The impact of loss of income and medicine costs on the financial burden for cancer patients in Australia

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Background The cost of medicines may prove prohibitive for some cancer patients, potentially reducing the ability of a health system to fully deliver best practice care.

Objective To identify nonuse or nonpurchase of cancer-related medicines due to cost, and to describe the perceived financial burden of such medicines and associated patient characteristics.

Methods A cross-sectional pen-and-paper questionnaire was completed by oncology outpatients at 2 hospitals in Australia; 1 in regional New South Wales and 1 in metropolitan Victoria.

Results Almost 1 in 10 study participants had used over-the-counter medicines rather than prescribed medicines for cancer and obtained some but not all of the medicines prescribed in relation to their cancer. 63% of the sample reported some level of financial burden associated with obtaining these medicines, with 34% reporting a moderate or heavy financial burden. 11.8% reported using alternatives to prescribed medicines. People reporting reduced income after being diagnosed with cancer had almost 4 times the odds (OR, 3.73; 95% CI, 1.1-12.1) of reporting a heavy or extreme financial burden associated with prescribed medicines for cancer.

Limitations Study response rate, narrow survey population, self-reported survey used.

Conclusion This study identifies that a number of cancer patients, especially those with a reduced income after their diagnosis, experience financial burden associated with the purchase of medicines and that some go as far as to not use or to not purchase medicines. It seems likely that limiting the cost of medicines for cancer may improve patient ability to fully participate in the intended treatment.

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n Australia in 2014, cancer accounted for about 3 of every 10 deaths and the risk of dying from Lancer before the age of 75 years was 1 in 9 for males and 1 in 13 for females.1 Optimising access to cancer care is important to improve equity and ensure optimal health outcomes. In 2001, the Institute of Medicine defined high-quality care as being safe, effective, timely, efficient, equitable, and patient centred.² Yet when cost becomes a barrier to access, cancer patients are denied treatment with effective therapies.3 Cost has a close alignment with equity because treatment and treatment-related costs have the potential to exclude those who cannot afford to pay, typically having a disproportionate impact on those with fewer available financial resources.

The cost of cancer care has been rising, largely

owing to the increased use and cost of chemotherapy.3 In addition, patient care continues to move toward outpatient services and long-term health maintenance.4 This can mean that patients incur more out-of-pocket expenses for services such as medicines, travel, and accommodation associated with day clinic appointments, mobility aids, and caregiver costs.4 These costs were previously provided by the state health system as part of inpatient services.

In Australia, the cost of medications listed on the Pharmaceutical Benefits Scheme (PBS) is usually shared between patients and the health system. Cost sharing is a policy lever that is used to expose patients to a "price signal" to contain costs.5 Patients contribute to the cost of their medications through PBS copayments, brand premiums, and

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therapeutic group premiums.^{3,5} The PBS is designed to improve equitable access to medicines; it has a progressive cost-sharing system whereby those with limited financial resources (concession patients) pay a lower copayment than that paid by general patients. Affordability is further protected by the operation of a safety net.⁶ Despite these protections, copayments in Australia are high by international standards.⁵

The entire cost of prescriptions for non-PBS listed prescription medications and over-the-counter (OTC) medicines is usually the responsibility of the patient. The increased need for supportive OTC medications (such as mouthwashes, skin creams, and supplementary nutrition) to help manage the side-effects of cancer treatment,7 and the substantial associated costs could have an impact on the degree to which people fully access health care. In 2009, the Australian Bureau of Statistics (ABS) reported that 9% of adult Australians reported delaying or not filling prescriptions because of cost.8 A recent study of disadvantaged Australians found almost half (47%) of the sample reported delayed or nonuse of medicines as a result of cost.9 The cost of cancer medicines may prove prohibitive for some patients, which could reduce the ability of a health system to fully deliver best practice care.

