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ORIGINAL ARTICLE

Responses by breast and prostate cancer patients to out-of-pocket costs in Newfoundland and Labrador

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ABSTRACT

Purpose

Cancer patients face substantial care-related out-of-pocket (OOP) costs that may influence treatment decisions, attitudes, and use of drug- or appointment-related cost-saving strategies. We examined the relationship between OOP costs and care-related responses by patients.

Methods

We surveyed 170 prostate and 131 breast cancer patients presenting at clinics or support groups, or listed on the cancer registry in Newfoundland and Labrador.

Results

In the 3-month period before the survey, 18.8% of prostate and 25.2% of breast cancer patients had OOP costs greater than $500. Those OOP costs consumed more than 7.5% of quarterly household income for 15.9% of prostate and 19.1% of breast cancer patients. Few patients (8.8% prostate, 15.3% breast) ever adopted any drug- or appointment-related cost-saving strategy. Few patients (7.2% prostate, 9.6% breast) said OOP costs influenced treatment decisions, told their physicians about their OOP costs (27.0% prostate, 21.1% breast), or were aware of available financial assistance programs (27.3% prostate, 36.9% breast). Compared with patients having low or moderate OOP costs (22.9% prostate, 16.7% breast, and 25.7% prostate, 58.3% breast respectively), a larger proportion of prostate (56.0%) and breast (58.3%) cancer patients with high OOP costs said that those costs created stress. Among prostate cancer patients, a larger proportion of those having high OOP costs (compared with low or moderate costs) used drug-related (22.2% vs. 3.3% and 9.6% respectively) and appointment-related (11.1% vs. 1.1% and 3.8% respectively) cost-saving strategies, said OOP costs created an unusual amount of stress (48.0% vs. 18.4% and 10.4%), and had difficulty paying those costs (29.2% vs. 6.2% and 10.4%).

Conclusions

For a small group of breast and prostate cancer patients, OOP costs are high, but rarely lead to the use of care-related cost-saving strategies or influence care decisions.

KEY WORDS

Out-of-pocket costs, financial barriers, patient responses

1. INTRODUCTION

Several groups of researchers in Canada have examined the out-of-pocket (OOP) costs associated with cancer care. Those groups have found that OOP costs are a substantial financial burden for a small proportion of patients[1–5].

Longo *et al.*[1] noted that, of cancer patients surveyed in Ontario, 20.4% reported that OOP costs for cancer care created a significant or unmanageable financial burden. Those authors examined costs related to travel, lodging, and meals (for the patient and companion); drugs and supplies (including prostheses and wigs); and lost wages, if applicable.

Some authors have also suggested that, in addition to a negative emotional and psychological impact, OOP costs may influence care-related decisions made by patients[6–14]. For example, researchers in Canada have suggested that high OOP costs may have discouraged rural, low-income, and insurance-deprived patients from pursuing certain forms of treatment such as breast-conserving surgery[10–14]. Using qualitative interviews with cancer care providers, researchers in Newfoundland and Labrador (hereinafter Newfoundland) suggested that patients may adopt care-compromising strategies (such as skipping appointments or rationing drugs) and that providers may change treatments to ease the financial burden for patients[8]. Despite such reports, we were unable to find Canadian studies that directly examined the association between OOP costs and cost-related responses by patients.

The objective of the present study was to examine the relationship between OOP costs and care-related cost-saving behaviours and attitudes. Despite their public medical insurance program ("Medicare"), Canadians continue to face financial barriers to health care. The present study aimed to provide evidence of the impact of OOP costs on the care of cancer patients. It also set out to provide information that may help to improve the availability, responsiveness, and use of financial assistance programs.

2. METHODS

The Human Investigations Committee of Memorial University approved this study (HIC reference 07.37). Using a self-administered written questionnaire, prostate and breast cancer patients in Newfoundland were surveyed during 2008–2009. Surveys were distributed at all regional cancer clinics, support groups, and retreats across the province. Surveys were also mailed to individuals identified through the provincial cancer registry. Each survey package contained a letter outlining the project, a questionnaire, and a prepaid return envelope. To calculate response rates, the total number of surveys distributed and returned was tracked.

