

RESEARCH ARTICLE

Financial toxicity among public oncology patients in Australia: A qualitative analysis

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Abstract

Background: As cancer treatments become more complex, financial toxicity—encompassing direct and indirect costs to patients and families—has emerged as a significant issue. In our recent study of public patients with cancer in Australia, we found that a substantial proportion experienced financial toxicity, which was associated with poorer quality of life. A deeper understanding of its sources is needed to inform interventions.

Objective: This study explored the spectrum of costs, restrictions on spending, impact on work, and treatment adherence among public patients receiving anti-cancer therapy.

Methods: A cross-sectional qualitative study was conducted using semi-structured telephone interviews with patients purposively sampled from those with the highest levels of financial toxicity, based on Comprehensive Score for Financial Toxicity questionnaire scores. Interviews were audio-recorded, transcribed, coded in NVivo, and analyzed using inductive thematic analysis.

Results: Twelve patients were interviewed; data saturation was reached at the 12th interview (median age = 52.7 years; 66.7% women). Three key themes emerged: (i) increased cancer-related out-of-pocket costs, including diagnostic imaging, general practitioner and specialist follow-up, treatment complications (e.g., lymphedema), parking, and personal expenses; (ii) reduced financial resources from lost employment and productivity; and (iii) mitigation strategies, such as restricting non-health expenditures (e.g., luxuries, travel), accessing sickness benefits, and drawing on savings.

Conclusion: Even within a universal healthcare system, patients with cancer face significant, unexpected out-of-pocket costs from diagnostic tests, medications, treatment complications, travel, and income loss. Participant narratives suggest that these financial pressures may influence treatment adherence, psychosocial well-being, and holistic care. Greater awareness and improved access to mitigating strategies are needed to reduce financial toxicity and its impact on patients and families.

Keywords: Financial toxicity; Comprehensive Score for Financial Toxicity; Cancer; Public health; Interviews

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1. Introduction

As cancer treatment becomes increasingly complex, financial toxicity has emerged as an under-recognized issue. Financial toxicity refers to the distress and hardship resulting from the financial burden of cancer and encompasses both direct and indirect costs of a cancer diagnosis and treatment for both patients and their families.¹ Direct costs can include consultation fees, hospital admission costs, dispensing costs of treatment, and supportive medications. Indirect costs can include loss of income from time off work (for both patients and caregivers), reduced productivity due to illness, travel and accommodation costs for treatment, and increased household expenses due to dietary changes or increased heating/cooling. These financial costs have been shown to negatively impact patient psychological well-being and quality of life, affecting all patients whether they are undergoing surgery, systemic therapy, or are being followed during survivorship.²

In Australia, residents have universal access to government-funded healthcare. Through the Medicare Benefits Schedule and Pharmaceutical Benefits Scheme, a wide range of medical services and prescription medications are subsidized or provided at low cost. Alongside the public system is a regulated private health sector that offers patients a greater choice of doctors and hospitals with additional out-of-pocket expenses. Around half of Australians hold private insurance to offset these costs.³

The Comprehensive Score for Financial Toxicity (COST) was developed to assess the financial burden and distress experienced by people with cancer.⁴ This 11-item patient-reported tool was initially validated in an American cancer population and has more recently been validated in Australian populations.^{2,5,6} In its original validation study of 233 American patients, higher financial toxicity (demonstrated by lower scores on the COST measure) was linked with poorer quality of life.⁷ Key factors contributing to this toxicity included employment status, race, and income. Loss of productivity and reduced participation in both paid and unpaid work also contributed to this burden.⁷

In 2020, we conducted a pilot study ($n = 66$) using the COST questionnaire⁴ to quantify the impact of financial toxicity in the Australian public healthcare system.² In this pilot study, we found that despite a universal health care model, a substantial proportion of patients receiving cancer therapy experienced financial toxicity, and this was associated with poorer quality of life.² This impact was independent of age, gender, and regional/rural

postcode. Univariate analysis identified that younger age was associated with greater financial toxicity ($p < 0.001$). Therefore, the present study aims to explore the lived experiences and perspectives of Australian cancer patients reporting financial hardship by conducting in-depth interviews with participants who demonstrated significant financial toxicity in our pilot study.

