treatment in Australia, all states and territories have established Patient Assisted Travel Schemes (PATS) that provide limited travel and accommodation subsidies to eligible patients. Other forms of financial assistance and practical support may come from private health insurers, the government Home and Community Care program and numerous not-for-profit organisations (eg. state and territory Cancer Councils, the Leukaemia Foundation etc). However, some patients with cancer and their clinicians are not aware of these available support systems.¹³ While clearer information on patient costs may encourage health professionals to identify patients who may benefit from referral to appropriate support agencies, it may also help those diagnosed with cancer to plan for anticipated costs. The purpose of this study was to quantify the actual out-of-pocket costs and identify factors for high-costs incurred by non-urban cancer consumers accessing their nearest tertiary cancer treatment centre.

Methods

Patients presenting consecutively to Townsville Hospital Cancer Centre, Queensland, were recruited through their treating oncologist or clinic staff (n=439). Adult patients were eligible if they had been diagnosed or treated for cancer at the centre within the previous 30 months and had most recently visited the centre within the six months prior to study commencement. Patients with prostate cancer were excluded due to a pre-existing study.¹⁴ Ethical clearance was obtained from the Townsville Health Service District Human Research Ethics Committee.

Data collection occurred from August 2006 to February 2007, and consenting participants were assessed through a computer-assisted telephone interview. Questions covered items on: demographic characteristics; medical treatment; symptoms; use of psychosocial care services; and travelling and other expenses. No standardised or validated instrument was available to assess self-

reported out-of-pocket cost information, so the authors developed these items. Economic questions included: mode of travel; number of visits to the centre; postcode of residence; accommodation needs (prompts for known donors); health service expenditure specifically attributable to cancer using prompts (eg. GPs, other health professionals, medical tests or exams, medications, support services, other such as private nursing, child care, home assistance); financial support received for travel/accommodation and other expenses and associated donor(s); and other out-of-pocket expenses (eg. for wigs, prosthetics, lymphoedema sleeve, bills, food vouchers, etc). The questionnaire was pre-tested with a sample of 10 cancer patients, supporting the face and content validity of the economic questions. Similar questions have been previously used in a published study.¹⁵

The analysis was intended to be descriptive and exploratory rather than inferential. Cost items were quantified directly from survey responses and may or may not have been abstracted from other sources (eg. receipts, insurance/tax records). Travel costs were calculated by identifying the road distance (kms) from the patient's home suburb to Townsville Hospital using internet mapping services and valued using Australian Taxation Office vehicle running cost estimates (\$0.70 per km for a medium-size car).¹⁶ Descriptive statistics showing cost distributions (ie. means, standard deviations, medians, interquartile range) and sums are presented by major cost types. Proportions of each cost type to total cost were used to gauge the relative magnitude of each cost component. To handle the skewed nature of the cost data (with many participants having zero or minimal values in some categories and a small proportion of participants having very high values), mean costs per participant were obtained using bootstrapping statistics. This was achieved by drawing 1000 re-samples from the original skewed distribution, with replacement and using the bias-corrected approach. The Wald test assessed statistically significant subgroup differences.^{17,18} Subgroups of interest included: distance from home to treatment centre (≤ 100 kms v > 100 kms); private health insurance (nil v some); age (≤ 50 years v > 50 years); time since diagnosis (≤ 6 months, 6-12 months, 13-18 months, 19-24 months, > 24 months); type of cancer grouping, with breast cancer being the referent; and type of adjuvant treatment received (radiation, chemotherapy, hormone therapy, other). Spearman's rank correlation coefficient assessed the correlation between net cost and living distance from the Townsville Hospital. Tests were two-sided and results were considered statistically significant when $p < 0.05$. Costs were brought forward to 2008 Australian dollars using the Consumer Price Index. Data were analysed using STATA/SE V9.¹⁹

Results

A total of 439 participants were recruited to the study representing a 61% response rate. Compared to participants, non-participants were more likely to be male (48 v 41%, $p=0.08$), aged over 75 years (21 v 6%, $p < 0.001$), have respiratory/thoracic cancer (12 v 7%), head and neck cancer (14 v 9%) and less likely to have breast cancer (24 v 33%, $p=0.06$). There were no differences

between participants and non-participants with regard to postcode at diagnosis. A total of 29 participants (7%) were excluded from the cost-analyses; six had missing data, 10 had very extreme responses on at least one cost item (considered invalid), three had unusually large support payments with no corresponding match in expenses and 10 had not started treatment. Compared to the remaining participants (n=410), the excluded participants were more likely to be male (66%, p=0.01) and less likely to have breast cancer (14%, p=0.02). Response rates for the individual economic survey questions were >97% owing to the telephone method used.