To be included in the study, respondents had to be 19 years of age or older, residents of Newfoundland, and diagnosed with breast or prostate cancer. Only female breast cancer patients were included in the study. We further limited the analysis to patients who were being treated for their first cancer diagnosis, who were not being treated for any other cancer, and who were not enrolled in a clinical trial, because the foregoing criteria might influence OOP costs for the patients.

The survey included questions on sociodemographic characteristics, cancer diagnosis, treatment regimen, quality of life, OOP costs, use of care-related cost-saving strategies, and attitudes and beliefs about the impact of OOP costs and assistance programs. Survey questions were developed based on a review of the literature; previous surveys of cancer patients in Newfoundland; and consultation with prostate and breast cancer patients, support group organizers, cancer care providers, researchers, and representatives from the Newfoundland and Labrador Division of the Canadian Cancer Society. The surveys were in English, had been written at a grade eight reading level, and had been pre-tested by eight individuals (former cancer patients, cancer advocates, and researchers). Changes in wording and format—but not content—were made as a result of the pre-test.

To gather information on costs, patients were asked to indicate the amount of OOP money spent (described as "costs not covered by insurance or assistance programs") in relation to treatment for their cancer in the 1-month and 3-month periods preceding the survey. We asked patients to indicate the amount spent on drugs (prescription, over-the-counter, complementary and alternative medicines), and supplies (bandages, incontinence supplies, wigs, sleeves, and so on). We also inquired about travel (gasoline, bus and air tickets, meals, lodging) for themselves and for anyone who accompanied them. Lastly, we gathered information on costs related to communication (for example, costs for long-distance telephone calls to family) and to child or elder care. Our study focused on quarterly costs. We considered both dollar value and the proportion of income consumed by OOP costs for cancer care.

The survey asked respondents to indicate annual household income. This survey question was based on questions included in the 2007 Canadian Community Health Survey[15]. To limit missing data, we used the median income of the respondent's community if the income question was not answered. If the respondent did not name a community of residence, their postal code was used to identify their community through the Canada Post Web site (http://www.canadapost.ca/cpotools/apps/fpc/personal/findByCity?execution=e1s1). Once a community was determined, the median annual income was retrieved from the Government of Newfoundland and Labrador Community Accounts Web site (http://nl.communityaccounts.ca/). The dollar value of OOP costs was analyzed in three category groups: \$0, \$0.01–\$499.99, and \$500.00+. These category cut-offs were based on frequencies. Similar categories were used to analyze the proportion of income consumed by out-of-pocket costs: 0%, 0.01%–7.49%, and ≥7.5%. Those categories corresponded to program eligibility cut-offs used by the provincial drug insurance subsidy program[16].

To gather data on care-related responses to OOP costs by patients, we asked respondents to use a 5-point Likert scale to rate how frequently they used a variety of drug- and appointment-related cost-saving strategies (Table I). Because of the very small number of respondents indicating that they had ever used any of the strategies, we re-coded the responses to those questions into two main variables: "used any drug-related cost-saving strategy" and "used any appointment-related cost saving strategy." Each variable was coded "yes" if respondents indicated any use of the individual drug- or appointment-related items (that is, they answered "not very often," "some of the time," "most of the time," or "all of the time") and "no" if they answered "never" for all of the individual drug- or appointment-related items.

TABLE I List of items suggested as drug- and appointment-related strategies

Drug-related cost-saving strategies included *ever* doing *any* of the following:

- Spread out a medication over a longer period of time to make it last longer.
- Replaced the medication prescribed by the doctor with another, cheaper one.
- Skipped one or more doses of medication to save on costs.
- Bought only what the patient thought was the most important medication.
- Not filled a prescription because of the cost.
- Delayed filling a prescription because of the cost.
- Asked the doctor for free samples of a drug.

Appointment-related cost-saving strategies included *ever* doing *any* of the following:

- Spread out the time between visits to the doctor for follow-up.
- Missed or cancelled an appointment with the cancer clinic to save money.
- Missed or cancelled a scheduled cancer treatment to save money.

