


Suboptimal experiences with out-of-pocket costs, financial disclosure, and support information among people treated for cancer

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The direct and indirect costs of cancer care are rising and can influence treatment decisions and outcomes for patients.¹ Several patient-level characteristics are risk factors for financial burden, including lower age, chemotherapy, and poorer general health.² Health professionals have a role in providing information, resources, and support to mitigate financial distress for patients.³

We investigated patient experiences of costs, financial disclosure, and support information during cancer care in an analysis of data collected for the 2019 Cancer Patient Experiences Survey, commissioned by the Victorian Department of Health.⁴ All Victorian public hospitals identified people aged 16 years or more who had received cancer care (including monitoring) during the 2018 calendar year and supplied their contact details to a specialist survey administrator. The survey administrator mailed each person eligible for the study a survey with a cover letter stating that the survey was being conducted by the Victorian Department of Health. Respondents who spoke English could complete an electronic or paper version of the survey; people who preferred a language other than English (information provided by the hospitals) completed a professionally translated paper version. The survey items were based on the United Kingdom National Cancer Patient Experience Survey,⁵ a literature review,

and information from patient and health professional focus groups and interviews.⁴ The survey was pilot tested at nine health services.⁴

In this article, we report on responses to nine items about medical bills, costs information, and the provision of information about financial support programs and services. As in other studies,^{4,5} responses were coded as binary variables; ie, optimal (eg, “Yes, I was fully informed”) or suboptimal experiences (eg, “Yes, I was informed of some costs”; “No, I was not informed of the costs”); responses indicating no need for support or information were excluded from analysis (Supporting Information, table 1). Our analyses included self-reported characteristics — gender, age group (under 60, 60–69, 70 or more years), general health (excellent, very good, good, fair, poor), cancer type, public or private care — as well as socioeconomic status (Index of Relative Socioeconomic Advantage and Disadvantage)⁶ and accessibility/remoteness based on residential postcode.⁷ Associations between characteristics and responses were assessed in multivariable logistic regression models adjusted for all other characteristics. No adjustment was made for multiple testing. The study was approved by the Peter MacCallum Cancer Centre human research ethics committee (HREC/76910/PMCC).

Suboptimal experiences with out-of-pocket costs, financial disclosure, or support information reported by 4181 respondents to 2019 Cancer Patient Experiences Survey (Victoria): summary of results*

Experience	Cancer type treated							
	All	Colorectal	Breast	Prostate	Blood	Lung	Melanoma	Other
Had some bills to pay								
Surgery	22%	20%	21%	26%	25%	16%	18%	24%
Radiotherapy	14%	11%	12%	17%	11%	11%	22%	16%
Chemotherapy	27%	39%	26%	21%	30%	21%	16%	26%
Not told about costs beforehand								
Surgery	42%	53%	45%	31%	38%	44%	46%	38%
Radiotherapy	36%	28%	21%	53%	32%	47%	17%	43%
Chemotherapy	50%	46%	48%	35%	54%	43%	50%	52%
Health professionals did not provide information								
Financial support programs	40%	50%	35%	38%	34%	38%	37%	45%
Financial planning services	55%	66%	47%	54%	52%	54%	62%	61%
Accessing superannuation, income protection	54%	68%	52%	43%	51%	46%	69%	60%

* The raw data for this table and the results of the multivariable analyses for each of the nine outcomes (experiences) are reported in the Supporting Information, tables 3 to 6. ♦

Of 10 662 mailed surveys, 4998 were returned (47%); the responses from the 4181 respondents who had received anti-cancer treatment (84% of all respondents), including 2128 women (51%), were included in our analysis (Supporting Information, table 2). The overall proportions of people who reported out-of-pocket costs were 22% for surgery, 14% for radiotherapy, and 27% for chemotherapy. In multivariate analyses, the likelihood of reporting out-of-pocket costs was greater for people under 60 years of age than for older people who underwent surgery or chemotherapy, and for those who underwent surgery or radiotherapy as private rather than public hospital patients (Box; Supporting Information, tables 3 to 5).

The proportions of people with out-of-pocket costs who were not fully informed about these costs in advance were 42% for surgery, 36% for radiotherapy, and 50% for chemotherapy (Box). In multivariate analyses, the likelihood of not being informed about radiotherapy costs was lower for people over 70 years of age than for those under 60 (Supporting Information, tables 3–5).

Overall, 40% of respondents reported not being informed about financial support programs, 54% about accessing superannuation or income support, and 55% about financial planning services (Box). In multivariate analyses, people with fair or poor general health (self-rated), living in major cities or in areas of middle or high socio-economic status, or treated as private patients, and women more frequently reported not being informed in one or more of these areas than people in comparator groups for these categories (Supporting Information, table 6).

Significant proportions of Australians treated for cancer reported suboptimal experiences with regard to out-of-pocket costs, prior financial disclosure, and information provided by health care professionals about available financial support. Our findings are consistent with those of other studies of the financial burden for people treated for cancer.² Our finding that higher socio-economic status was linked with greater frequency of some suboptimal experiences is probably attributable to greater access to and higher costs associated with private care. People need more preparatory information and support when making decisions about medical care. Health care policy and clinical practice should support more consistent financial disclosure and support.

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Supporting Information

Additional Supporting Information is included with the online version of this article.