On average, participants were aged 57 years at the time of interview. Most were partnered (70%), 42% were retired and 55% had household incomes of <\$40,000 (table 1). Only 15% of participants lived alone, while 57% lived with one other person and 27% lived with two or more persons. Forty per cent of participants were diagnosed with cancer within one year of the interview, 39% between 1-2 years and 20% >2 years. Overall, 46% of participants lived greater than 100km from Townsville Hospital and of these, 92% required accommodation, with 33% staying with family or friends and 19% staying at Cancer Council Queensland's Gluyas Lodge. Twelve (3%) participants lived greater than 600km from Townsville Hospital in locations such as Mt Isa and Weipa. Overall, 75% of participants started treatment within six weeks of diagnosis and there was no evidence of delays in starting treatment for participants living remotely from Townsville Hospital.

As a percentage of total costs, travel expenses represented the highest share (71%) followed by medical appointments (10%) and co-payments for medications (9%). Some type of financial support was received by 44% of participants, mainly for travel and accommodation expenses, with all support payments received totalling \$211,427 (median \$53, interquartile range \$0-470) or 11% of total costs. Over an average time of 16 months since diagnosis, a net total of \$1,767,357 was spent on out-of-pocket expenses relating to cancer for 410 regional men and women (mean \$4311, median \$2263, interquartile range \$563-\$6231) (table 2).

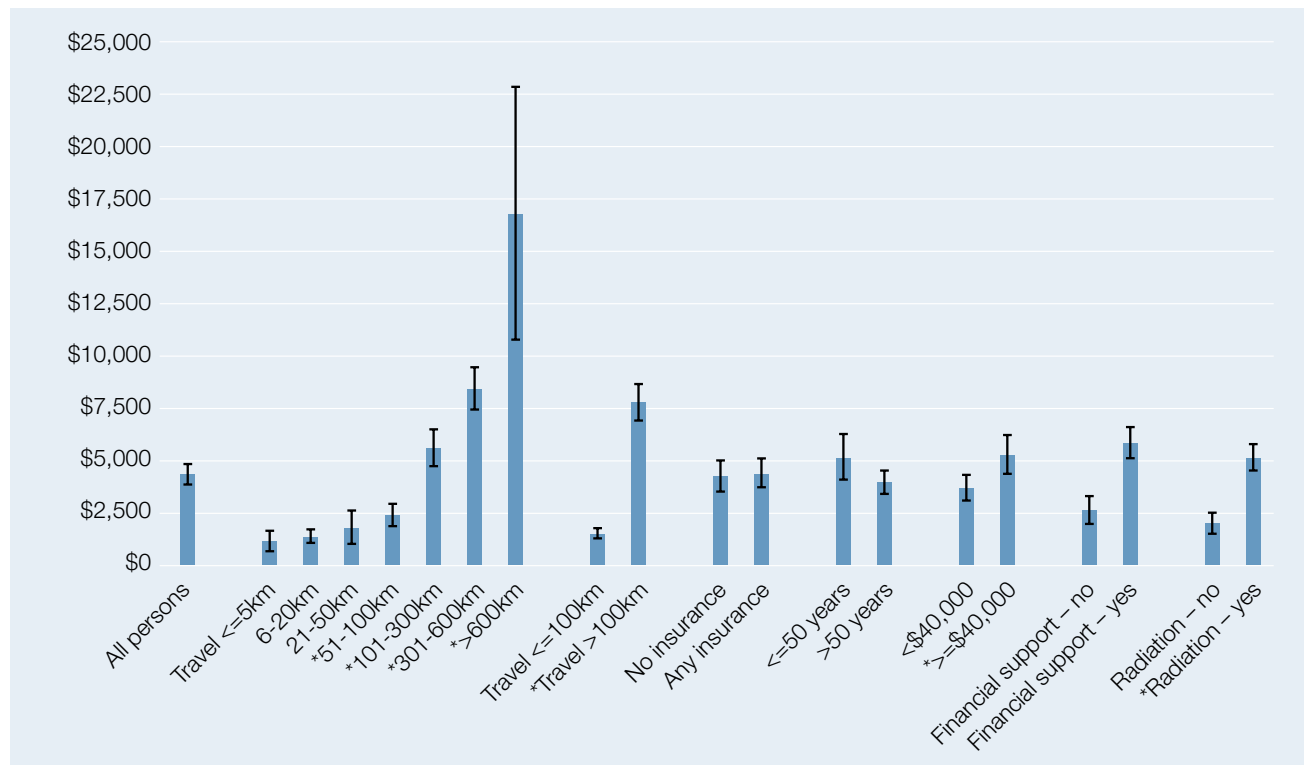
Table 1. Demographic and clinical profile of participants (n=410)

