

## Impact of financial costs of cancer on patients – the Australian experience

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### Abstract

Although healthcare in Australia is largely publicly funded, there are out-of-pocket costs associated with diagnosis, treatment and survival, even in the public system. In Australia, people with cancer report relatively high out-of-pocket health costs and a heavy burden of out-of-pocket costs relative to income. These costs include travel, hospital stays, specialist fees, parking, treatment prescriptions and over-the-counter medications for supportive care. The financial impacts of the disease extend to reduced or lost employment, early retirement and reduced incomes. The financial costs of cancer in Australia are also unequally distributed in that some cancer types are more costly to the individual. Those living in rural and remote areas also face greater out-of-pocket costs, as do those who use the private health system. Cancer-related costs are not restricted to those experiencing a diagnosis of cancer, but also extend to carers and families and can be enduring. While reducing costs is an important long-term goal, ameliorating financial impacts is also important in the short term. The heavy burden associated with cancer may be reduced if the expected costs of treatment and the availability of assistance become part of treatment conversations and processes.

The large and growing number of cancer survivors in Australia is likely to mean that many Australians experience the costs and financial consequences of cancer for themselves, a family member or friend.<sup>1</sup> Therefore, it is important to understand the perspectives of Australian patients and carers regarding the magnitude and impact of these costs; along with views about current forms of financial support for people affected by cancer.

### What the 'patient' pays for cancer care and how much it varies

Although healthcare in Australia is largely publicly funded, there are out-of-pocket costs associated with diagnosis, treatment and survival in the public system. A moderate proportion of cancer care occurs in the private system (either self-funded or under insurance),<sup>2</sup> where out-of-pocket costs can be substantially higher than in the public system. Older Australians with cancer, high blood pressure, diabetes or depression are more likely than those without chronic illness to report high out-of-pocket health costs, and those with cancer or diabetes were more likely than others to spend more than 10% of household income on out-of-pocket costs.<sup>3</sup>

The out-of-pocket costs associated with cancer include general practitioner and specialist gap payments, scans or tests outside the public system, over-the-counter medications for pain relief and other purposes, medical devices, travel, accommodation and personal care, such as managing mouth ulcers during radiotherapy.<sup>4,5</sup> In addition to these costs, many patients also use complementary medicines or therapies such as nutritional supplements, or herbal medicine to support their well-being. For example, a 2010 study of 381 Australian cancer patients found 65% had used complementary or alternative medicine, with users likely to have a higher income than non-users.<sup>6</sup>

In Australia, the estimated lifetime health system cost of cancer treatment was \$33,400 per patient in 2008, of which \$5000 was borne by individuals.<sup>7</sup> As medical treatment costs escalate, particularly with advances in personalised medicine and supportive care,<sup>8</sup> current costs to the individual may be substantially higher than the 2008 estimate. These overall figures also mask wide personal variation in costs related to cancer type, stage and treatment options. For example, one patient with an early-stage localised solid tumour may have a single surgery, while another patient with haematological cancer may have very long-term treatments involving substantial travel, medications and permanent lifestyle changes.<sup>9</sup> The way in which specific tumour groups are diagnosed can result in particular groups incurring greater personal costs for diagnostic tests. Further, in relation to treatment costs, people diagnosed with breast and prostate cancer are personally responsible for 20% and 32% of treatment costs respectively. On average, cancer patients carry 15% of treatment costs.<sup>7</sup>

It is not known how well out-of-pocket costs are communicated to patients in Australia. The limited available data suggests advance warning about actual out-of-pocket treatment costs is not generally provided. Up to 70% of Australians diagnosed with prostate cancer reported that they spent more for their cancer treatment than expected.<sup>10</sup> In line with this finding and the ongoing emphasis on informed participation in treatment decisions as part of patient-centred care, there have been recent calls for Australian health professionals to disclose the cost of treatment pathways and alternative options to patients while forming treatment plans.<sup>8,11</sup>

## What cancer patients report about the actual costs of cancer treatment

While the patient bears a relatively small proportion of the total costs of cancer treatment in Australia,<sup>12</sup> these costs can translate into hundreds of dollars out-of-pocket per month, although this varies considerably between patients. Gordon et al found that while 5% of men who had been diagnosed with prostate cancer reported spending \$250 or less for treatment, the median spend for recently diagnosed men was \$8000 and some spent up to \$17,000.<sup>10</sup> Within this study, 171 men underwent radical prostatectomy and reported a median spend of \$6000, which was higher than those who underwent watchful waiting (\$3000), active surveillance (\$5000), or androgen deprivation therapy (\$3375). As the proportion of men who receive radical prostatectomy, particularly robotic-assisted, is likely to increase in the future,<sup>13</sup> the costs of this treatment approach needs to be monitored. In examining other treatment approaches, a survey of 255 cancer patients with multiple tumour types found almost half (46.7%, 95% CI=40.5, 52.8) had medicines prescribed for them solely in relation to their cancer, and a further 11.4% (95% CI= 7.4, 15.3) had been prescribed both cancer-related and non-cancer-related medicines.<sup>14</sup> The preferred strategies by patients for reducing their out-of-pocket costs for cancer treatment were to reduce the costs of parking, medications and treatment-related travel.<sup>15</sup> A study of regional cancer patients also identified travel expenses as the highest share of out-of-pocket costs (71%) followed by medical appointments (10%) and co-payments for medications (9%). Over an average time of 16 months from diagnosis, regionally based cancer patients reported a mean of \$4311, and median of \$2263 in out-of-pocket costs.<sup>16</sup> Costs were higher for those residing further away from the treating hospital.

