

‘... If I don’t have that sort of money again, what happens?’: adapting a qualitative model to conceptualise the consequences of out-of-pocket expenses for cancer patients in mixed health systems

Jade C. Newton  ¹ BHSc(Hons), Research Assistant

Harry Hohnen ¹ BA, GradCertPopHlth, Research Assistant

Claire E. Johnson ^{1,2,3} RN, RM, PhD, Professor

Angela Ives ¹ DipAppSc, MSc, PhD, Research Fellow

Sandy McKiernan ⁴ RN, MPH, Director

Violet Platt ⁵ RN, MN, EMBA, Associate Professor

Christobel Saunders ¹ MBBS, FRCS, FRACS, Professor

Neli Slavova-Azmanova ^{1,6} MD, PhD, Research Associate

¹UWA Medical School, The University of Western Australia, M507, 35 Stirling Highway, Crawley, WA 6009, Australia. Email: harry.hohnen@uwa.edu.au; angela.ives@uwa.edu.au; Christobel.Saunders@uwa.edu.au; jade.newton@uwa.edu.au

²School of Nursing and Midwifery, Monash University, Wellington Road, Clayton, Vic. 3800, Australia. Email: Claire.Johnson@easternhealth.org.au

³Eastern Health, Box Hill, Vic. 3128, Australia.

⁴Cancer Council Western Australia, 420 Bagot Road, Subiaco, WA 6008, Australia. Email: sandy.mckiernan@svdpwa.org.au

⁵WA Cancer and Palliative Care Network, 4th Floor, A Block, Verdun Street, Nedlands, WA 6009, Australia. Email: Violet.Platt@health.wa.gov.au

⁶Corresponding author. Email: Neli.Slavova-Azmanova@uwa.edu.au

Abstract.

Objective. The aim of this study was to explore Western Australian cancer patients’ experiences of out-of-pocket expenses (OOPE) during diagnosis and cancer treatment using a phenomenological approach.

Methods. Semi-structured interviews were conducted with a purposive convenience sample of 40 Western Australian cancer patients diagnosed with breast, lung, prostate or colorectal cancer. Participants were asked about the impact of their diagnosis, the associated costs and their experience within the health system. Data were analysed using thematic content analysis.

Results. Three key themes influencing participant OOPE experiences were identified: (1) personal circumstances; (2) communication with health providers; and (3) coping strategies. Despite Australia’s public healthcare system, several participants found the costs affected their financial security and resorted to coping strategies including medication rationing and restrictive household budgeting. The key themes had a complex and interrelated effect on patient OOPE experiences and were used to adapt Carrera *et al.*’s model of economic consequences of cancer treatment on the patient and patient coping to describe these relationships in a mixed healthcare system.

Conclusion. Organised efforts must be implemented to mitigate maladaptive coping strategies being used by cancer patients: (1) health providers should seek informed financial consent from patients before commencing treatment; and (2) financial aid and support schemes for cancer patients should be reviewed to ensure they are delivered equitably.

What is known on this topic? The financial cost of cancer can have significant adverse effects on cancer patients. Although financial transparency is desired by cancer patients, its implementation in practice is not clear.

What does this paper add? This study adapts a conceptual model for the economic consequences of a cancer diagnosis and repurposes it for a mixed public–private health system, providing a framework for understanding downstream consequences of cancer costs and highlighting opportunities for intervention.

What are the implications for health practitioners? Health practitioners need to initiate discussions concerning treatment costs earlier with cancer patients. There are several resources and guides available to assist and facilitate financial transparency. Without urgent attention to the financial consequences of cancer treatment and related expenses, we continue to leave patients at risk of resorting to maladaptive coping strategies, such as medication rationing and restrictive household budgeting.

Additional keywords: financial burden, health expenditure, outer metropolitan population, qualitative research, rural population.

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Introduction

Out-of-pocket expenses (OOPE) associated with cancer can result from direct (treatment and travel to treatment centres) and indirect (e.g. loss of income due to time taken off work) costs.¹ The magnitude of expenses varies across health systems, yet even citizens in countries with universal healthcare systems, such as Australia and Canada, can incur life-altering costs associated with their treatment.² The worst effects of financial stress are termed ‘financial toxicity’,^{3,4} which is measured through monetary (absolute costs accrued by the patient), objective (methods used to ease financial burden) and subjective (perceived financial burden) measures.²

Although some researchers and clinicians are attempting to incorporate price transparency into conversations with patients,^{5,6} the effects of cancer costs remain an issue of growing importance,^{7–10} and are a primary issue that Australian health consumers and cancer patient organisations have identified requiring further action.^{11–13} To support health services and policy makers to address their concerns, a model or framework underpinning the patient experiences in a public–private setting would contribute towards identifying areas to target and address. Carrera *et al.*¹⁴ have developed a model to describe the economic consequences of cancer treatment on patients and patient coping based on research undertaken in private health systems.