Using a 5-point Likert scale, we also asked patients how strongly they agreed with a series of statements related to the impact of OOP costs, knowledge by their physicians of those costs, stress caused by the costs, and awareness of assistance programs. Because responses were heavily skewed, we recoded each item as "disagree" ("strongly disagree" or "disagree") or "agree" ("neither agree or disagree", "agree," or "strongly agree"). The "neither agree or disagree" response was included with the "agree" category to produce the most conservative results.

The SPSS data entry software was used to enter the questionnaire responses into a database, and the data were analyzed using the SPSS software (version 19: IBM, Armonk, NY, U.S.A.). Data entry errors were identified using frequencies and cross-tabulations. Wherever possible, we consulted the original survey to correct responses. To assess the representativeness of the sample, we used chi-square tests to compare age (less than or greater than 65 years) and community of residence (urban or rural) of respondents with data provided by the provincial cancer registry (used to mail the surveys).

We used frequencies to describe the characteristics of our sample and to summarize OOP costs, income consumed by OOP costs, and responses to OOP costs. We used chi-square tests to examine differences in the responses to OOP costs relative to the proportion of income consumed by those costs. Where significant differences were found, additional *post hoc* chi-square tests were used to identify the specific groups that differed.

3. RESULTS

Of 761 prostate cancer surveys and 544 breast cancer surveys distributed, 202 prostate cancer and 161 breast cancer surveys were returned, for response rates of 26.5% and 29.6% respectively. We excluded 32 prostate cancer surveys (14 respondents had a previous cancer diagnosis; 4 were receiving treatment for another cancer; 8 were in a clinical trial; 5 did not report income, community, or postal code; and 1 was not a resident of Newfoundland) for a final sample of 170 prostate cancer patients. We excluded 30 breast cancer surveys (16 had a previous cancer diagnosis, 9 were receiving treatment for another cancer, 4 were in a clinical trial, and 1 did not report income or community) for a final sample of 131 breast cancer patients. The sample was representative of community of residence (urban or rural) for prostate and breast cancer patients in Newfoundland (data not shown). The sample was also representative of age for prostate cancer patients, but breast cancer patients less than 65 years of age were overrepresented (sample 70%, population 58.8%).

Most prostate cancer patients were more than 65 years of age, lived in a rural community, were partnered, were retired, had less than $50,000 in annual household income, had private insurance, had been diagnosed with cancer 1 year earlier or less, and had incurred no OOP costs in the preceding 3 months (Table II). Almost 1 in 5 prostate cancer patients (18.8%) spent more than $500 OOP for care-related costs, which, for 15.9% of prostate cancer patients, accounted for more than 7.5% of quarterly income.

Most breast cancer patients were younger than 65 years, lived in a rural community, were partnered, were retired, had less than $50,000 in annual household income, had private insurance, and had been diagnosed 1 year earlier or less. More than one quarter of breast cancer patients (25.2%) spent more than $500 OOP for care-related costs, which, for 19.1% of breast cancer patients, was more than 7.5% of their quarterly income.

A detailed breakdown of OOP costs shows a wide person-to-person range within each cost category (Table III). On average, for prostate and breast cancer patients incurring moderate costs ($0.01–$499.99) and for breast cancer patients incurring high costs ($500+), the costs of drugs and supplies and travel comprised roughly equivalent proportions of total costs. However, travel costs comprised a larger proportion of average costs for prostate cancer with high costs ($500+). We observed no significant relationship between costs and current treatment type for either prostate or breast cancer patients.