Characteristic	N	%
Age at interview – mean (sd)	57.4 (12)	–
Gender – female	249	61
Education level		
Primary	78	19
Secondary	185	45
Trade/certificate/diploma	71	17
Bachelor degree	65	16
Marital status		
Never married	30	7
Married/living together	287	70
Separated/divorced/widowed	93	23
Work status		
Employed full-time	86	21
Employed part-time/casual	65	16
Home duties/student/unemployed	50	12
Retired	186	42
Permanently ill/disabled	35	9
Other	5	1
Household income		
< \$40,000	226	55
≥ \$40,000	153	37
Unknown	31	8
Private health insurance		
None	220	54
Hospital plus extra	138	34
Hospital only	34	8
Some	78	4
Cancer type		
Breast	139	34
Hematology/blood	60	15
Digestive	58	14
Skin	38	9
Head/neck	36	9
Respiratory	27	7
Genitourinary	29	7
Other	23	6
Completed cancer treatment		
Yes	323	79
No	87	21
Cancer treatment (not mutually exclusive)		
Surgery	314	77
Radiation therapy	303	74
Chemotherapy	265	65
Hormone therapy	88	21
Other treatment	43	11
Time since treatment started (months)		
mean (sd), range	16 (10)	range 1-55

Table 2. Summary of out-of-pocket costs over an average 16 month period post-diagnosis by type of cost (n=410) (AUD 2008)

Cost category	Persons affected N (%)	Mean \$	SD \$	Median \$	Interquartile range \$	Total \$	% Net Total
Travel	408 (99%)	3430	4889	956	180-5013	1,399,540	0.71
Accommodation	179 (44%)	255	704	0	0-222	45,688	0.02
GP visits	83 (20%)	243	324	161	41-228	20,159	0.01
Health professional visits	135 (33%)	1408	1746	751	285-2048	190,035	0.10
Medical tests	99 (24%)	869	875	555	222-1138	86,075	0.04
Medications	208 (51%)	823	2904	261	111-798	171,123	0.09
Support services	19 (5%)	1275	1474	833	222-1707	24,216	0.01
Other services/aids	35 (9%)	1199	1645	433	213-1593	41,979	0.02
Total costs	410	4826	5852	2661	699-6660	1,978,814	100.00
Financial support received							
Travel & accommodation	182 (44%)	671	969	400	100-850	122,182	-0.06
Additional items	4 (1%)	13,500	15,695	6000	5000-22,000	54,000	-0.03
Other	66 (16%)	534	697	365	300-500	35,245	-0.02
Total support received	410	516	2045	53	0-470	211,427	-0.11
Net Total	410	\$4311	\$5257	\$2263	\$563-\$6231	\$1,767,357	

Figure 1. Bootstrapped mean net costs by sub-groups (95% confidence intervals) (*indicates statistical significance)



Net out-of-pocket costs were five times higher, on average, for individuals living more than 100km from Townsville Hospital compared to those within 100km (\$7752 v \$1481, $\chi^2=187.5$, $p<0.001$) (figure 1). In addition, the positive relationship between net costs and living distance from Townsville Hospital was significant (Spearman's rho 0.714, $p<0.001$). Net costs were also higher among patients with incomes \geq \$40,000 v $<$ \$40,000 (\$5252 v \$3693, $\chi^2=7.9$, $p=0.01$), those who received radiation therapy compared to those who did not (\$5135 v \$1976, $\chi^2=55.1$, $p<0.001$) and those who received hormone therapy (\$5537 v \$3979, $\chi^2=5.2$, $p=0.02$) (table 3, figure 1). Costs were similar for patients regardless of their health insurance status (figure 1). While costs appeared to be higher for women with breast cancer compared with hematology/blood, digestive or genitourinary cancers, no differences were shown when compared to skin, head/neck, respiratory or 'other' cancer types (table 3). Most out-of-pocket costs appear to accumulate during the first 18 months from the start of treatment, with a mean \$6510 (95% CI \$5232-\$7789) in those first treated 13-18 months prior to being interviewed.