We are aware of one qualitative study that has explored this issue within Australia,^{15–19} and several others undertaken internationally.^{20–22} Due to the heterogeneity in patient cost experiences largely related to personal, financial and treatment-related factors,²³ further qualitative research would elaborate on cancer patient experiences in a public–private health system and contribute to developing a framework through which we can identify areas to improve patient cost experiences.

In this study we explored the complex narratives of cancer patients undergoing treatment and the impact of OOPE on their experience to gain an insight into their subjective and objective experiences of financial toxicity.

Methods

Context and setting

Most tertiary hospitals in Western Australia (WA) are located in the capital city, Perth. Some densely populated outer-metropolitan suburbs and large regional towns have hospitals

with specialised cancer units. Patients in rural and remote areas are exposed to larger non-medical expenses because they travel to and stay near treatment centres.^{24–27} Some medical treatments and pharmaceutical costs are covered by Medicare (the universal Australian health scheme), and all Australian residents have access to free treatment in hospitals that are publicly owned, or public–private partnerships.²⁸ Private health insurance (PHI) is available for Australians to opt into and provides varying levels of cover for access to private hospital and ancillary health services. Concession and healthcare cards are available to pensioners, social security recipients and people with low incomes to subsidise health service and medication costs.²⁹ Australians who are not eligible for a healthcare card are supported by a ‘safety net’, whereby they pay the same subsidised rates once a certain out-of-pocket threshold for out-of-hospital services and medication has been reached.^{30,31} Between 2014 and 2017, 46–47% of Australians had PHI coverage for hospital treatment, and 56% had PHI coverage for ancillary services.^{32,33} To reduce pressure on the public system, the Australian government incentivises PHI uptake through income taxation. An income-tested Medicare levy of 1–1.5% is incurred by taxpayers who do not have PHI coverage for hospital treatment. Furthermore, PHI holders earning below a threshold amount receive an income-tested PHI rebate, which is an amount that the government contributes towards the cost of their PHI premiums.²⁸ Financial assistance is available through the Patient Assistance Travel Scheme (PATS) to supplement travel costs for patients, provided strict eligibility criteria are met.³⁴ Additional financial support is available from non-governmental organisations (NGOs) such as the Cancer Council.

Study design, recruitment and participants

A purposive convenience sample of 40 rural and outer metropolitan participants who had participated in the Out-of-Pocket Expenses Study³⁵ participated in semistructured, in-depth interviews after treatment completion. The sample was chosen to obtain a diverse range of participants based on the cancer type, demographic, treatment and financial characteristics, as presented in Table 1. Participant recruitment via the WA Cancer Registry has been described elsewhere.³⁵

Of 559 participants who consented to the study, 339 (61%) consented to follow-up contact and 59 (11%) were contacted. Of the 59 participants contacted, 10 participants declined the

Table 1. Participant characteristics

Characteristic	No. participants (<i>n</i> = 40)
Age (years)	
<50	<5
51–65	12
≥66	24
Sex	
Male	22
Female	18
Cancer diagnosis	
Breast	11
Prostate	11
Lung	7
Colorectal	11
Employment status at diagnosis	
Full-time	14
Part-time	<5
Self-employed	5
Retired	14
Unemployed	5
Other	<5
Area of residence	
Rural	
South West	10
Great Southern	<5
Midwest	<5
Goldfields	<5
Outer metropolitan	
Peel	6
Joondalup	<5
Wanneroo	6
Rockingham	<5
Insurance status	
Medicare only	14
Hospital and ancillary extras cover	22
Hospital cover only	<5
Ancillary extras cover only	<5

interview request and nine were lost to follow-up. Forty participants consented to being interviewed. Ethics approval was obtained from the WA Country Health Service Ethics Committee (#2014:10) and the Department of Health WA Human Research Ethics Committee (#2014/26).

Data collection and analysis

Interviews were conducted by research assistants in 2016 and 2017. Training in the interview process was provided by an experienced member of the research team (CEJ). Prior to commencing interviews, the research assistants were familiarised with the interview guide (Table 2). Interviews were audio recorded and, on average, were 37 min long. Interviews were guided by seven broad questions designed to focus on the patient experience throughout diagnosis and treatment, with particular attention to the impacts of the costs of cancer diagnosis and treatment.

