

How important are out-of-pocket costs to rural patients' cancer care decisions?

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Objective: We examined the importance of 5 items (stage of illness, personal feelings, travel costs, drug costs and child care costs) in the cancer treatment decisions of urban and rural residents after they had started treatment for their cancer.
Methods: We surveyed 484 adults who presented for care at cancer clinics in Newfoundland and Labrador from September 2002 to June 2003. Respondents rated the importance of each of the 5 items in their cancer care decisions on a 5-point Likert scale, which was later collapsed into 2 categories, "important" and "not important." We used χ^2 tests and multiple logistic regression to compare the responses of urban and rural residents.
Results: In our sample of 484 respondents, there were 258 (53.3%) urban and 226 (46.7%) rural residents. After controlling for other significant predictors, we found that rural residents were more likely to report that travel costs (odds ratio [OR] 1.79, 95% confidence interval [CI] 1.21–2.63), drug costs (OR 1.69, 95% CI 1.13–2.23) and child care costs (OR 2.33, 95% CI 1.09–4.96) were "important" in cancer treatment decisions compared with urban residents. Stage of disease and personal feelings were equally important to urban and rural residents.
Conclusion: Financial impediments disproportionately affect rural residents' decisions about cancer care and highlight the need to ensure that centralized specialist care, such as cancer treatment, is accessible.

Objectif : Nous avons étudié l'importance de cinq éléments (stade de la maladie, sentiments personnels, frais de déplacement, coûts des médicaments et frais de garde d'enfants) dans les décisions relatives au traitement du cancer chez des résidents de la ville et de la campagne après le début de leur traitement.
Méthodes : Nous avons interrogé 484 adultes traités dans des cliniques d'oncologie de Terre-Neuve-et-Labrador entre septembre 2002 et juin 2008. À l'aide d'une échelle de Likert en cinq points, les répondants ont évalué l'importance qu'ils accordaient à chacun de ces cinq éléments lors de prises de décision concernant leur traitement pour le cancer; l'échelle a ensuite été scindée en deux catégories plus larges, soit «important» et «non important». Nous avons utilisé le test du 2 et une analyse de régression logistique multiple pour comparer les réponses entre résidents des milieux urbains et ruraux.
Résultats : Dans notre échantillon de 484 répondants, 258 sujets (53,3 %) vivaient à la ville et 226 (46,7 %) vivaient à la campagne. Après contrôle pour tenir compte d'autres prédicteurs importants, les résidents d'un milieu rural étaient plus susceptibles de mentionner que les frais de déplacement (rapport des cotes [RC] 1,79; intervalle de confiance [IC] à 95 %, 1,21–2,63), le coût des médicaments (RC 1,69; IC à 95 %, 1,13–2,23) et les frais de garde d'enfants (RC 2,33; IC à 95 %, 1,09–4,96) étaient «importants» lors de leurs prises de décision relatives à leur traitement contre le cancer, comparativement aux résidents de milieux urbains. Le stade de la maladie et les sentiments personnels ont revêtu la même importance pour les résidents des milieux urbains et ruraux.
Conclusion : Les contraintes financières affectent de manière disproportionnée les résidents des régions rurales lors de prises de décision relatives au traitement du cancer et rappellent la nécessité d'assurer l'accès aux soins spécialisés centralisés, par exemple dans le cas des traitements pour le cancer.

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INTRODUCTION

The treatment of complex diseases such as cancer requires highly specialized professionals, equipment and services. For example, in Newfoundland and Labrador, the bulk of cancer services is centralized in St. John's, the provincial capital where, in 2007, 183 469 (36.2%) of the province's 506 275 population lived.[1] St. John's has the sole radiotherapy facility in the province and is home to all the province's oncologists. However, 42.2% (213 370) of the province's population lives in rural communities.[2] Some chemotherapy and follow-up may be offered in a number of the regional centres in the province (e.g., Corner Brook, Gander, Grand Falls–Windsor and Burin).