Few prostate cancer patients used any drug- (8.2%) or appointment-related (3.5%) cost-saving strategy or agreed (7.2%) that OOP costs influenced their treatment decisions (Table IV). More than one quarter of prostate cancer patients (27.0%) agreed

TABLE II Characteristics of prostate and breast cancer patients in the sample

Characteristic	*Cancer site* [n *(%)]*	
	Prostate[a]	*Breast*[b]
Patients	170	131
Age		
<65 Years	66 (38.8)	91 (70.0)
≥65 Years	104 (61.2)	39 (30.0)
Community type		
Urban (≥10,000)	78 (45.9)	48 (36.9)
Rural (<10,000)	92 (54.1)	82 (63.1)
Marital status		
Un-partnered	20 (12.1)	26 (19.8)
Partnered	145 (87.9)	105 (80.2)
Employment status		
Full-time/self-employed	18 (10.7)	22 (16.8)
Part-time/semi-retired	14 (8.3)	11 (8.4)
Seasonal/sick leave/ unemployed/other	14 (8.3)	51 (38.9)
Retired	123 (72.8)	47 (35.9)
Education		
Less than high school	56 (33.7)	37 (29.1)
Completed high school	34 (20.5)	26 (20.5)
Some postsecondary	24 (14.5)	22 (17.3)
Completed postsecondary	30 (18.1)	29 (22.8)
Graduate/professional degree	22 (13.3)	13 (10.2)
Income		
<$19,999	24 (14.1)	13 (9.9)
$20,000–$29,999	38 (22.4)	31 (23.7)
$30,000–$39,999	33 (19.4)	28 (21.4)
$40,000–$49,999	25 (14.7)	19 (14.5)
$50,000–$59,999	19 (11.2)	12 (9.2)
$60,000–$69,999	10 (5.9)	10 (7.6)
≥$70,000	21 (12.4)	18 (13.7)
Have private insurance		
Yes	104 (64.6)	92 (70.2)
No	57 (35.4)	39 (29.8)
Time since diagnosis		
0–6 Months	32 (19.2)	41 (31.3)
7–12 Months	58 (34.7)	45 (34.4)
13–24 Months	39 (23.4)	25 (19.1)
24+ Months	38 (22.8)	20 (15.3)
OOP cost[c]		
$0	91 (53.5)	50 (38.2)
$0.01–$499.99	47 (27.6)	48 (36.6)
$500+	32 (18.8)	33 (25.2)
Income consumed by OOP costs[c]		
0%	91 (53.5)	51 (38.9)
0.01%–7.49%	52 (30.6)	55 (42.0)
≥7.50%	27 (15.9)	25 (19.1)

[a] Group answers may add to less than 170 because of missing data.
[b] Group answers may add to less than 131 because of missing data.
[c] In the preceding 3 months.
OOP = out-of-pocket.

that their doctor was aware of their costs, but only 13.3% agreed that their doctor took OOP costs into account when prescribing drugs. Although OOP costs created a lot of stress for 27.3% of prostate cancer patients and were more stressful than other things for 21.3%, only 12.5% agreed that they had trouble paying the costs. Just more than one quarter of prostate cancer patients (27.3%) were aware of available financial assistance programs, and only 12.9% agreed that the programs were well advertised. A larger proportion of prostate cancer patients with high OOP costs (≥7.50% of income) than of those with lower or no OOP costs used drug- and appointment-related cost-saving strategies, agreed that costs created a lot of stress (and more stress than other things), and had trouble paying the costs.

Among women with breast cancer, 14.5% and 4.6% respectively used a drug- or appointment-related strategy, and 9.6% agreed that OOP costs influenced their treatment decisions (Table V). Roughly 1 in 5 breast cancer patients (21.1%) agreed that their doctor was aware of their costs, and 13.8% agreed that their doctor took OOP costs into account when prescribing drugs. More than one third of breast cancer patients (34.2%) agreed that OOP costs created a lot of stress; 22.2% agreed that OOP costs created more stress than other things. About 1 in 10 women (10.1%) agreed that they had trouble paying OOP costs. More than one third of breast cancer patients (36.9%) were aware of financial assistance programs, but few (4.6%) agreed that the programs were well advertised. A larger proportion of breast cancer patients with high costs (≥7.50% of income) than of patients with lower or no OOP costs agreed that the costs created a lot of stress.

4. DISCUSSION

Although a large proportion of prostate and breast cancer patients reported incurring no OOP costs in the 3 months preceding our survey, a small proportion of patients reported high OOP costs (7.5% or more of their income). Those findings are consistent with previous studies of OOP costs for cancer patients in Newfoundland[5], in Ontario[1–3], and in Quebec[5]. Understanding the actual dollar value of OOP costs is important, but determining the proportion of income consumed by such costs provides a better understanding of the financial burden of cancer to individuals[9] and facilitates comparisons between jurisdictions.