2. Materials and methods

2.1. Ethical considerations

This study was approved by the St. Vincent's Human Research and Ethics Committee (LRR 100.19), and all participants provided written informed consent prior to participation. Privacy and confidentiality were maintained accordingly, with all electronic data de-identified in transcripts for each participant and stored on secure, password-protected computers, and paper forms stored in locked compactors within our research department. Data were used only for this research project and destroyed after five years from publication. Additionally, this study was conducted in accordance with the ethically approved protocol and Good Clinical Practice standards.

2.2. Patients

During our prior pilot study², adult patients (≥ 18 years) with a diagnosis of solid organ malignancy were recruited from a single large inner-city tertiary public hospital cancer center. Patients were receiving active systemic therapy at the time of questionnaire completion, including chemotherapy, immunotherapy, targeted therapy, or hormonal therapy. Treatment could be administered in the neoadjuvant, adjuvant, or metastatic setting. Participants were required to be able to complete study questionnaires and interviews in English.² Family members or friends could provide limited informal assistance with questionnaire completion; professional interpreters were not used. Patients unable to complete the questionnaires in English were excluded.

From this broader sample, we identified patients who self-reported financial hardship using the COST questionnaire. The COST questionnaire comprises 11 items scored on a Likert-type scale (0–4), yielding a total score range of 0–44, with lower scores indicating greater financial toxicity. Items assess financial strain, cost concerns, and the perceived impact of these pressures on cancer care. We recalculated COST scores for participants from our pilot study² according to the scoring criteria described by de Souza *et al.*⁴ Scores were then ranked from lowest (greater financial toxicity) to highest.

Participants were purposively invited for an interview, prioritizing those with greater financial toxicity. We

initially contacted the 15 lowest-scoring participants to assess interest, with plans to recruit additional participants if thematic saturation was not achieved. All participants provided written informed consent. Semi-structured interviews were conducted via telephone between January and March 2022 by a single researcher (TY), who has experience in clinical oncology and research methodology.

2.3. Study design and methods

This cross-sectional, exploratory qualitative study was underpinned by a thematic analysis approach. A semi-structured interview schedule was used to guide the interview process, ensure consistency, and facilitate subsequent data analysis. The schedule was designed to explore patient experiences and is presented in Table 1. The interview schedule was based on existing literature and expert experience in the field. Participants each took part in a single interview and had no established relationship with the interviewer prior to the interviews. Interviews continued until data saturation was achieved. All participants were interviewed via telephone. The interviewer maintained field notes capturing reflections and key points from each session, which were used to inform assessments of data saturation.

All interviews were audio-recorded and transcribed verbatim. Transcripts were not returned to participants for comment. De-identified transcripts were analyzed using NVivo version 13 software (Lumivero, USA)⁸ by one researcher (TY) following a framework analysis approach.⁹ Codes were generated inductively from the data, grouped into categories, and iteratively mapped to establish thematic relationships. Data collection and analysis occurred concurrently, with systematic efforts to refine categories and themes. Interim findings were regularly presented to the investigator group (SAM and LM) for discussion, resolution of discrepancies, and consensus on the final thematic structure. Inductive thematic saturation was reached after 12 interviews.

The research team included clinicians and qualitative researchers with experience in oncology care. We acknowledge that our clinical backgrounds may have shaped both data collection and interpretation. We engaged in regular reflexive discussions to ensure that themes remained grounded in participant accounts.

Reporting of this qualitative study followed the Consolidated Criteria for Reporting Qualitative Research guidelines, with the completed checklist provided in the Supplementary File.

3. Results

A total of 15 patients were approached, 13 agreed to be

interviewed, and 12 were ultimately interviewed, at which point data saturation was reached. Interview lengths varied from 10 to 30 minutes, with an average length of approximately 20 minutes.

The median age of patients was 52.7 years at the time of interview, with 66.7% (8/12) female. The median COST score was 14.3 (range: 0–26). Patient characteristics are listed in Table 2.

Three major themes emerged from the analysis of the interviews: (i) increased cancer-related out-of-pocket costs, (ii) reduction in financial resources, and (iii) mitigation strategies.