The interviews were transcribed verbatim by a third party, and were stored and managed in NVivo 11 (QSR International Pty Ltd, Melbourne, Vic., Australia). Data were analysed using a phenomenological approach, with emphasis on the subjective meaning of the participants' experiences. This approach was chosen due to the moderate body of research that has been undertaken thus far into

Table 2. Questions in the semi-structured interview guide

1. How has your cancer diagnosis and treatment affected you and your family?
2. How did you find navigating the health system for all the treatments you needed?
3. How have the costs associated with treatment affected you and your family?
4. What has been helpful and not helpful as you dealt with the health system?
5. How has the cost of the various treatments and tests affected your decisions about treatments and where you will have them?
6. Do you think out-of-pocket expenses are an important issue for rural people with cancer?
7. What do you think government and non-government organisations could do to help rural people with cancer cover out-of-pocket costs?

cancer patients' OOPE; hence, we did not want to constrain the analysis with preconceptions and potentially overlook important aspects of participants' experiences.³⁶

Transcripts were reviewed and a preliminary coding list was developed in NVivo through collaborative discussions and mutual agreement. Once established, thematic content analysis was undertaken by research assistants.³⁷ A cross-comparative approach across the raw data, codes and emerging themes facilitated confirmation and validation of the conclusions. Themes were audited by a team member (NSA) who did not participate in the content analysis to ensure they were congruent with the transcripts.

Results

Patient experiences of OOPE

Participants' experiences of OOPE fell into three broad themes that mediated their OOPE experiences: patient circumstances, communication and patient coping strategies.

All participants accrued medical and non-medical OOPE while accessing cancer care and treatment. Their experiences were affected by the size of the OOPE incurred, patient-specific circumstances and their ability to navigate the healthcare system. Representative quotes are presented in Table 3. Some participants had most or all treatment costs covered by Medicare and their PHI (42.5%). Four participants who had PHI discovered that the diagnostic tests or treatment they required were not covered by their insurance company. Nine participants (22.5%) noted the effect of 'incidental' expenses, such as products required for the management of side effects and complications (Table 3, Q2.1).

Four participants noted their OOPE were outweighed by the importance of regaining their health (Table 3, Q2.7 and Q2.8). Conversely, two participants found the cumulative costs for medications burdensome, and stopped seeking treatment to manage side effects and complications to alleviate their financial burden (Table 3, Q2.5 and Q2.6). Patient OOPE experiences were further ameliorated or exacerbated by patients' personal circumstances and communication with health providers, which, in turn, affected the strategies they used to deal with their OOPE.

Patient circumstances

Proximity to treatment locations and personal financial and employment situations were factors affecting participant experiences, as illustrated by representative quotes presented in Table 4.

Table 3. Western Australian cancer patients' experiences of out-of-pocket expenses during their diagnosis and treatment

Participant identifiers are coded: M = outer metropolitan; R = rural. PHI, private health insurance; Q, quote

Issue	Impact on participants	Quote ID	Representative quotes
Financial burden of treatment	Medical costs were covered by Medicare or PHI	Q2.1	Uh, treatment side of it was alright but when you're on a pension...so you only get \$300 a week anyway and if you're spending nearly \$100 on incidentals, you're down to \$200. (M-07)
		Q2.2	No, I had no out-of-pocket expenses. It was all covered by the health system and I was allocated a cancer care nurse who gave me a lot of support and that was at no extra cost too. (R-01)
	Insufficient coverage of medical costs by Medicare or PHI	Q2.3	And I have a cousin who went through the same bloke because he was covered with health insurance which we don't have, I mean this cost is \$24 000 and Medicare paid – we got \$2000 back for it. Y'know, I mean it's exorbitant. (M-09)
		Q2.4	Well, I couldn't afford private radiotherapy, not after private chemo so I had to come back into the public system. I could have had the whole lot publically. I was just concerned about the time frame. I needed to work – we're still paying off a mortgage. (R-02)
Perception of health-related costs	Financial burden outweighed symptom management	Q2.5	... I don't think I was fully aware of what the costs were going to be and for how long, because the ah, the medicines she gave me. I just couldn't afford, I just had to sort of take half of 'em, and, miss a couple of weeks...and sort of spin it out. (R-03)
		Q2.6	The doctor gives you a script and says go and try this one. And you find that it is causing you know more side effects too. So then what do you do? You spent the full rate on the medication and then you can't go back to the doctor and get another script for a different type of medication to try and see if it works or not. So the little things but it all adds up at the end of the day and you feel that it is better just to you know rough it out but then how long can you rough it out for? (M-11)
	Cost of good health outweighs financial burden	Q2.7	It was just the surprise of such a cost, yes. I would rather not have parted with \$10 000 but yeah alright so I've bought my life for \$10 000. (M-12)
		Q2.8	...if we had to go into massive debt, we would've to make sure that I had gotten the best possible treatment, treatment plan, people around me or, yeah. (R-18)

Proximity to treatment

Participants reported great variation in proximity and access to the services they required. Participants saw being able to easily access the treatment centre as a great benefit. Hospital parking fees were considered a big contributor to OOPE.