We found that many patients had no or low OOP costs—a finding that may be related to informal financial assistance programs available to patients such as "compassionate release" of drugs through the local ambulatory-care cancer clinic[17–19]. In such programs, drug companies may provide drugs at reduced or no cost to patients in need. In Newfoundland, the program is informally run, with requests made by health care providers in the cancer clinic[19]. Formal programs include public and private insurance

TABLE III Detailed breakdown of out-of-pocket costs for prostate and breast cancer patients

Out-of-pocket cost type	*Cancer site and out-of-pocket cost level*			
	Prostate		*Breast*	
	$0.01–$499.99 (n=47)	*$500+ (n=32)*	*$0.01–$499.99 (n=48)*	*$500+ (n=33)*
Drugs and supplies				
Mean	76.66	247.19	99.73	1,163.58
Median	21.00	42.50	54.05	500.50
Standard deviation	118.64	402.21	114.60	2,148.78
Range	475.75	1,500.00	465.00	10,000.00
Travel				
Mean	89.30	1,199.86	102.73	1,138.46
Median	42.00	923.00	60.00	596.00
Standard deviation	114.47	1,357.61	102.15	1,496.15
Range	455.00	6,872.00	484.00	5,735.00
Other costs				
Mean	11.91	540.63	19.92	179.83
Median	0	0	0	0
Standard deviation	60.13	2,200.71	39.38	582.33
Range	400.00	12,000.00	180.00	2,700.00
Total				
Mean	177.87	1,987.68	168.09	2,122.53
Median	132.00	1,440.00	115.50	1,000.00
Standard deviation	145.17	2,318.30	1,489.23	29,995.82
Range	468.76	12,105.00	480.00	13,073.00

plans and subsidy programs, and programs offered by charitable organizations, including subsidies for travel and lodging, drug cost-sharing programs, and financial grants. Cancer care providers play a key role in raising the awareness of and enabling access to such programs[20].

In our study, roughly 1 in 4 patients agreed that their doctor was aware of their OOP costs, and fewer than 1 in 7 agreed that the doctor took costs into account when prescribing drugs for them. Those findings concur with results in U.S. studies, in which authors found that only 15%–16% of patients discussed drug-related OOP costs with their physicians[21,22] and that only one third of physicians discussed drug costs with their patients[21]. Without knowledge of the financial concerns of their patients, care providers may not refer patients to assistance programs.

It is important to note that we asked only about physicians in our study. Many other health professionals might potentially be involved in the care of cancer patients and assessment of their financial concerns. Physicians may learn about financial concerns through a variety of sources (direct discussion, screening tools, discussion with other care providers, and so on). Nonetheless, fewer than 40% of the patients in our study were aware of financial assistance programs, and few (12.9% of prostate cancer and 4.6% of breast cancer patients) believed that the programs were well advertised. Those findings highlight the need to educate patients about resources available to them to reduce the financial burden related to cancer care.

Very few patients in our study reported ever using cost-saving strategies or suggested that OOP costs affected decisions about their care. The slightly higher rate reported for the use of drug-related compared with appointment-related cost-saving strategies may be a result of drug-related strategies being "less conspicuous" to health care providers, given that the providers might be less likely to know about or to notice a missed pill than a missed appointment. Moreover, patients may believe that some treatment (for example, rationing or substituting drugs) is better than no treatment (that is, missing an appointment).