3.1. Increased cancer-related out-of-pocket costs

This theme comprised three subthemes. Overall, participants described a significant financial burden resulting from their cancer diagnosis and treatment. This burden extended beyond routine medical expenses. Direct diagnostic and treatment costs included medications and diagnostic procedures/imaging. The second subtheme captured indirect costs of cancer care, such as travel to treatment centers, income loss, and reduced work productivity. Another prominent theme was the financial impact of treatment complications, such as alopecia and lymphedema.

3.1.1. Direct diagnostic and treatment costs

Although most hospital-based systemic anti-cancer therapy is covered by Medicare, take-home medications were commonly reported by patients to incur out-of-pocket expenses that were burdensome. This included supportive drugs such as antiemetics, analgesics, and growth colony-stimulating factors.

One participant highlighted this issue: “Some medication was not on the government schedule. I had to pay for that... probably about AUD 30 or AUD 40 every three weeks on medication, was quite a lot for me at the time” (Participant [P] 8).

Other patients cited substantial costs associated with diagnostic investigations and procedures that they paid for outside of the public system to avoid significant delays: “Originally, I paid privately for my own colonoscopy and also my first CT scan, because there was no way in the world, I was waiting on the public list... there was just a couple of thousand (dollars) in that” (P2). These costs were reiterated by another participant: “My MRI was private. That was an AUD 500 charge” (P8).

Participants described how their cancer diagnosis and treatment often necessitated visits to multiple doctors, including their general practitioner. These consultations

Table 1. Sample interview questions

No.	Sample interview questions
1	Has financial hardship or cost prevented you from getting the treatment or medications you needed?
2	To receive treatment for your cancer, have you needed to access funds beyond your savings?
3	Are you concerned about out-of-pocket costs when thinking about your cancer treatment?
4	Have you or your carer had to change your usual work arrangements due to your cancer treatment?
5	What impact does this financial pressure have on you and your family?

Table 2. Patient characteristics

Characteristic	Value (<i>n</i> = 12)
Age (median; years [range]) ^a	52.7 (34.7–82.3)
COST score (median [range]) ^b	14.3 (0–26)
Gender (<i>n</i> [%])	
Male	4 (33.3%)
Female	8 (66.7%)
Marital status ^b (<i>n</i>)	
Married/partnered	5
Divorced/separated	3
Widowed	0
Single	3
Not provided	1
Financial support ^b (<i>n</i>)	
Age pension	1
Disability support pension (full)	4
Disability support pension (sickness allowance)	1
Carer's benefit	0
Private income protection disability insurance	1
None	5
Employment status (<i>n</i>)	
Full-time	3
Part time/casual	1
Unemployed	3
Retired/pension	5

(Cont'd...)

Table 2. (Continued)

Characteristic	Value (<i>n</i> = 12)
Household income (AUD per annum ^b ; <i>n</i>)	
<50,000	6
50,000–75,000	2
75,000–100,000	1
>100,000	2
Not reported	1

Notes: ^aAge at time of the interview. ^bData were collected through questionnaires administered in the pilot study.²

represented an ongoing expense. While some were able to access bulk-billing services through Medicare, most reported having to pay out-of-pocket consultation fees, commonly in the range of AUD 75–90. For example, one participant commented: “In that time, I went to the GP quite often...it was like AUD 75 each visit” (P7).

In addition, some patients paid for private specialist follow-up, as well as allied health and supportive services including dietitians, psychologists, and exercise physiologists. Another participant mentioned, “I enrolled support from people like a psychologist and a dietician and acupuncture, and that was all quite expensive” (P1).

3.1.2. Indirect cancer care costs

A majority of patients reported substantial travel-related expenses, including costs for parking, fuel, and public transport. These expenses were especially burdensome for those travelling from regional areas to access treatment. One participant described the cumulative impact, noting, “AUD 26 to park!! So, when you're doing a treatment every fortnight, you've got all those travel expenses...those sorts

of things are the things that add up” (P2).

The lack of affordable parking options near hospitals was also highlighted, “...I think every patient should deserve free public parking...it’s too difficult to try and get one on the street, so you just bite the bullet” (P2). For some, accommodation close to treatment centers added further financial strain, as one participant reflected, “...it was about AUD 140 a night, and that was the subsidized cost of being close to the hospital” (P3).