Some participants acknowledged the role of clinicians in minimising their travel by arranging for treatment close to participants' residences. Others felt the burden of travel was not taken into account in their diagnostic and treatment pathways (Table 4, Q3.2). Participants commented on the implications of travel for treatment on their employment situation, continuity of care and the complex effect on their need for social support. Participants also acknowledged the role of financial travel and accommodation assistance and support from NGOs.

The emotional and physical need for social support had a varied impact on participants' travel-related OOPE (Table 4). Several participants reported family and friends taking them to appointments, eliminating the need to use public transport, yet in other instances this increased OOPE as participants sought to repay family and friends. Rural participants staying in Perth needed to travel home to provide and receive emotional support from families, or their family members travelled to Perth, often exhausting their employment leave and increasing travel costs (Table 4, Q3,5).

Financial situation and employment

Table 4 demonstrates the range of experiences for participants with different employment situations. Fifty per cent of participants continued to work after their diagnosis. Working

participants discussed the ability to work during treatment as being beneficial for their quality of life, mental well-being and financial situation. Participants with supportive employers and/or sufficient leave were less affected by OOPE. Continuing to work contributed to staying on top of the additional OOPE and maintaining a sense of normalcy. This was contingent upon participants having a job that allowed flexible or reduced work hours and non-physically intensive duties.

Five participants (12.5%) lost their positions due to treatment and/or side effects. (Table 4, Q3.8 and Q3.9). Self-employed participants struggled with loss of income when attending or recovering from treatment (Table 4, Q3.12 and Q3.13). Some retired participants also had difficulties managing OOPE: although they had access to subsidies, the additional expenses were challenging to manage on their tight weekly budget. Retired participants with sufficient savings were less affected by OOPE.

Communication

Communication was a key factor in patients' ability to successfully access financial assistance, make an informed decision about their treatment and associated costs, use their PHI or attempt to minimise OOPE, as demonstrated by representative quotes in Table 5.

Clinicians and service providers did not always mention costs, public versus private treatment options or the financial aid available when discussing treatment options with participants (Table 5, Q4.1, Q4.2, Q4.6 and Q4.7). Conversely, other participants acknowledged transparency in the communication of costs involved or the aid available (Table 5, Q4.3 and Q4.4).

Table 4. Patient circumstances that affected out-of-pocket expenses (OOPE)

Participant identifiers are coded: M = outer metropolitan; R = rural. Q, quote

Patient circumstance	Impact on participants	Quote ID	Representative quotes
Proximity to treatment	Accessing treatment centre	Q3.1	Well public transport takes a little bit longer and sometimes when I was on chemo, I got a little bit paranoid I suppose about people coughing and sneezing on me and infections, so I liked to drive then when I was going down. (M-02)
		Q3.2	...so I'm going next week back to Perth... and I'm flying so it's costing me \$350, \$360 to fly because I can't drive myself, my husband can't get time off work, I'm not sitting on a bus for 10 hours because it's just too far. And then yeah, so I think I'm taking three days off work for one days' worth of appointment. So yeah, it's a bit of an expense but I am very lucky that I have full time work which means I have paid sick leave. (R-12)
	Consequences of distance from treatment centre	Q3.3	...I think that once that...sick feeling is over, then you want to be involved in your business still...but when you're away for sort of four to six weeks it's very difficult to continue running if you are your own business... you just gotta say, that's it, put my business on hold, for however, you know indefinite length of time, and hope that I can pick it up when I'm, you know, I'm ready. (R-03)
	Clinicians' consideration of patient location	Q3.4	...[My doctor] transferred me down to [Hospital 1] in [outer metropolitan suburb A] because I live in [outer metropolitan suburb B] which was only a quarter of an hour to go in and have my chemo instead of coming in and out to [Hospital 2] which was a good hour away and a train. So everything just went bloody smoothly. (M-04)
Social support	Impact of friends or family on patient OOPE	Q3.5	I did go back [home]... and see the kids and the grandkids and stuff like that... so they could see that I was doing really good, because a couple of my grandkids were quite upset about the whole process. It was good for them to see me doing so well. But the added expense of getting home was over \$500. (R-12)
		Q3.6	...if it hadn't of been for my mum and dad having a holiday house in [suburb], we would've been stuffed probably... and it would've been a really testing, horrible – or more horrible time. (R-18)
Financial situation and employment	Disruption to work	Q3.7	But in the country you haven't got that option [to work during treatment]. You go up and stay there until your time is up and then... you can do a few things like go and see people and walk around and that but you can't really do any work because you're too far away from it. (R-15)
	Loss of employment	Q3.8	I've got to change my lifestyle, I've got to change my work... I was a bar manager and I can't lift anything more than 5 kg or be on my legs for too long now... My worry now is getting back a job. (R-08)
		Q3.9	I was just a casual worker. I had the surgery and after three weeks I let them know that I was good again and I could come back into the office and they [tell] me that they had replaced me, that someone else would do the work now and I never heard back from them. (M-17)
		Q3.10	...I sort of thought that it was about time with my age that I should start cutting back on the sort of heavy lifting that I had been doing for about 45 odd years. I had thought that was a good reason to explore going more into the management side of what I had been doing. (R-14)
	Retired due to diagnosis	Q3.11	Far too tired to work. I looked at returning to work. And what happened is that I had some ups and downs in my treatment. I was able to be signed off for medical leave and now the long service leave started this week, and I will finish in [month], and I won't go back... I think now if I go back I don't think I'll be as good as what I was. (R-05)
	Affected self-employed	Q3.12	The worst part of it was... because that I'm, sole operator of my own business, and being off work means I'm not paid. So it was a straight loss of income. I had to put my business on hold. (R-03)
		Q3.13	... when you're self-employed, if you are relatively successful, and then it all stops, what do you do? I've got a business that just ticks along, but it's only minimal at the moment, only sort of covering expenses. (R-16)
	Worked through diagnosis	Q3.14	I carried on with my normal work, I carried on with my exercise and I did that so that it was as normal as possible for my son who is [a young teenager], and also for my husband and also for my own mental well-being. (M-05)
		Q3.15	...that wasn't such a problem because I went to work and left work early and had treatment on my way home. I tried to work when I had the chemo but... I just wasn't able – I wasn't well enough to go. (M-15)
	Sufficient leave	Q3.16	I had sick leave for all of that. I work for [company] and their attitude was 'get right, come back'. (R-10)