## How financial costs impact on the experiences of Australian cancer patients

Approximately one-third (34%) of cancer patients in Australia perceived that they had experienced a moderate, heavy or extreme financial burden in the prior three months due to prescribed medicines for cancer treatment or recovery.<sup>14</sup> The consequences of a financial burden included the use of cost-saving strategies, with 12% reporting at least one of the following regarding cancer-related medicines: using over-the-counter rather than prescribed medicine; using medicines from home rather than filling a new prescription; or, using medicines from someone else.<sup>14</sup> Cost-related factors were reported to influence decision-making about cancer treatment by 19% of the cancer patient sample, particularly the costs of travelling to and from treatment (14%), loss of income (14%) and actual costs of treatments (11%). Those who nominated at least one factor influencing their treatment were asked how those factors influenced their decision – 71% indicated the cost-related factor made the decision difficult, but did not change their decision, while a small number chose a different treatment, had treatment for a shorter time or at a lower dose, delayed treatment, or decided not to have treatment due to cost.<sup>17</sup> This finding of forgoing and limiting health service or medication use as a cost-saving strategy has been noted in other Australian studies.<sup>10,18,19</sup> Patients with private health insurance had significantly higher odds of reporting that financial factors had influenced their treatment decision

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making,<sup>14</sup> suggesting that patients in the private system face substantial and potentially prohibitive costs which they would not incur if treated in the public system.

The experience of cancer has financial impacts beyond the direct costs of diagnosis, treatment and self-care. The 2003 Survey on Disability, Ageing and Carers reported that for those individuals who were actively undergoing cancer treatment, the probability of employment was reduced by 41% in males and 17% in females.<sup>7</sup> A more recent study found that for those who were employed at the point of cancer diagnosis, almost two-thirds (63.5%, 95%CI=54.1,72.9) experienced a reduction in their household income.<sup>17</sup> The reduction in income for the study sample was approximately half. The Gordon et al study of prostate cancer patients found that on average, respondents in paid employment at diagnosis stated that they had retired four to five years earlier than planned.<sup>10</sup> The experience of substantial out-of-pocket costs, combined with reduced employment or income, has the potential to exacerbate emotional distress associated with cancer. For example, one in five prostate cancer patients, many of whom reported being financially comfortable and university-educated, felt treatment costs caused them a great deal of distress.<sup>10</sup> In a qualitative study of 97 individuals with chronic conditions, including cancer, the financial burden associated with treatment was perceived to be more problematic than even the side-effects and adverse events from medication use.<sup>19</sup> A qualitative study of people with haematological cancer found cancer can "facilitate a spiral to acute and irreversible financial distress."<sup>20</sup>

## Which patients bear the greatest burden of cancer care costs

Out-of-pocket costs and the experience of financial burden can vary widely. People with private health insurance have reported double the out-of-pocket costs of cancer than those without insurance, regardless of time since diagnosis.<sup>10</sup> This may be due to higher gap payments, lack of access to subsidised medicines and paying for treatments which would have been free or subsidised if accessed under the public system. Little is known about whether privately-treated or high-income cancer patients perceive they receive (or actually receive) value for money compared to patients treated in the public system. Expenses also appear to be higher among: the recently diagnosed; those living at a greater distance from treatment; those bound to certain treatment types e.g. costs may be higher for radiotherapy; and those residing in certain Australian states.<sup>10,14,16</sup> Those living outside the major cities have 17 times the odds of reporting locational or financial barriers to care compared to those living in metropolitan areas.<sup>15</sup>

While most middle-aged individuals gradually return to work within five years after diagnosis, those who were diagnosed with blood, head and neck, or nervous system cancers, are often unable to resume employment, with middle-aged cancer survivors more likely to choose early retirement or use superannuation funds.<sup>7</sup> The potential income loss associated with cancer survivorship is also experienced by childhood cancer survivors, as this group are less likely to obtain a university education and their average earnings is approximately 10% lower.<sup>7</sup>

## How the cost of cancer extends to carers and families

The financial burden of cancer does not rest on patients alone, with the overall cost to the household estimated to be \$47,200. In addition, approximately 1.3 million hours of informal care were provided to individuals with cancer in New South Wales alone.<sup>7</sup> Almost three-quarters (72%) of cancer carers reported a negative financial impact of caring and 51% of those previously working full-time had taken leave or reduced working hours. Accessing financial support and government benefits were listed as an unmet need for this group.<sup>21</sup> Often carers do not have access to travel and accommodation schemes. As informal caregivers, individuals are often required to reduce the number of hours of paid employment,<sup>22</sup> often without access to patient-oriented travel and accommodation schemes.