3.1.3. Costs of treatment complications

Treatment complications generated their own costs, most commonly related to prescription medications used to alleviate immediate chemotherapy side effects such as antiemetics, laxatives, and anti-diarrheal agents. As one participant noted, “Medication was the big one from the treatment... which was like nausea stuff, all these kinds of tablets” (P7).

Beyond pharmaceuticals, alopecia was also identified as a significant concern, with the purchase of a high-quality wig representing an important, though costly, personal expense: “...this wig cost me AUD 3,000, so that was ridiculous... but it made me feel good, and it was well worth the investment” (P1).

Longer-term complications—such as peripheral neuropathy and lymphedema—introduced further financial burdens, with patients describing expenditures on chemical-resistant gloves to manage cold dysesthesia, compression sleeves to reduce swelling, and ongoing consultations with private hand and lymphedema specialists. As participants explained, “I had to buy chemical gloves while I was on chemo to open doors, turn on taps. That neuropathy is bad. It really is a shocker,” (P2) and “I was seeing a lymphedema therapist... I think that was like about AUD 130 every time” (P6).

3.2. Reduction in financial resources

3.2.1. Loss of employment opportunities and productivity

Compounding the increased costs of cancer treatment was a reduction in financial resources with many patients and their family members needing to take time away from paid employment, relying on variable amounts of leave entitlements. As one participant explained, “I had to stop (working) completely right away” (P12), while another shared, “I haven’t been able to drive, so my husband usually takes a day off work” (P5). Many patients reported exhausting their accrued paid sick leave entitlements and relying on other forms of support. For example, “I had to take all my sick leave, all my annual leave, which was a bit

disappointing” (P1).

3.2.2. Inability to return to work

Not all patients were able to return to work, and for those who did, there was often a prolonged period before full recovery was achieved. Several participants described either attempting to continue working during treatment or resuming employment prematurely, sometimes against medical advice, due to significant financial pressures. As one participant reflected, “If the surgeon says that I’m clear to work, maybe I can go back to it, but I’m worried” (P12).

3.3. Mitigation strategies

3.3.1. Sickness benefits

Coping with financial toxicity often relied on access to government income support, such as the Disability Support Pension administered through Australia’s Centrelink, or employer-based measures including insurance schemes and return-to-work programs. As one participant reflected, “Because I was on Centrelink, there were a lot of costs that I didn’t need to pay... otherwise I think we’d be living in a tent” (P3).

Another described, “My work said you can take as much time as you like to get ready to return to work, and then they implemented a return-to-work program” (P1). Most patients reported being largely compliant with treatment recommendations, prioritizing medical costs and avoiding the need to forgo essential care. However, there was a strong consensus that without regular benefit payments, the out-of-pocket expenses would have been unaffordable.

3.3.2. Use of savings

Most participants reported accessing a substantial portion of their personal savings to manage cancer-related expenses, with some selling investment properties and others drawing on accumulated retirement funds (“superannuation” in Australia) earlier than planned. One participant explained, “My savings account probably went down over AUD 5,000 during the last two years as a direct result” (P2).

3.3.3. Reduction in non-healthcare expenditure

Many patients reported reducing discretionary spending to manage the financial impact of cancer, cutting back on luxuries such as holidays and non-essential clothing or accessories. As one participant noted, “Yeah, you have to budget—there’s things that you put off or postpone. If you’re serious about getting better, well, you cut out on other things” (P2). Another participant reflected, “Because it was more like a financial thing, I needed to make sure that I could be able to pay rent after” (P7).

3.3.4. Family support

The availability of support from family and friends was also crucial in helping patients manage the financial and logistical burdens of cancer care. One participant shared, “My children have taken turns in driving me to oncology appointments, for blood tests, to the hospital and back” (P8).

4. Discussion

This study highlights the pervasive nature of financial toxicity experienced by Australian patients undergoing cancer treatment and demonstrates that even in a “universal” healthcare model, patients still face substantial unexpected or hidden costs. Participants described a spectrum of expenses extending beyond the medical encounter itself, including costs related to travel, parking, accommodation, and supportive care. Many participants also reported disruptions to employment and household finances. These narratives suggest broader consequences for psychosocial well-being and financial security.