Discussion

This research highlights the financial costs associated with having cancer incurred by individuals living in regional Queensland. With the exception of patients with prostate cancer, for a group of mostly typical cancer patients, many of whom were retired and/or on low incomes, patient costs associated with cancer treatment were dominated by travel expenses. Overall, patient out-of-pocket costs varied widely and were commonly between \$563 and \$6231. However, 25% of individuals in our sample incurred costs higher than this. Costs were especially high if the person lived further away from treatment, required

radiation therapy (74% of participants in our sample), or had higher incomes regardless of whether they had private health insurance.

Although accommodation costs were expected to be higher than shown here, over half the participants were able to stay with family or friends in Townsville, whereas others were able to avail the low cost or free supportive care lodgings of the non-government organisations located in Townsville. These costs would have been significantly higher for regional patients with cancer relocating to Brisbane and forced to use rental or motel accommodation near the major hospitals. The lack of self-catering facilities further increases living away costs.⁷ In addition, our cohort was relatively young and financially disadvantaged, with 57% living with another person and 27% living with two or more people. Therefore, it is likely that our participants had dependent spouses or others and the potential implications and consequences for these families may have been considerable if the participant travelled long distances, stayed away from home and incurred significant costs for receiving cancer treatment.

Our results complement two previous studies on the economic impact of breast cancer to individuals and families in urban Australia.^{20,21} International studies on out-of-pocket costs from cancer have limited application because they reflect different health care systems, are dated and may not reflect current treatment regimens and have small convenience samples.^{8,22-25} However, similar to our findings, identified factors that are associated with higher individual out-of-pocket costs include advanced disease and associated medications, hormone therapy, insurance gap payments and greater travelling distances to the hospital.

Table 3: Bootstrapped mean net costs by subgroups (95% CIs)

	Mean \$	95% CIs \$	Chi ²	P-value†
<i>Overall cost</i>	4,311	(3818, 4803)	-	-
<i>Distance to treatment</i>				
<=5km	1133	(707, 1559)	ref	
6-20 km	1371	(1037, 1706)	0.70	0.40
21-50 km	1782	(1004, 2561)	2.10	0.15
51-100 km	2369	(1834, 2905)	11.99	**
101-300 km	5575	(4716, 6,434)	82.49	**
301-600 km	8418	(7423, 9413)	175.00	**
>600 km	16771	(10,724, 22,817)	25.66	**
>100 km	7752	(6887, 8617)	187.48	**
<=100km	1481	(1245, 1718)		
<i>Private health insurance</i>				
nil	4249	(3505, 4994)	0.07	0.80
any	4382	(3711, 5052)		
<i>Age</i>				
<=50 years	5140	(4062, 6219)	3.65	0.06
>50 years	3947	(3387, 4507)		
<i>Household income</i>				
<\$40,000	3693	(3085, 4300)	7.93	*
>=\$40,000	5262	(4338, 6186)		
<i>Cancer type</i>				
breast	5469	(4541, 6397)	ref	
hem/blood	3240	(2323, 4157)	10.99	**
digestive/gas	3259	(2223, 4295)	9.45	*
skin	4257	(2466, 6048)	1.38	0.24
head/neck	4471	(2858, 6085)	1.13	0.29
respiratory/t	5552	(2377, 8728)	0.00	0.96
genitourinary	2168	(924, 3413)	17.64	**
other	3834	(1913, 5755)	2.36	0.12
<i>Treatment received</i>				
Radiation therapy - no	1976	(1455, 2497)	55.14	**
Radiation therapy - yes	5135	(4492, 5779)		
Chemotherapy - no	4228	(3363, 5094)	0.06	0.81
Chemotherapy - yes	4356	(3744, 4968)		
Hormone therapy - no	3976	(3431, 4520)	5.22	*
Hormone therapy - yes	5537	(4299, 6775)		
Other - no	4351	(3810, 4892)	0.11	0.74
Other - yes	4056	(2413, 5700)		
<i>Financial support received</i>				
No	2610	(1965, 3254)	44.53	**
Yes	5823	(5096, 6551)		
<i>Time from start of treatment to interview</i>				
≤ 6 mths	2857	(1806, 3907)	ref	
7-12 mths	4120	(3284, 4955)	3.46	0.06
13-18 mths	6510	(5232, 7789)	18.99	**
19-24 mths	4187	(2860, 5514)	2.40	0.12
>24 mths	2574	(1934, 3214)	0.20	0.65