Patient medication adherence affects cancer treatment effectiveness and treatment response. 10-14 Nonuse of prescribed cancer medicines is also associated with increased physician visits, higher rates of hospitalisation, longer average length of time spent in hospital for cancer patients 12,15,16 and higher health service costs. 15,17 In Australia, little is known about the proportion of cancer patients who do not take prescribed or recommended medications as a result of cost-related factors. The importance of this issue is reflected in the position statements of cancer advocacy groups. 18,19

The affordability of medicines for cancer patients and survivors can be affected by pre-diagnosis sociodemographic factors, but is also likely to be affected by the impacts of the disease or treatment on an individual's employment status and financial situation. Data from Ireland⁷ and the United States²⁰ have highlighted this issue, finding a significant reduction in income for cancer patients and survivors. Internationally, cancer reduces employment rates by 27% on average.⁴ Similarly, in Australia, having cancer reduces the probability of employment by 29% in men and 24% in women.⁴

Despite initiatives designed to assist patients in defraying cancer costs, there remains the possibility that some patients with limited financial resources – either before their diagnosis or as a result of having cancer – may find prescription medicines unobtainable due to cost. A clearer understanding would inform the policy discussion on how to minimise the barriers for cancer patients' access to potentially life-saving medicines.

The aims of the study were to identify the proportion of patients who did not use or did not purchase cancer-related medicines due to cost; the degree to which prescribed medicines for cancer were considered a financial burden; and patient-related factors (sociodemographic characteristics, disease, treatment characteristics, and recruitment location) associated with nonuse of medicines or perceived financial burden.

Method

Human research ethics approval was obtained from the University of Newcastle Human Research Ethics Committee, NSW Population & Health Services Research Ethics Committee, and Melbourne Health Human Research Ethics Committee.

A cross-sectional self-report survey was completed by outpatients attending for treatment or appointments at Australian oncology clinics. To represent a range of patient experiences relating to geographic location, patient volume and models of service delivery the study involved 2 metropolitan hospitals; 1 in a regional New South Wales city, and 1 in a Victorian capital city. Data were collected during January-July 2014.

Adults with a confirmed diagnosis of cancer and at least one previous clinic appointment were invited by a trained research assistant to complete the 30-minute pen-and-paper core questionnaire when presenting for an outpatient medical oncology consultation. Patients who did not speak English, were physically or mentally incapable of completing the questionnaire, or unable to provide informed consent were not eligible for the study. The age and gender of nonconsenters were collected to assess consent bias. Consenting participants were mailed a follow-up questionnaire, which contained the medicine affordability items 4 weeks after completion of the core questionnaire. If no response was received, then reminder letters were sent at 3 and 6 weeks later.

Measure

Demographic characteristics (core questionnaire). Age, gender, education, marital status, country of birth, employment status, private health insurance status, having a concession card, smoking status (Table 1). In Australia, holding private health insurance is an indicator of higher socioeconomic status and the likelihood of using private health services, which incur an out of pocket cost. Having a concession card is an indicator of low income.

Disease and treatment characteristics (core questionnaire). Cancer type, time since diagnosis, current treatment, and treatment location.

Medicine affordability (follow-up questionnaire). A subset of items from previous studies were used to assess medicine affordability (Table 2).⁵ Participants were asked:

Over the past 3 months, have you used any medicines including prescription and over-the-counter medicines?

Answer options Yes/No

- Over the past 3 months, because of costs, have you:
 - Bought over-the-counter-medicines rather than get prescription medicine from your doctor?
 - Asked your doctor or pharmacist for a cheaper generic version of a prescribed medicine?
 - Used medicines you have had at home rather than obtain a new prescription?
 - Used a medicine belonging to someone else rather than obtain a new prescription

Answer options Item response categories distinguished between cancer-specific (Yes, for my cancer treatment or recovery) and noncancer specific medications (Yes, but not for my cancer treatment or recovery).

Over the past 3 months, has a doctor, specialist, or nurse practitioner prescribed medication for you?

Answer options Yes, and the prescription related to my cancer treatment or recovery; Yes, but the prescription was not related to my cancer treatment or recovery; or No. If the response was Yes, then they were asked: Did you: Obtain all medicines prescribed; Obtain some but not all; or None of the prescribed

 How much of a financial burden were the prescribed medicines for your household?

Answer options No burden/slight burden; moderate burden; heavy burden; or extreme burden.

The follow-up questionnaire also assessed change in income since cancer diagnosis.