Thematic analysis revealed three interlinked domains: (i) increased out-of-pocket costs, (ii) reduction in financial resources, and (iii) mitigation strategies. These findings align with and extend prior research, underscoring that the economic burden of cancer is not simply an individual challenge but a systemic issue requiring coordinated responses from health systems, employers, and policymakers.

Another Australian study found that one in 10 people with cancer in New South Wales incurred healthcare costs exceeding AUD 10,000 in the first year following diagnosis, while 43% reported out-of-pocket expenses greater than AUD 1,000 within 12 months.¹⁰ Similarly, all participants in our study reported increases in out-of-pocket spending. Consistent with prior research, participants described both direct costs related to cancer diagnosis and treatment, as well as indirect costs such as parking and accommodation.^{11,12}

In a study by Panattoni *et al.*¹², patients reported difficulties in regularly attending their treatment centers due to the distance from their homes. Our participants also highlighted these difficulties and the financial strain placed on them through covering costs for parking, fuel, and transport. Although the Australian healthcare system differs from the insurance-based model in the United States, there remain hidden or unexpected costs related to outpatient care. Participants also reported substantial non-medical costs associated with treatment side effects. For example, one participant described spending AUD 3,000 on a wig, while another required regular lymphedema

specialist appointments costing AUD 130 per visit. These findings highlight that, despite the protections of a universal healthcare system, financial toxicity persists, with indirect and hidden expenses such as transport and parking emerging as significant burdens.

Income loss resulting from work absenteeism by patients and their carers is a well-established contributor to financial hardship¹³⁻¹⁵, and a reduction in financial resources emerged as a prominent theme in our interviewed cohort. Carlson *et al.*¹⁶ previously explored the relationship between cancer and employment-related financial toxicity through in-depth interviews of 21 Australian cancer survivors. Their findings highlighted the dynamic interplay between cancer and work, showing how treatment disrupts employment pathways, generates psychosocial distress, and forces patients into difficult trade-offs between health and financial security. Our results align with these observations, underscoring the multifaceted and interconnected nature of cancer-related financial hardship and the need for both medical and employment systems to adapt in order to protect patient well-being. This impact also extends to family and caregivers, who may also need to take time off work to accompany patients to appointments, as reflected in our interviews.

Higher degrees of financial toxicity have been reported among caregivers of cancer patients¹⁷⁻¹⁹, highlighting the importance of extending financial and psychosocial support services beyond patients to their families. Another Australian study explored the perspectives of healthcare professionals on financial toxicity through an online survey ($n = 277$) and highlighted systemic barriers such as inadequate services, lack of training, and discomfort in raising financial concerns with patients, while also emphasizing the cross-disciplinary responsibility to address the issue.²⁰ While this study underscored the structural and professional blind spots that can limit effective financial toxicity management, our study illuminates the day-to-day financial realities and sacrifices patients endure, even within a universal healthcare system.

Participants in our study also employed a range of mitigation strategies to cope with financial toxicity, including reliance on government benefits, use of personal savings, reductions in discretionary spending, and support from family and friends. Access to income support, such as the Disability Support Pension or employer-based schemes (i.e., sick leave), was reported as critical for maintaining treatment adherence, highlighting the role that social safety nets play in buffering against significant health expenditure. Similar to other reports, patients frequently drew down on savings or superannuation, or liquidated assets, highlighting the long-term economic consequences

of cancer beyond the treatment period.^{21,22} Reductions in discretionary spending were also reported, aligning with prior qualitative work that describes financial toxicity as reshaping patients' broader financial decision-making and limiting participation in normal social and leisure activities.^{21,23} Finally, family and informal caregiving networks provided vital financial and logistical support, a finding echoed in previous studies that emphasize the hidden costs and burdens borne by carers.²⁴⁻²⁶ Collectively, these strategies demonstrate patient resilience but also reinforce the inadequacy of existing structural supports, strengthening calls in the literature for systemic integration of financial counseling and proactive linkage to relevant resources within cancer care pathways.