Although centralization of resources such as radiotherapy facilities is necessary to ensure cost-effective, high-quality care,[3–6] rural residents must travel and incur travel-related costs to receive needed services. This is in addition to the psychological impacts of leaving home for cancer treatment.[7,8] Roughly 9% of all cancer patients (19.5% of rural patients), had more than $1000 in travel-related costs for a single trip to access cancer care.[9]

With the increasing shift from hospital-based to ambulatory care, patients may also have to incur the costs of drugs provided outside a hospital setting. Although Canada's universal public health insurance covers the costs of all medically necessary drugs provided in-hospital, prescription medications provided outside a hospital setting are not covered. For cancer patients, these may include new oral chemotherapy agents that can be administered at home or supportive drugs given to combat the side effects of treatment (e.g., antiemetic or pain medications). Public drug insurance plans exist in all provinces but are not universal; they are usually available to individuals with very low incomes or who are 65 years of age and older.

Although out-of-pocket travel and drug expenses may be cost-shared through private (supplementary) health insurance, it is usually offered as a benefit for full-time employees.[10,11] Rural residents are more likely to be in seasonal or self-employed industries (e.g., agriculture or fishery) and may not be eligible for group health plans. Although private insurance is also available to individuals, it is usually at higher premiums than employee-based group plans. As a result, larger proportions of rural residents may not purchase supplementary health insurance and therefore have fewer resources with which to pay for care-related costs.

A number of studies have suggested that the treatment choices of rural residents may be related to out-of-pocket travel and drug costs.[6,12–19] However, we were unable to find studies that quantified the influence that these costs have on rural residents in a publicly insured health care system. In this study, we examine the importance of out-of-pocket costs and other factors in the treatment decisions of adults who are seeking care for breast, lung, prostate or colorectal cancer. We hypothesize that, compared with urban residents, cost-related factors play a greater role in the decisions of rural residents.

METHODS

Sample

We surveyed adult cancer patients (who had decided to have cancer care) presenting for an appointment at the 4 cancer centres in the province from September 2002 to June 2003. To be eligible for inclusion in the study, individuals had to be residents of Newfoundland and Labrador; able to communicate in English; 19 years of age or older; and seeking treatment or follow-up for breast, lung, colorectal or prostate cancer. These cancers were selected for study because they are the most common cancer types in the province and represent the majority of new cancers each year. For example, in 2007 these 4 cancers made up 60.8% of all estimated new cases in the province.[20]

To comply with ethics guidelines, participants were initially approached by either clinic registration or nursing staff, and informed about the study. Willing participants were referred to a research assistant sitting in the waiting area who screened individuals for eligibility, obtained consent and conducted the survey.

Survey

The survey instrument included questions to assess eligibility, clinical and sociodemographic characteristics, home community and care-associated costs. Respondents were also asked to rate the importance of 5 items on their decisions "about the treatment for [their] cancer" on a 5-point Likert scale, in which 1 was "not at all important" and 5 was "very important." These items were stage of illness, personal feelings (e.g., fear, anxiety), travel costs, drug costs and child care costs. These items were identified through a review of the literature and consultations with cancer care providers, cancer patients

and representatives from the provincial division of the Canadian Cancer Society. As a largely descriptive and exploratory study, given the wide range of patients surveyed (i.e., 4 different types of cancers, patients at different treatment and follow-up phases), we did not specify types of decisions. We conducted extensive pretesting with patients and cancer care providers to ensure the reliability of the questions.

Analysis

We analyzed data using SPSS software, version 14.0 (SPSS, Inc.). The dependent variables of interest in this analysis were the importance of each of the 5 items in decision-making. The 5-point Likert scale ratings for each of the items were collapsed into 2 categories ("not important" and "important"). Responses 1–3 were coded as "not important" and 4–5 were coded as "important."

The independent variable was home community, which was coded as "urban" or "rural." Rural communities had populations of less than 10 000 based on estimates from the Newfoundland and Labrador Statistics Agency[21] and were at least 1 hour (or 80 km) away from the clinic where the patient had sought care.[22] Clinical and sociodemographic characteristics were included as covariates in the analysis.

Frequencies were used to describe the characteristics of the study sample and χ^2 tests were used to detect differences between urban and rural residents in each of the 5 outcomes and covariates (shown in tables). For each outcome, significant variables from the χ^2 analyses (not shown in tables) were included in a multiple logistic regression. The final regression model included only significant predictors. Collinearity between predictor variables was examined a priori and large standard error values, indicative of multicollinearity, were not found in the regression models.