Analysis of population data from the Australian Bureau of Statistics found carers of individuals with neoplasms, blood diseases or immune system disorders were approximately 6.5 times more likely to be out of the workforce as compared to non-carers, even after controlling for age, sex, and education.<sup>22</sup> Qualitative interviews with patients and carers in an Australian community-based cancer palliation program reported carer costs of \$370 per month and revealed that the double burden of both individuals' reduced employment caused strain on personal relationships.<sup>18</sup>

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Where carers are the parents of children with childhood cancers, the greatest perceived impact of the cancer was perceived financial burden, with extra financial burden associated with vehicle expenses (parking, petrol and additional maintenance) and additional food (ordered meals, meals away from home, maintaining multiple residences).<sup>23</sup> A study by Heath et al found that the highest costs for these parents were associated with airfares (for a minority) and childcare/babysitting (for the majority).<sup>23</sup> Families also reported that community support was mostly in the form of recreational and social activities, with less aid directed to financial assistance. More than three-quarters (77%) of these families reported disruption to work activities. For these families, the estimated family income lost in the 12 months immediately following diagnosis ranged from \$500-\$50,000. Almost three-quarters (74%) of parents reported experiencing a great or moderate degree of economic hardship following a diagnosis of cancer in a child.

## Financial assistance for cancer patients

Government assistance to help relieve the financial stress of cancer includes income support, concessions and subsidies.<sup>24,25</sup> However, government assistance in the form of concessions or subsidies is often insufficient to cover living and medical expenses.<sup>18</sup> Non-government assistance is offered by organisations such as Cancer Council, Leukaemia Foundation and Can Assist, particularly for patients who live in rural areas. Interviews with representatives from Australian Consumer Health Organisations highlighted that professionals within these community-based organisations are keenly aware of the financial burden associated with chronic conditions, particularly the compounding effect of expensive polypharmacy and reduced or lost employment.<sup>26</sup> Some state Cancer Councils can assist with transport and accommodation costs, and in some cases can provide accommodation for regional patients and their carers who travel long distances for treatment. Assistance from Cancer Council and other cancer charities in some states can also include financial counselling, interest-free loans and small one-off payments. Many banks, utility and telecommunications providers have hardship provisions to assist with or restructure debts or regular payments, although anecdotally it appears that awareness of and offer of these services is limited. A survey of 255 oncology outpatients in Australia found 74% did not access financial assistance.<sup>17</sup> Of those not using financial assistance, 43% did not need it, while 37% did need it, but were unaware that financial assistance was available, and 16%, reported there were no relevant forms of assistance. Difficulties with accessing financial assistance included a lack of information, the amount of money being insufficient, the need for up-front payment, applications being too difficult and payments not covering the type of help needed.<sup>17</sup> It is important that financial assistance and counselling is accessed as soon as possible after diagnosis to avoid financial problems spiralling out of control.

## What else we need to know about the costs and financial impact of cancer

There is relatively little ongoing, system-wide information about the actual (rather than estimated) out of pocket costs of cancer care experienced by patients and their carers/support persons in Australia, particularly from a life-time perspective and within the private system. There is also very little known about how much and how well the likely out-of-pocket costs are communicated to patients or carers as part of decision-making for their treatment and care. It is likely that such communication is highly challenging, given the emotional and information burden already faced during the diagnostic and decision-making phase.

Longer term financial impacts can be even harder to estimate, including those at the palliative and terminal stages of life. In addition to out-of-pocket costs and loss of income, cancer survivors may face financial discrimination, including difficulty in finding employment, taking out a home or other loan, and obtaining life/health/travel insurance. To date, there is only anecdotal data available regarding these questions, although Legal Aid NSW is currently working with Cancer Council NSW to conduct a survey to gain a better understanding on how health conditions may impact on people's ability to access insurance products in Australia.

## Conclusion

The costs and financial impacts of cancer – although partially met by Federal, state and non-government support – remain a substantial and enduring burden for many patients and their families,

with some groups bearing a disproportionate burden. Better monitoring and support in relation to these out-of-pocket costs and exploration of the 'value for money' proposition within the private system are targets for future research. While reducing costs is an important long-term goal, ameliorating financial impacts is also important in the short term. The heavy burden associated with cancer may be reduced if the expected costs of treatment and the availability of assistance become part of treatment conversations and processes.

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