Table 5. Patient–provider communication that affected participant out-of-pocket expenses (OOPE)

Participant identifiers are coded: M = outer metropolitan; R = rural. Q, quote

Communication topic	Impact on participants	Quote ID	Representative quotes
Discussion of treatment-related OOPE	No discussion of treatment costs	Q4.1	...it was very quick and the cost wasn't mentioned at any stage... I didn't realise until after the operation, I found out then that it was going to cost \$10 000 and I thought, God well at least I've got the money. (M-12)
		Q4.2	To be honest I don't think there was ever a cost mentioned. (R-17)
	Patient initiated	Q4.3	I did ask about the radiotherapy if I had to pay and they said it was covered. I asked at the chemo, they said that was covered. The only thing I had to pay for were the visits to the oncologist. So yeah, I had a good run really. (R-06)
		Q4.4	No, I think each time I went to an appointment I was told up front how much it was going to cost and how much my Medicare rebate was going to be. I actually found that really quite helpful – so that I was prepared. (M-05)
	Patient reluctance to discuss OOPE	Q4.5	Yeah, those tests... and I didn't want to say anything to anyone referring me to these tests, to say 'do you know how much this costs?'. A CT scan can be around \$800, of which you get back – I don't know – \$350 or something... like that. So they just mount up. (M-20)
Discussions regarding treatment pathway and/or treatment planning	Limited discussion of public treatment pathway options	Q4.6	My doctor thought he was doing the right thing because I have private health he sent me to a private clinic to have [diagnostic imaging] done but when I got there I had to pay for everything they didn't do private health cover... my... doctor found me a good surgeon after finding out what had happened with the tests, he got a surgeon that would cover my cost of surgery for the health rebate and Medicare. So I didn't have any out of pocket expenses at all for my surgery. (R-11)
		Q4.7	The question after [the diagnosis] was 'are you privately insured by the way' and they want you to say yes... but they don't make any allowances to maybe if you want to have it done locally, and you don't have to go privately. I did discover after a little bit of work... I realised that [I could have my treatment in a public hospital]. And [after having treatment in a public hospital] I found that very good, I couldn't fault the hospital in any way. Everything was excellent. (R-05)

Some participants who experienced difficulty managing their OOPE expressed discomfort at discussing these issues with their doctors (Table 5, Q.5). A participant who chose to discuss unexpected private imaging fees with their general practitioner (GP) found that from that point onward their GP made every effort to minimise their OOPE (Table 5, Q4.6).

Coping strategies for OOPE

Coping with OOPE was reliant on patient financial circumstance and the financial support and assistance available. Participants with sufficient financial resources and/or employment with sufficient leave did not have concerns about OOPE. Coping strategies involved using savings, superannuation, obtaining a credit card to pay costs up front, using available subsidies and strict or maladaptive budgeting; representative quotes from participants are listed in Table 6.

Having to use savings or superannuation jeopardised nine participants' (22.5%) financial security (Table 6, Q5.4–Q5.6).