†* <0.05 , ** <0.001

Like previous research in this area,¹⁵ the analysis relied on self-reported survey data with the associated potential for recall bias, although telephone interview techniques helped maximise survey completion. Unfortunately, these economic data are unavailable from more objective sources, which necessitate survey methods. The demographic and clinical profiles of the participants may not be widely generalised as our sample had a higher proportion of women due to men with prostate cancer being excluded from the study. The study was observational, reflecting real life practice and included a wide mix of patients and cancer types in regional Queensland. On the other hand, the costs here are likely to be underestimated because any lost income arising

from cancer treatment or symptoms was omitted. In our study, 37% of the sample was working at the time of being told they had cancer. Productivity losses due to disease is an area of emerging research.²⁶ In addition, participants may have had more than one cancer concurrently and our questions asked respondents to concentrate on one 'main' cancer only.

For the Australian health system, the average cost per cancer case in 2001 was \$21,900²⁷ (or \$27,200 in 2008 dollars). Our findings show that individuals are contributing, on average, between 2-19% of the total cost burden of their cancer. The role of Australian governments in providing adequate transport assistance is widely regarded as having failed, while many non-

government organisations play a critical role in addressing the accommodation needs of families with cancer. Since 2000, several inquiries into cancer treatment and services have occurred.²⁸⁻³⁰ In 2007, an inquiry into the special concerns for rural patients was undertaken¹¹ and, as a result, urgent calls were made to the Council of Australian Governments to: increase funding levels (unchanged since 1987) to better reflect the real costs of travel and accommodation; improve the equity and standardisation of benefits to achieve equality in health outcomes such as cross-border flexibility; allow carers of patients to receive funding; and streamline the current inefficient administrative and difficult application processes.

Beyond government, some research has suggested that clinical trial research groups, private health insurers and community groups could also have a more active role in providing travel and out-of-pocket funding to promote equity in the delivery of health services among regional Australia in the course of their respective core business.³¹ While a number of community groups already play a role in the provision of access to health services for regional and remote Australians, more detailed investigation is required to understand the capacity of the non-government health sector and how they can most effectively articulate with the broader health system to respond to these needs. It has been argued that by not providing good transport assistance schemes, it creates a false economy because there will be additional health system costs to both federal and state governments, due to late diagnosis or treatment of conditions and increased costs to the community associated with more severe illness.¹¹ Our findings showed no differences in the time elapsed to starting treatment among those living within or beyond 100km from the Townsville Hospital. However, we did not compare directly with cancer patients living in Brisbane. Nor does it obscure the fact that cancer survival outcomes are reduced for country living Queenslanders compared to those in the city.⁵ Our research design selected participants attending a clinical centre and therefore we have missed individuals who may have opted out of treatment completely due to their inability to access health services. Anecdotally, this appears to be occurring for some patients however, further research is required to confirm these claims.¹¹ Unfortunately, due to privacy restrictions, we were unable to provide clinical treatment information on the 39% of patients who chose not to participate in the study and therefore, we cannot rule out the possibility that treatment experiences, including delays starting or receiving treatment, were different for non-participants. There were no differences between participants and non-participants by postcode at diagnosis, which may suggest that out-of-pocket travel and accommodation expenses were similar across groups.

In conclusion, this research adds an important dimension for understanding the impact of cancer; the findings may be used to help improve supportive care services for people and families confronted by cancer. Formal travel and accommodation assistance is lacking for participants travelling more than 100km for cancer treatment. Out-of-pocket expenses necessary to access a comprehensive treatment centre for cancer are likely to be causing

financial hardship for a significant proportion of individuals living in regional, rural and remote areas in Queensland.

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