Studies in the United States have reported higher rates of cost-saving strategies. For example, Piette *et al.*[22] found that, overall, 18% of patients surveyed reported using some form of drug-coping strategy or "underuse" of medication at least once in the preceding year. They also found that 14% of all respondents underused medication at least once per month during

TABLE IV Responses of prostate cancer patients to costs incurred, according to proportion of income consumed by out-of pocket (OOP) costs

Question	*OOP cost level [n (%)]*				p *Value*[b]
	Overall	*0%*	*0.01%–7.49%*	*≥7.50%*	
Use any drug-related strategy					
No	156 (91.8)	88 (96.7)	47 (90.4)	21 (77.8)	0.007[c]
Yes	14 (8.2)	3 (3.3)	5 (9.6)	6 (22.2)	
Use any appointment-related strategy					
No	164 (96.5)	90 (98.9)	50 (96.2)	24 (88.9)	0.046[c]
Yes	6 (3.5)	1 (1.1)	2 (3.8)	3 (11.1)	
OOP costs influenced treatment decisions					
Disagree	116 (92.8)	49 (94.2)	47 (95.9)	20 (83.3)	0.129
Agree	9 (7.2)	3 (5.8)	2 (4.1)	4 (16.7)	
Doctor aware of my OOP costs					
Disagree	84 (73.0)	32 (68.1)	38 (32.6)	14 (63.6)	0.156
Agree	31 (27.0)	15 (31.9)	8 (17.4)	8 (37.4)	
Doctor takes costs into account					
Disagree	99 (86.8)	36 (80.0)	44 (93.6)	19 (86.4)	0.154
Agree	15 (13.2)	9 (20.0)	3 (6.4)	3 (13.6)	
Cancer costs create a lot of stress					
Disagree	88 (72.7)	37 (77.1)	40 (83.3)	11 (44.0)	0.001[d]
Agree	33 (27.3)	11 (22.9)	8 (16.7)	14 (56.0)	
Cancer costs more stressful than other things					
Disagree	96 (78.7)	40 (81.6)	43 (89.6)	13 (52.0)	0.001[d]
Agree	26 (21.3)	9 (18.4)	5 (10.4)	12 (48.0)	
Trouble paying for my cancer costs					
Disagree	105 (87.5)	45 (93.8)	43 (89.6)	17 (70.8)	0.018[d]
Agree	15 (12.5)	3 (6.2)	5 (10.4)	7 (29.2)	
Aware of assistance programs					
Disagree	88 (72.7)	36 (70.6)	38 (79.2)	14 (63.6)	0.361
Agree	33 (27.3)	15 (29.4)	10 (20.8)	8 (36.4)	
Assistance programs well advertised					
Disagree	115 (87.1)	8 (13.3)	6 (12.8)	3 (12.0)	0.986
Agree	17 (12.9)	52 (86.7)	41 (86.7)	22 (88.0)	

[a] Item responses may add to less than 170 because of missing data.
[b] Based on chi-square tests comparing the three levels of costs.
[c] Post hoc tests show significant differences between the 0% and ≥7.50% groups, but no other differences.
[d] Post hoc tests show significant differences between the ≥7.50% group and the 0% and 0.01%–7.49% groups, but no other differences.

the preceding year. However, that study included patients with chronic conditions such as diabetes and hypertension. We hypothesize that patients may be less willing to compromise cancer-related care than care for other chronic conditions. Further research is needed to test that hypothesis.

We observed only a limited association between costs and use of any care-related cost-saving strategy. Although researchers in a qualitative study suggested that patients use care-related cost-saving strategies to curb OOP costs in cancer[8], we found that the use of such strategies is generally rare among prostate and breast cancer patients. Prostate and breast cancer patients with high OOP costs equally agreed that the costs created stress, but only prostate cancer patients with high costs agreed that the stress was greater for those costs than for other things in their life and that they had trouble paying the costs. These differences between prostate and breast cancer patients may be attributable to the larger proportion of prostate cancer patients who were older and retired (and likely on a fixed income). Men may also be the person in the household responsible for finances and more acutely aware of the burden created by OOP costs. The overrepresentation of younger women (less than 65 years of age) in the sample may underestimate the impact of high OOP costs in our sample of breast cancer patients.