The cost of managing treatment side effects proved challenging for some participants. Alarming, one participant reported rationing their medication to tolerate the OOPE, whereas another did not use heating during winter to reduce their electricity bill and balance the household budget against their unexpected treatment costs (Table 6, Q5.8–Q5.10).

Many participants successfully accessed financial assistance such as the PATS scheme to recoup travel and accommodation costs. Some found the paperwork difficult to complete (Table 6,

Q5.13–Q5.15). For participants living week to week on low incomes, partial cover of travel expenses by PATS was useful, but sometimes left them in financially stressful positions (Table 6, Q5.14).

Discussion

The diverse range of experiences reported by participants in this study highlights inconsistencies in cost communication for treatments and financial assistance. Participants' experiences were similar to those reported previously in Australia's and Ireland's mixed private–public healthcare systems.^{16,22} In this study we built on published definitions and models of financial toxicity^{2,38} to develop a modified version of the Flowchart of Economic Consequences of Cancer Treatment on the Patient and Patient Coping developed by Carrera *et al.*¹⁴ to describe patient experiences in Australia's public–private healthcare system. Our model recognises the multitude of factors that influence the initial treatment-seeking behaviour in the mixed healthcare setting, where PHI is not a limiting factor for treatment-seeking behaviour. Instead, PHI affects the decisions that patients make regarding their treatment type, location and providers. This model can be used to identify areas of patients' needs and develop support and strategies to optimise care. It also serves as an impetus for health professionals and service providers in developing greater cost transparency.

This study and the growing body of cancer cost literature show OOPE had less of an effect on the patient experience than a

Table 6. Coping strategies employed by participants to cope with out-of-pocket expenses

Participant identifiers are coded: M = outer metropolitan; R = rural. NGOs, non-governmental organisations; PATS, Patient Assistance Travel Scheme; PHI, private health insurance; Q, quote

Coping strategy	Resource used	Quote ID	Representative quotes
No coping strategies necessary	Medicare or PHI	Q5.1	Cost-wise, it was negligible because it was all covered. I had the travel was partially paid for by the [travel] scheme down here, so there was some sort of contribution towards my driving and staying in Perth. (R-09)
	Sufficient financial resources	Q5.2	My husband and I both work full-time so we were very fortunate in that obviously we were able to cover those costs that we incurred that were out of pocket. (M-05)
		Q5.3	Well it didn't cost us anything to stay at [the free accommodation provided by the Cancer Council], you can stay there for free, and the treatments didn't cost us anything. (R-19)
Accessed extra financial resources	Used savings	Q5.4	Sometimes you needed to have enough money to finance the treatment so you could then get the money back, so like getting the port implanted was \$1000 up front and I got a lot of it back but you had to have the money to start with which I was in a position to have but maybe other people don't. (M-15)
	Used superannuation	Q5.5	... when I was initially diagnosed I used a portion of my superannuation to pay for all of that, that is thinning down at the moment so where do I go from here? I just don't know what the solution is. (M-11)
		Q5.6	My super pays my wages at the moment. (R-08)
	Used credit card	Q5.7	Yeah well we had to put it on the credit card and then try and pay it off afterwards sort of thing. (R-19)
		Q5.8	See Q2.5 and Q2.6 in Table 3 for representative quotes of maladaptive coping strategies
	Non-adherence	Rationed medication or ceased help-seeking behaviour	Q5.9
Restricted household spending		Q5.10	It is pretty cold at the moment but how do you pay your electricity bill or your gas bill? So we can't use it the same way that we used to use it before so we just have to have the cold. (M-11)
Accessed financial assistance	NGOs	Q5.12	They're [the Cancer Council] there 24/7. They're there if you want to talk, you can talk, you can go and have meetings with them. And they [the Cancer Council] did help out on, like, \$500... like with medication wise and that, which is really good. (R-08)
	PATS	Q5.13	It needs something done to it, because I know friends of mine who are the same as me – 'Oh, it's such a hassle, it's not worth the bother'. (M-19)
		Q5.14	Yeah. You went to the PATS... and they paid for so much. For fuel and stuff. You had to wait for that for about six weeks after and that... its fair dinkum for fuel but being on a pension it's a bit tough sometimes, if it's not pay week sort of thing it's a little bit tough, but otherwise you just sort of grin and bear it. (R-19)
		Q5.15	It might sound so stupid, but when you're having chemotherapy your brain is just mush. So like the PATS forms and stuff – it's so hard to know where to get them, where to send them, like who you've got to get to find them, all of that sort of stuff. You miss out, you miss out because it's too bloody hard. (R-18)

patient's personal financial situation, eligibility for support, experience within the healthcare system and health literacy, which can have devastating downstream ramifications for patients.^{12,13,23,39} This is reflected in Fig. 1. For example, participants with substantial savings reported less financial difficulties than pensioners without financial resources who had many, but not all, costs subsidised. Although some patients comfortably used savings and superannuation to pay for treatment, the financial sacrifice had a larger effect on others with extraneous debts or family circumstances. Future research into financial toxicity must couple monetary measures with objective and subjective measures to understand the effects of OOPE because current monetary measures, such as the concept of a financial catastrophe, which is defined as an individual spending more than 10% of their household income on care,⁴⁰ may not sufficiently account for participants' savings and disposable assets.