We received ethics approval from the Human Investigations Committee of Memorial University of Newfoundland and the Newfoundland Cancer Treatment and Research Foundation Research Management Committee for this study.

RESULTS

We interviewed 484 cancer patients between September 2002 and June 2003. These patients represented 96.2% of the 503 patients who were willing to participate in the study. Three patients were ineligible (1 person did not reside in Newfoundland and Labrador, and 2 did not have one of the 4 cancers under study), and 16 patients terminated the interview before it was completed.

Over half the sample were urban residents, female, under 65 years of age, retired, and had a high school education or less, a high income level (> $40 000) and private insurance (Table 1). The largest proportion of respondents was seeking follow-up care, had breast cancer and had been diagnosed with cancer less than 2 years previously. Most of the study population said the stage of their illness and personal feelings were important considerations in their care decisions, but that travel costs, drug costs, child care costs, travel time and other commitments were not important.

A significantly larger proportion of rural than urban residents had a partner, had less than a high school education, did not have private health insurance, were undergoing radiotherapy or chemotherapy during their visit, had prostate or lung cancer, and had been diagnosed less than 2 years previously. A significantly larger proportion of rural than urban residents said that travel costs, drug costs and child care costs were important in their decisions about care (Table 2). There were no differences in terms of sex, age, employment status, income or the importance of stage of illness and personal feelings in their decisions about care.

Table 3 summarizes the logistic regression models for the 5 outcomes. Each column presents the odds ratios for rural residence and the significant covariates for a given outcome. Rural residence was a significant predictor for 3 of the 5 outcomes considered in the study. After controlling for other significant predictors, compared with urban residents, rural residents were 1.79 times, 1.69 times and 2.33 times more likely to report that travel costs, drug costs and child care costs, respectively, were important considerations in their cancer care decisions. Rural residence was not related to the consideration of either stage of illness or personal feelings as important in cancer care decisions.

DISCUSSION

For most patients, regardless of place of residence, their stage of illness and personal feelings were the most important considerations in their decisions about care. However, rural residents were, on average, roughly twice as likely as urban residents to report that financial costs were important considerations in their care decisions after they had begun treatment. These results were consistent across

cancer types and were consistent whether respondents were having active treatment (radiotherapy, chemotherapy or other treatment) or seeking follow-up care. These findings highlight that the financial barriers that remain in Canada's publicly insured health care system disproportionately affect rural residents, who make up almost 20% of the country's population.[2]

These findings identify the groups for whom financial considerations remain an impediment to accessing care. In addition to rural residents, patients without private health insurance and those with low incomes were more likely to consider costs for drugs or travel in their decisions about care. Education level was also related to 2 of the items (travel costs and drug costs). Respondents with higher education levels were less likely to report that these items were important in their decisions about care. We believe that these findings reflect that highly educated people are more likely to hold full-time employment (and thus likely have private health insurance) and work in larger urban centres (and thus have fewer travel costs to access cancer care).

Although we did not directly link cost considerations to patients' actual treatment decisions, our findings are consistent with previous studies that suggest that rural cancer patients may forgo or alter their care because of travel and its associated costs.[12,13] For example, earlier Canadian studies have reported lower rates of breast conserving surgery among eligible women who live in rural regions, have longer travel times to a cancer treatment centre or have a low income.[5,14–17] Breast conserving surgery usually requires adjuvant radiotherapy, which is normally available in larger urban centres. In these studies, researchers suggested that the considerable financial

Table 1. Characteristics of 484 cancer patients interviewed between September 2002 and June 2003 while presenting for care at 4 cancer centres