 Demographic characte 	eristics of the study sample ^a		
Characteristic	No. of respondents (%) (N = 255)	Characteristic	No. of respondents (N = 255)
cruitment location		Concession card ^b	
Centre 1 (regional city)	129/255 (50.6)	Yes	165/251 (65.7)
Centre 2 (capital city)	126/255 (49.4)	No	86/251 (34.3)
ender		Smoker	
Male	101/253 (39.9)	Current	24/250 (9.6)
Female	152/253 (60.1)	Former	115/250 (46)
ge at diagnosis, y		Never smoked	111/250 (44.4)
<60	77/250 (30.8)	Cancer type	
60 or older	173/250 (69.2)	Breast	94/204 (46.1)
lationship		Colorectal	51/204 (25)
Married/living with	158/251 (62.9)	All others	59/204 (28.9)
partner	93/251 (37.1)	Diagnosis time	
Single/divorced/ separated/widowed		≤12 months ago	113/252 (44.8
ucation		>12 months ago	139/252 (55.2
High school or less	122/251 (48.6)	Chemotherapy	
University, vocational	129/251 (50.6)	Yes	177/252 (70.2)
or other		No	75/252 (29.8)
ountry of birth		Reason for visit	
Australia	180/252 (71.4)	To discuss treatment	23/244 (9.4)
All others	72/252 (28.6)	To receive treatment	32/244 (13.1)
nployment Full-time	42/051/0511	Checkup during treatment	83/244 (34.0)
ruii-time Part-time	63/251 (25.1) 42/251 (16.8)	Checkup after treatment	95/244 (38.9)
Not employed	145/251 (58.0)	Other	11/244 (4.5)
ealth insurance		Fortnightly income, AUD ^c	
Yes	75/251 (29.9)	Mean (SD)	1834.10 (1130.8
No	176/251 (70.1)	Median (min; max)	1550.00 (346; 800

AUD, Australian dollars

oSome numbers do not add up to the total (255) owing to missing values. Having a concession card is an indicator of being on a low income. Fortnightly income before diagnosis; those who were employed before diagnosis (n = 86).

Analysis

Descriptive statistics (frequencies, proportions, and 95% confidence intervals [CIs]) were calculated for all survey items. Chi-squared or Fisher exact tests were used to explore associations between participant characteristics (sociodemographic characteristics, disease, treatment characteristics, and recruitment location) and each outcome. Participant characteristics with an association of P < .1 were included in a multivariate logistic regression model for each outcome. Location of recruitment (centre 1 vs centre 2) was included in multiple logistic regressions.

Results

Of the 402 patients who were approached to complete the core questionnaire at the 2 sites, 321 (79.9%) completed the core survey and 255 (63.4%) completed the follow-up questionnaire that contained the medicine affordability items. A higher proportion of women consented to completing the affordability items (Fisher exact P = .0205), compared with nonconsenters, and no difference in age was observed between the 2 groups (exact P = .8250). There were no differences in age or gender between those who completed the core survey and those who completed the affordability items in the follow-up survey (exact P = .05). The demographic and disease characteristics of the participants are listed in Table 1.

Nonuse or nonpurchase of cancer-related medicines due to cost

In all, 90.8% (227/250; 95% CI, 87.2-94.4) of participants who completed the follow-up questionnaire had used a prescription or OTC medicine in the previous 3 months. As shown in Table 2, as a result of cost, in the previous 3 months: 9.1% (19/209) had used OTC medicines rather than prescribed medicines for cancer, 17.3% (36/208) had asked for cheaper or generic versions of medicines for cancer, and 3.8% (8/209) had used existing medicine rather than obtain a new prescription for cancer. In addition, 11.8% (25/211) reported at least 1 of the following regarding cancer-related medicines: using OTC rather than prescribed medicine, using medicines they had at home rather than filling a new prescription, or using medicines from someone else.