TABLE V Responses of breast cancer patients to costs incurred, according to the proportion of income consumed by out-of pocket (OOP) costs

Item	*OOP cost group [n (%)]*				*p Value*[b]
	Overall[a]	*0%*	*0.01%–7.49%*	*≥7.50%*	
Use any drug-related strategy					
No	112 (85.5)	47 (92.2)	46 (83.6)	19 (76.0)	0.150
Yes	19 (14.5)	4 (7.8)	9 (16.4)	6 (24.0)	
Use any appointment-related strategy					
No	125 (95.4)	50 (98.0)	53 (96.4)	22 (88.0)	0.131
Yes	6 (4.6)	1 (2.0)	2 (3.6)	3 (12.0)	
OOP costs influenced treatment decisions					
Disagree	103 (90.4)	34 (89.5)	49 (94.2)	20 (83.3)	0.319
Agree	11 (9.6)	4 (10.5)	3 (5.8)	4 (16.7)	
Doctor aware of my OOP costs					
Disagree	86 (78.9)	24 (70.6)	46 (88.5)	16 (69.6)	0.065
Agree	23 (21.1)	10 (29.4)	6 (11.5)	7 (30.4)	
Doctor takes costs into account					
Disagree	94 (86.2)	25 (75.8)	47 (90.4)	22 (91.7)	0.111
Agree	15 (13.8)	8 (24.2)	5 (9.6)	2 (8.3)	
Cancer costs create a lot of stress					
Disagree	73 (65.8)	26 (74.3)	37 (71.2)	10 (41.7)	0.018[c]
Agree	38 (34.2)	9 (25.7)	15 (28.8)	14 (58.3)	
Cancer costs more stressful than other things					
Disagree	84 (77.8)	26 (81.3)	43 (82.7)	15 (62.5)	0.123
Agree	24 (22.2)	6 (18.8)	9 (17.3)	9 (37.5)	
Trouble paying for my cancer costs					
Disagree	98 (89.9)	30 (88.2)	48 (94.1)	20 (83.3)	0.326
Agree	77 (10.1)	4 (11.8)	3 (5.9)	4 (16.7)	
Aware of assistance programs					
Disagree	67 (63.2)	18 (52.9)	33 (66.0)	16 (72.7)	0.277
Agree	39 (36.8)	16 (47.1)	17 (34.0)	6 (27.3)	
Assistance programs well advertised					
Disagree	106 (94.6)	11 (27.5)	16 (30.8)	5 (20.0)	0.611
Agree	6 (5.4)	29 (72.5)	36 (69.2)	20 (80.0)	

[a] Item responses may add to less than 131 because of missing data.

[b] Based on chi-square tests comparing the three levels of costs.

[c] Post hoc tests show significant differences between the ≥7.50% group and the 0% and 0.01%–7.49% groups, but no other differences.

4.1 Limitations

Given the very small number of respondents with high costs, our study may not have sufficient power to detect significant differences. Our sample size also limited our ability to conduct multivariate analyses. Moreover, we conducted multiple comparisons, thereby increasing the likelihood that some of the differences found are attributable to chance. We are also unable to report on cancer stage, because a large number of responses were missing or unusable (for example, "tumour only," "not too bad").

Our study examined just two groups of patients in a single province. We considered only patients who had not previously been diagnosed with cancer and who were receiving care for only one type of cancer. More research is needed to examine patients with other cancers or multiple cancers, and those residing in other provinces.

5. CONCLUSIONS

A large proportion of prostate and breast cancer patients in Newfoundland incurred no or few OOP costs, but a small proportion incurred substantial costs (in excess of $500 or 7.5% of household income over the preceding quarter). High OOP costs rarely led to the use of care-related cost-saving strategies or influenced decisions about care. The amount of OOP costs and patient responses to those costs varied by cancer type. Although high OOP costs created stress for prostate and breast cancer patients alike, those costs were significantly associated with the use of drug- and appointment-related cost-saving strategies and unusual stress (more than other things), and were associated with payment difficulties for prostate cancer patients only. Despite the concerns of patients regarding OOP costs, relatively few told their physicians about those costs or were aware of available financial assistance programs. Those findings suggest that there is a need to educate patients about subsidy programs and to promote discussions between patients and health care providers about care-related costs.

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7. CONFLICT OF INTEREST DISCLOSURES

The authors declare that no financial conflict of interest exists.

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