Variable	No. (%) of patients	Variable	No. (%) of patients
Sex		Cancer type	
Male	211 (43.6)	Breast	201 (41.5)
Female	273 (56.4)	Lung	71 (14.7)
Age		Colorectal	101 (20.9)
< 65	262 (54.5)	Prostate	96 (19.8)
≥ 65	219 (45.5)	≥ 2 sites	15 (3.1)
Marital status		Time since diagnosis, mo	
Unpartnered	99 (20.6)	< 12	115 (23.8)
Partnered	382 (79.4)	12–23	127 (26.2)
Employment status		24–35	57 (11.8)
Full-time	46 (9.6)	36–59	89 (18.4)
Part-time/seasonal	34 (7.1)	60–119	74 (45.3)
Sick leave/long-term disability	60 (12.5)	≥ 120	22 (4.5)
Unemployed/unpaid sick leave	28 (5.8)	Stage of illness	
Retired	252 (52.4)	Not important	25 (5.3)
Homemaker/student/caregiver	61 (12.7)	Important	450 (94.7)
Education		Personal feelings	
Less than high school	180 (37.4)	Not important	51 (10.7)
Completed high school	122 (25.4)	Important	427 (89.3)
Some postsecondary	63 (13.1)	Travel costs	
Completed postsecondary	95 (19.8)	Not important	245 (51.3)
Graduate/professional degree	21 (4.4)	Important	233 (48.7)
Income		Drug costs	
High (> $40 000)	139 (30.2)	Not important	237 (50.2)
Low (≤ $40 000)	321 (69.8)	Important	235 (49.8)
Has insurance		Child care costs	
Yes	273 (56.8)	Not important	291 (89.5)
No	208 (43.2)	Important	34 (10.5)
Visit type		Home community	
Radiotherapy	78 (16.1)	Urban	258 (53.3)
Chemotherapy	58 (12.0)	Rural	226 (46.7)
Follow-up	330 (68.2)		
Other	18 (3.7)		

and social costs associated with this treatment discourage rural patients from choosing breast conservation. Similar findings (and rationales) have been reported in studies in Australia.[18,19] We are currently conducting studies linking actual out-of-pocket costs to specific cost-reduction strategies.

Our study highlights the need for programs and policies that address barriers to cancer care (and other specialized services) for rural residents. In Canada, most provinces provide medical travel subsidies for patients who must travel outside their region to access health services, although eligibility criteria and subsidy rates vary considerably. In response to recent national commissions,[23,24] Canadian provinces are expanding provincial drug insurance programs. Recently, the Government of Newfoundland and Labrador introduced drug coverage for residents with low incomes or who have catastrophic drug costs.[25]

In terms of care delivery, providers can ease the financial and psychological burdens of travel by providing care closer to the homes of rural patients, through either regional clinics or tele-oncology. A tele-oncology program was introduced in New-

Table 2. Differences between 258 urban and 226 rural residents interviewed between September 2002 and June 2003 while presenting for care at 4 cancer centres

Variable	No. (%) of residents		*p* value*	Variable	No. (%) of residents		*p* value*
	Urban	Rural			Urban	Rural	
Sex			0.05	Cancer type			0.030
Male	102 (39.5)	109 (48.2)		Breast	117 (45.3)	84 (37.2)	
Female	156 (60.5)	117 (51.8)		Lung	34 (13.2)	37 (16.4)	
Age			0.99	Colorectal	58 (22.5)	43 (19.0)	
< 65	139 (54.5)	123 (54.4)		Prostate	39 (15.1)	57 (25.2)	
≥ 65	116 (45.5)	103 (45.6)		≥ 2 sites	10 (3.9)	5 (2.2)	
Marital status			0.032	Time since diagnosis, mo			0.021
Unpartnered	62 (24.3)	37 (16.4)		< 12	51 (19.8)	64 (28.3)	
Partnered	193 (75.7)	189 (83.6)		12–23	63 (24.4)	64 (28.3)	
Employment status			0.07	24–35	28 (10.9)	29 (12.8)	
Full-time	30 (11.8)	16 (7.1)		36–59	52 (20.2)	37 (16.4)	
Part-time/seasonal	11 (4.3)	23 (10.2)		60–119	51 (19.8)	23 (10.2)	
Sick leave/long-term disability	29 (11.4)	31 (13.7)		≥ 120	13 (5.0)	9 (4.0)	
Unemployed/unpaid sick leave	14 (5.5)	14 (6.2)		Stage of illness			0.46
Retired	135 (52.9)	117 (51.8)		Not important	15 (6.0)	10 (4.5)	
Homemaker/student/ caregiver	36 (14.1)	25 (11.1)		Important	236 (94.0)	214 (95.5)	
Education			< 0.001	Personal feelings			0.13
Less than high school	72 (28.2)	108 (47.8)		Not important	22 (8.7)	29 (12.9)	
Completed high school	71 (27.8)	51 (22.6)		Important	232 (91.3)	195 (87.1)	
Some postsecondary	39 (15.3)	24 (10.6)		Travel costs			< 0.001
Completed postsecondary	56 (22.0)	39 (17.3)		Not important	152 (60.1)	93 (41.3)	
Graduate/professional degree	17 (6.7)	4 (1.8)		Important	101 (39.9)	132 (58.7)	
Income			0.07	Drug costs			0.001
High (> $40 000)	82 (33.9)	57 (26.1)		Not important	145 (57.5)	92 (41.8)	
Low (≤ $40 000)	160 (66.1)	161 (73.9)		Important	107 (42.5)	128 (58.2)	
Has insurance			0.001	Child care costs			0.033
Yes	164 (64.1)	109 (48.4)		Not important	159 (93.0)	132 (85.7)	
No	92 (35.9)	116 (51.6)		Important	12 (7.0)	22 (14.3)	
Visit type			< 0.001				
Radiotherapy	23 (8.9)	55 (24.3)					
Chemotherapy	43 (16.7)	15 (6.6)					
Follow-up	180 (69.8)	150 (66.4)					
Other	12 (4.7)	6 (2.7)					