Participant experiences suggest inconsistent communication from health professionals regarding treatment costs and financial aid available. Because some participants felt uncomfortable

discussing treatment costs with their doctor, there is a need to destigmatise these conversations given their potential for reducing patient OOPE. In light of evidence that some clinicians use age, healthcare card status and PHI as proxies for income and charge presumed high-income patients more for appointments,⁴¹ routine assessment of financial needs throughout the patients' cancer journey would contribute to an objective referral system for financial support. The importance of such a practice is demonstrated by the experience of one participant, who only learned of the total cost of their treatment, which was around A\$10 000, after their surgery (Table 3, Q2.7). An adaption of the 'Ask, Advise, Refer' approach and financial transparency guidelines have been developed for health professionals and service providers to tackle the issue of information asymmetry, using the concept of informed financial consent to convey the gravity and associated responsibility of informing patients of costs associated with their care.^{13,42} In addition, recommendations from the Actuaries Institute suggest the development of simple trauma insurance to provide financial

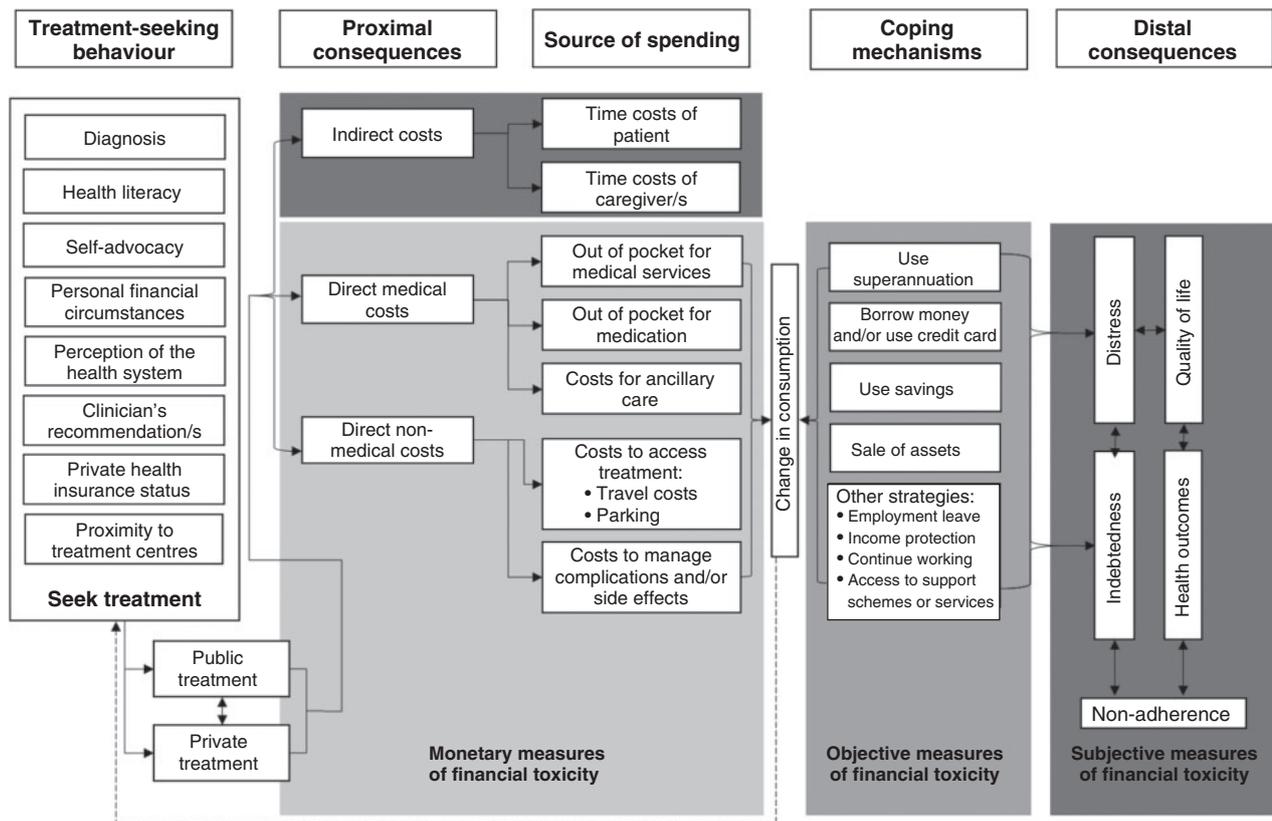


Fig. 1. Flowchart of economic consequences of cancer treatment on the patient and patient coping in a mixed public–private health care setting, adapted from Carrera *et al.*¹⁴ Upon receiving a cancer diagnosis, a patients' decision to seek treatment in the public or private setting is influenced by a wide range of personal and financial factors. The resultant costs associated with accessing treatment and managing side effects impose an unexpected financial burden that must be met. Without sufficient financial resources or assistance available, patients may need to use maladaptive coping mechanisms in order to meet these costs, which can have negative and potentially lifestyle-changing implications.