Of the 255 participants, 119 (46.7%; 95% CI, 40.5-52.8) had medicines prescribed for them solely in relation to their cancer, and another 29 (11.4%; 95% CI, 7.4-15.3) had been prescribed both cancer-related and noncancer-related medicines. For cancer-related prescriptions, 132 of 146 participants (90.4%; 95% CI, 85.6-95.2) reported they had obtained all the prescribed medicines, and 14 of 146 (9.6%;, 95% CI, 4.8-14.4) reported obtaining some but not all of the medicines prescribed. Responses for cancer-related versus noncancer-related medicines seemed to follow a similar pattern, with the

TABLE 2 Respondents who did not use or did not purchase medicines (cancer-related or noncancer-related) because of their costs

No of respondents^a

204/210 (97.1% [94.9,99.4])

	Question, response options	(% [95% CI])
	Bought over-the-counter medicines r from your doctor?	ather than get prescription medicine
	Yes, for cancer	19/209 (9.1 [5.2,13.0])
	Yes, not for cancer	29/209 (13.9 [9.2,18.6])
	No	157/209 (75.1 [69.2,81.0])
	Not sure	4/209 (1.9 [0.0,3.8])
	Asked your doctor or pharmacist fo prescribed medicine?	r a cheaper generic version of a
	Yes, for cancer	36/208 (17.3% [12.1,22.5])
	Yes, not for cancer	56/208 (26.9% [20.9,33.0])
	No	115/208 (55.3% [48.5,62.1])
	Not sure	1/208 (0.5% [0.0,1.4])
	Used medicines you have had at he prescription?	ome rather than obtain a new
	Yes, for cancer	8/209 (3.8% [1.2,6.5])
	Yes, not for cancer	7/209 (3.4% [0.9,5.8])
	No	194/209 (92.8% [89.3,96.4])
	Used a medicine belonging to some prescription	eone else rather than obtain a new
	Yes, for cancer	3/210 (1.4% [0.0,3.1])
	Yes, not for cancer	3/210 (1.4% [0.00,3.1])

At least 1 of: over-the-counter rather than prescription, meds from home rather than prescription, or meds from someone else rather than prescription.

Yes, for cancer	25/211 (11.8% [7.5, 16.2])
No, or not for cancer	186/211 (88.2% [83.8, 92.6])

^aSome numbers do not add up to the total due to missing values.

Νo

exception that asking for a cheaper generic version of the medicine was less likely for cancer-related prescriptions than for other prescriptions.

Financial burden associated with prescribed medicines for cancer

Participant responses to questions about whether the prescribed medicines were a burden for their household are listed in Table 3. A minority of the participants (52/140, 37.1%) indicated that cancer-related prescriptions were not a burden xxat all, whereas 11.4% (16/140) indicated the cancer-related prescriptions were a heavy or extreme financial burden.

Patient characteristics associated with nonuse of medicines or perceived financial burden

Univariate and multivariate analyses indicated that none

TABLE 3 How much of a financial burden were the prescribed medicines for your household?

Type of prescription	Level of burden	No. of respondents (% [95% CI])
	No burden	86/206 (41.8 [35.0,48.5])
	Slight	61/206 (29.6 [23.3,35.9])
All (n = 206)	Moderate	41/206 (19.9 [14.4,25.4])
	Heavy	16/206 (7.8 [4.1,11.5])
	Extreme	2/206 (1.0 [0.0,2.3])
	No burden	52/140 (37.1 [29.0,45.3])
_	Slight	41/140 (29.3 [21.7,36.9])
Cancer- related (n = 140)	Moderate	31/140 (22.1 [15.2,29.1])
(Heavy	15/140 (10.7 [5.5,15.9])
	Extreme	1/140 (0.7 [0.0,2.1])
	No burden	43/93 46.2 [35.9,56.6])
	Slight	26/93 (28.0 [18.7,37.3])
Noncancer- related (n = 93)	Moderate	16/93 (17.2 [9.4,25.0])
(11 = 70)	Heavy	7/93 (7.5 [2.1,13.0])
	Extreme	1/93 (1.1 [0.0,3.2])

of the patient sociodemographic or disease characteristics examined were associated with reporting any form of nonuse or nonpurchase of prescribed medicines for cancer.

Responses to the level of perceived burden associated with prescribed medicines for cancer care were grouped into No/Slight Burden compared with Moderate/Heavy/ Extreme Burden. Univariate analyses indicated that age, smoking, and reduced income after diagnosis may have been related to reported burden. A multiple logistic regression analysis indicated that a having a reduced income after being diagnosed with cancer was associated with reporting a heavy or extreme financial burden due to prescribed medicines for cancer (OR, 3.73; 95% CI, 1.1-12.1; Table 4).