*Based on χ^2 tests.

foundland and Labrador after we had completed our survey. Recent evaluations of regional and teleoncology programs in Canada have highlighted their positive reception by both patients and providers, particularly in terms of travel-related savings.[26,27]

Study limitations

Given the recruitment protocol, we were unable to calculate response rates since only willing respondents were referred to the research assistant and only eligible individuals were interviewed. Moreover, because we recruited patients who were presenting for treatment and follow-up appointments at cancer clinics, we did not capture individuals who decided to forgo cancer treatment altogether because of costs.

To assess the representativeness of our study sample, we compared the characteristics of our study sample with administrative data from the cancer registry for patients with breast, lung, colorectal or prostate cancer. Our sample underrepresents patients with lung and colorectal cancers and patients seeking care at the cancer centre in St. John's. It overrepresents patients with breast cancer and those seeking care at the 3 other clinics. Patients from St. John's may have been less interested in participating in the study if they felt that out-of-pocket costs were not an issue for them. The bias in our sample may overinflate the specific odds ratio values reported in the study. However, corroborating evidence from the literature support the overarching findings that cost-related factors are important considerations for rural residents.

CONCLUSION

Even with Canada's medicare system, out-of-pocket costs and travel requirements remain impediments to cancer care. Rural residents are more likely than their urban counterparts to take costs related to travel, drugs and child care into account in their decisions about cancer treatment. Developing strategies to reduce financial costs for rural residents is essential to enhancing the accessibility of centralized, specialist services such as cancer care.

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Competing interests: None declared.

Table 3. Summary of logistic regression models

Variable	Odds ratio (95% confidence interval)				
	Stage of illness	Personal feelings	Travel costs	Drug costs	Child care costs
Home community type					
Urban	1.00	1.00	1.00	1.00	1.00
Rural	NS	NS	1.79 (1.21–2.63)	1.69 (1.13–2.53)	2.33 (1.09–4.96)
Sex					
Male		1.00			
Female		2.15 (1.19–3.89)			
Has insurance					
Yes			1.00	1.00	
No			2.09 (1.37–3.18)	2.55 (1.61–4.04)	
Education					
Less than high school			1.00	1.00	
Completed high school			NS	1.94 (1.13–3.32)	
Some postsecondary			NS	NS	
Completed postsecondary			0.54 (0.31–0.96)	NS	
Graduate/professional degree			0.12 (0.03–0.54)	NS	
Income					
High (> $40 000)				1.00	
Low (≤ $40 000)				1.69 (1.02–2.80)	
Age, yr					
< 65					1.00
≥ 65					0.13 (0.04–0.42)

NS = not significant.

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