relief following a cancer diagnosis.⁴³ Beyond financial compensation and equipping patients to make informed healthcare decisions, the gaps in Australia's current fee-for-service model for some diagnostic tests, and in a landscape of rapidly emerging new and costly technology, deserve greater investigation to identify the best way to balance the costs borne by providers and participants in the delivery and receipt of health care.

The variability in patient awareness and utilisation of financial assistance further highlight the need for systematically integrating cost conversations into patient consultations. Financial assistance schemes could be reviewed to ensure they are equitably distributed and accessible for those who need it. Previous research undertaken in WA suggested that older patients were at risk of disadvantaged access to services and support.⁴⁴

The findings of the present study are consistent with the literature, which indicates that employed cancer patients are at a greater risk of financial toxicity and face employment-related challenges that require further attention and support.^{23,45} Strict eligibility criteria for financial assistance prevented several participants who became unemployed as a result of their diagnosis from accessing assistance, despite their drastic changes in circumstances and income. Given that these participants acknowledged the importance of working for their mental and financial well-being, financial support for self-employed

workers who fall ill should be considered. In addition, the adherence to fair work practices for casual employees who fall sick deserves further exploration based on these findings.

Surprisingly, the differences between rural and outer-metropolitan participants did not result in significant differences in the themes that arose; hence, it is not a focus of this paper. Due to the establishment of cancer treatment services in outer-metropolitan and rural settings, many participants undergoing chemotherapy and/or routine surgery did not have to travel great distances to receive all necessary care following their diagnosis. The effects of these rural services have recently been explored by Birch *et al.*,⁴⁶ who found that distance and the associated financial burden were important factors for rural cancer patients in accessing the most proximal care. We did note that outer-metropolitan participants more commonly discussed parking costs, whereas rural participants were more affected by accommodation issues (or lack thereof, when they successfully accessed subsidised accommodation provided by NGOs). More rural participants noted the disruption to their work that travel for appointments and treatment caused; however, most had sufficient leave to account for this. As discussed previously, those working in physically demanding roles (regardless of rurality) struggled the most with being unable to work, and eventually needing to change roles.

Ongoing treatment-related complications were common to many participants. These are particularly concerning as they decreased patients' and their families' standard of living and, as we found, resulted in maladaptive coping strategies that can have devastating implications on quality of life and clinical consequences. This highlights the importance of financial support mechanisms and subsidies for ongoing costs to maintain quality of life and alleviate financial distress. This issue is only addressed through the Medicare and Pharmaceutical Benefits Scheme safety nets in Australia, in which participants who do not qualify for concessions need to spend a certain amount before being eligible for concessions for some medications and services. The size of this problem needs further investigation to develop appropriate interventions.

Study strengths and limitations

We used a purposive sampling strategy to ensure a diverse range of participants was represented in the data, but this may have led to researcher bias based on our selective criteria. Although we focused on characteristics that would affect patient costs (Table 1) and took findings from similar studies into consideration, there may be other factors influencing patient costs not accounted for in this patient sample, such as socioeconomic status, marital status, social support available, home ownership status and disposable household income. In addition, lung cancer patients were underrepresented in the interviews, because some patients had become progressively sicker and many had passed away. Further research focusing on these cancer patient populations could add greater depth to the adapted model. Finally, patient validation was not used to confirm the themes extracted from the data. Instead, we relied on methods such as researcher triangulation and peer debriefing throughout the analysis to verify the themes identified.

Conclusion

OOPE affected all participants in various ways mediated by a complex range of personal, systemic and financial factors. Given the growing body of evidence highlighting the downstream effects of cancer costs, action is necessary to address the financial strain and distress caused by cancer costs. Health providers need to be more forthcoming with information about treatment costs and the financial support available to avoid unintentionally putting patients in financially compromising positions. Financial assistance schemes need to be reviewed to ensure they are equitably delivered and accessible for cancer patients who need assistance. Further research into cancer care pathways and cost communication interventions is warranted to identify potential interventions or models of care that can reduce the financial burden for cancer patients.

Competing interests

The authors declare no competing interests.

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