The present findings have several practical implications for cancer care delivery. Routine screening for financial toxicity in oncology clinics using validated tools such as the COST questionnaire may help identify patients at risk earlier in the treatment pathway. Clear referral pathways to social workers or financial counsellors could assist patients in navigating available supports, including government benefits, travel and parking subsidies, and medication subsidy programs. Greater awareness among clinicians of these resources may help reduce the financial burden experienced by patients undergoing treatment.

Financial toxicity has consistently been associated with younger age, lower income, and unemployment at diagnosis.^{2,6} Higher levels of financial toxicity, as measured by validated tools such as the COST questionnaire, also correlate with poorer quality of life.⁷ In our pilot study, greater financial toxicity was similarly associated with reduced quality of life, and younger age was linked to greater financial burden.² This study purposively targeted participants reporting greater financial toxicity (median COST score of 14.3), with two-thirds of the cohort being female (66.7%, 8/12). As recognition grows of the impact of financial strain on both treatment adherence and quality of life, there has been increasing support for incorporating financial consent into cancer care, particularly within the private sector. Evidence suggests that cost communication improves patient satisfaction and may alleviate some of the distress associated with financial hardship.²⁷⁻²⁹ Studies exploring the extension of such approaches to the public sector are warranted, given the clear evidence of financial strain in this setting, to promote equitable and patient-centered cancer care.

5. Limitations and future recommendations

As an exploratory qualitative study using purposive sampling of patients experiencing financial toxicity, these findings may not be generalizable to all cancer populations.

They are most relevant within the context of the Australian public healthcare system. This study also included participants with sufficient English proficiency to complete questionnaires and participate in interviews. This may have introduced selection bias and limited the representation of experiences among non-English-speaking patients. The cross-sectional design also limits the ability to assess how financial toxicity changes over time. Telephone interviews may also have limitations in relation to patient rapport and depth of discussion; however, a semi-structured format and open-ended questions were utilized to facilitate detailed participant responses.

Future studies should include larger, more diverse cohorts and longitudinal designs to better capture the evolving financial needs of patients across the cancer trajectory. Evaluating the impact of structured interventions—such as early cost communication, financial counseling, and policy-level support—will be essential for developing strategies to mitigate financial toxicity and improve patient outcomes. Calls for interventions to address financial toxicity have been gathering momentum³⁰⁻³², with groups such as the Clinical Oncology Society of Australia publishing a *Roadmap to Reducing Financial Toxicity Experience by People Affected by Cancer*, highlighting the growing recognition of this issue and the need for coordinated action in this field.³³

6. Conclusion

In this study, the participants reported substantial out-of-pocket expenses, reduced income from disrupted employment, and reliance on a variety of mitigation strategies, including government benefits, savings, and family support. While most patients prioritized adhering to recommended treatment, many did so at considerable personal and financial cost, underscoring the hidden burden carried by patients and carers even within a universal healthcare model. These results reinforce the need for routine clinical enquiry into financial strain as part of holistic cancer care. Integrating financial counseling and linking patients more systematically to available resources and support services may help reduce financial stress and support patients in maintaining treatment adherence and psychosocial well-being. At the level of government policy, expanding coverage for supportive medications, addressing non-medical costs such as travel and parking, and tailoring assistance for rural patients and carers may represent important steps towards mitigating the multifaceted and inequitable nature of financial hardship in cancer care.

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Conflict of interest

The authors declare no conflicts of interest.

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Ethics approval and consent to participate

This study was approved by the St. Vincent's Human Research and Ethics Committee (LRR 100.19), and all participants provided written informed consent prior to participation. Privacy and confidentiality were maintained accordingly, with all electronic data de-identified in transcripts for each participant and stored on secure password-protected computers, and paper forms stored in locked compactors within the research department. Data will be used only for this research project and destroyed after five years from publication. Additionally, this study was conducted in accordance with the ethically approved protocol and Good Clinical Practice standards.

Consent for publication

Written and verbal informed consent was obtained from all participants for participation in this study and for the publication of the results.

Availability of data

Datasets generated during and/or analyzed during the current study are available from the corresponding author on reasonable request.

Further disclosure

The results of this study were presented in poster form at the Clinical Oncology Society of Australia annual meeting in Brisbane (November 2–4, 2022).

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