Discussion

This study indicated that a small to moderate proportion of patients reported nonuse of medicines that were prescribed as part of their cancer care or recovery. The majority

TABLE 4 Factors associated with perceived heavy financial burden **Adjusted** Variable Odds (95% CI) P value .0789 Age, y <60 2.40 (0.90, 6.36) 60 or older Reference Smoker .4020 Current Reference Former 0.61 (0.15, 2.52) Never smoked 0.40 (0.10, 1.59) .0289 Reduction in income after cancer diagnosis 3.73 (1.14, 12.13) No or not sure Reference

reported that such medicines constituted a financial burden, particularly for those who had a reduced income after their cancer diagnosis.

Nonuse or underuse of prescribed medicines was reported by fewer than 10% of participants, compared with 3.4% of a general community sample that reported not filling all prescriptions because of cost. Internationally, reports of medicine underuse because of cost in the general population vary from 3% in the Netherlands to 20% in the United States.²¹ Unaffordable medicines may represent a significant loss of health status and wellbeing (eg, through ineffective management of pain or nausea) for the cancer patient or survivor. Nonadherence to prescribed cancer medications may also impinge on the investment already made in the diagnosis and treatment of an individual, resulting in higher downstream costs for both the patient and health provider.

It is worrying that 33.6% of the participants reported experiencing a moderate, heavy, or extreme financial burden in the 3 months prior to completing the survey because of the cost of their prescribed medicines for cancer treatment or recovery. It is of particular concern that those whose income had been reduced after being diagnosed with cancer had almost 4 times the odds of reporting a heavy/extreme financial burden associated with prescribed medicines for cancer. The combination of reduced income and increased medication costs may have particularly serious consequences for some patients. The change in financial situation may occur quite suddenly with little or no opportunity for financial adjustment to new circumstances. Therefore, a change in employment status should constitute a "red flag" to trigger assistance with treatment adherence. Metrics for a change in employment status or reported financial burden may need to be part of a process to prioritise access to financial assistance, even for patients who were reasonably well off before their diagnosis. Studies

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in the general population have also documented the relationship between financial stress and anxiety.⁹

This study, at the very least, identifies that the nonuse of prescribed medications as a result of cost or financial burden is having an impact on access to prescribed cancer care, which in turn highlights potential issues with the implementation of 2 objectives of Australia's National Medicines Policy.²² The 2 goals listed in the policy are that patients should have "timely access to the medicines that Australians need, at a cost individuals and the community can afford" and that there be "quality use of medicines." These findings suggest that for some, the goal of affordable medicines for individuals is not being met. Similarly, our survey's evidence of nonadherence to prescribed cancer medications suggests some patients, because of cost, are not meeting the goal of quality use of medicines. Greater efforts to limit the costs of prescribed medicines in cancer care - particularly for those on reduced incomes – may reduce the hardship experienced by cancer patients and improve their ability to fully participate in their intended treatment.

Limitations

The study response rate (55%), the choice of medical oncology outpatient clinics as a recruitment location and the use of only 2 hospital sites places limitations on the generalisability of the data to the wider population of cancer patients. Self-reported behaviour may also be subject to a small to moderate level of inaccuracy in the study context. There may also be a potential lack of sensitivity

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in the response categories for some variables such as time since diagnosis, and age group which may have hindered the ability of the study to identify associations between participant characteristics and the financial impacts of interest to the study. This lack of sensitivity extends to not including percentage of net income or disposable income spent on medicines as a measure, thus the financial burden from the cost of medicines cannot be quantified in this study. The lack of detail about which medicines were underused (such as whether they were chemotherapies or supportive medicines) and to what degree is also a study limitation.

Conclusion

This study provides some of the first Australian data regarding the financial impact of medicine costs on cancer patients and survivors. Greater efforts to limit the costs of prescribed medicines in relation to cancer care – particularly for those on reduced incomes - may reduce the financial hardship experienced by cancer patients.

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