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Factors associated with receipt of symptom screening in the year after cancer diagnosis in a universal health care system: a retrospective cohort study

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ABSTRACT

Purpose Patient-reported symptom data are collected prospectively by a provincial cancer agency to mitigate the significant symptom burden that patients with cancer experience. However, an assessment of whether such symptom screening occurs uniformly for those patients has yet to be performed. In the present study, we investigated patient, disease, and health system factors associated with receipt of symptom screening in the year after a cancer diagnosis.

Methods Patients diagnosed with cancer between 2007 and 2014 were identified. We measured whether 1 or more symptom screenings were recorded in the year after diagnosis. A multivariable modified Poisson regression with robust error variance was used to identify predictors [age, comorbidity, rurality, socioeconomic status, immigration status, cancer site, registration at a regional cancer centre (CC), and year of diagnosis] of being screened for symptoms.

Results Of 425,905 patients diagnosed with cancer, 163,610 (38%) had 1 or more symptom screening records in the year after diagnosis, and 75% survived at least 1 year. We identified variability in symptom screening by primary cancer site, regional CC, age, sex, comorbidity, material deprivation, rurality of residence, and immigration status. Patients who had been diagnosed with melanoma or endocrine cancers, who were not registered at a regional CC, who lived in the most urban areas, who were elderly, and who were immigrants were least likely to undergo symptom screening after diagnosis.

Conclusions Our evaluation of the implementation of a population-based symptom screening program in a universal health care system identified populations who are at risk for not receiving screening and who are therefore future targets for improvements in population symptom screening and better management of cancer-related symptoms at diagnosis.

Key Words Patient-reported outcomes, symptom screening, universal health care systems

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INTRODUCTION

All patients with cancer experience symptoms throughout the course of their illness; however, symptom burden and management are not equally distributed in various populations. In addition to having an immediate negative effect on well-being, unmanaged symptoms can lead to high rates of emergency department use, noncompliance with treatment, or end-of-life hospital admissions[1–5]. Patients from ethnic minority populations, those living in low-income neighborhoods, and those who are female, experience inequalities in symptom burden, severity, and management[6–11]. Studies in the United States have outlined racial and ethnic differences in the severity and management of pain in cancer patients[10,11]. One Canadian study found that cancer patients with a diagnosis of schizophrenia were less likely to be referred for palliative care or to receive opiates for pain management at the end

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of life[12]. Although disparities in symptom severity and management are well known to exist, less is known about symptom surveillance.

Routine collection of patient-reported outcomes (PROs) using standard, validated tools is one way to promote equitable system-wide symptom control and management, by encouraging discussion between clinicians and patients[13–16]. Some studies have demonstrated that routine symptom screening can decrease the number of emergency department visits and can also be used to better coordinate and improve access to cancer care by targeting patient groups who are at particular risk for distress[4,17–20]. Cancer Care Ontario (CCO), a provincial cancer agency, has systematically collected PROs at regional cancer centres (CCs) and affiliate institutions through the Ontario Cancer Symptom Management Collaborative, beginning in 2007 with a pilot project in lung cancer and palliative care patients, and later expanding to all cancers. The goal of the program was to improve symptom management and coordination of oncology care, with a secondary aim of data collection for research purposes. The symptom scores are provided to the oncology team before the patient visits the physician and are used to identify areas of poor symptom control and to understand the trajectory of symptoms for individual patients from visit to visit. The scores have been used to characterize symptom burden at end of life and in the year after diagnosis and also to investigate associations between symptom screening, emergency department visits, and opioid prescribing practices[4,21–26]. Physician preferences and attitudes influence the use of routine symptom screening data in the clinic[27,28]. However, it is unclear whether symptom screening occurs uniformly for all patient groups in the province[15,28].

An evaluation of program implementation is critical for understanding the factors associated with symptom screening and for identifying high-risk patients who are less likely to complete a symptom assessment. We therefore investigated patient, disease, and health system factors associated with receipt of symptom screening in the year after a cancer diagnosis, after the initiation of a large-scale symptom screening program in a universal health care system.

METHODS

Study Design and Population

This retrospective cohort study was designed to describe the implementation of a province-wide symptom screening program in Ontario and to identify predictors of screening in the year after cancer diagnosis. Ontario is Canada's most populated province, with 13.6 million inhabitants[29]. Cancer care in Ontario is provided publicly through a single-payer universal health care system; CCO-endorsed regional CCs are responsible for implementing provincial standards and programs for cancer care.

Patients with a cancer diagnosis in the Ontario Cancer Registry (OCR) between 1 January 2007 and 31 December 2014 were included. The OCR is a passive cancer registry containing 95% of cancer diagnoses. Patients less than 18 years of age at diagnosis, those who died on or before the date of diagnosis, and those who had a second cancer diagnosis at any time before or during the study period were excluded. The resulting cohort constituted a representative cross-section of patients in both the active treatment and end-of-life phases of care.

Data Sources

Provincial administrative health care datasets were linked to the province-wide symptom management database maintained by the Ontario Cancer Symptom Management Collaborative using unique encoded identifiers and were analyzed at ICES. The symptom management database contains province-wide PRO data, including symptom screening records, from outpatient visits at regional CCs and their affiliated outreach cancer clinics. The Registered Persons Database provided demographic and vital status information. The National Ambulatory Care Reporting System, Discharge Abstract Database maintained by the Canadian Institute for Health Information (CIHI), and the OHIP (Ontario Health Insurance Plan) database were used to measure physical and mental comorbidities[30,31]. Community-level information about marginalization and rural residence were provided by the 2006 census and Postal Code Conversion File databases[32]. The permanent residents database maintained by Immigration, Refugees and Citizenship Canada provided residency information for all individuals who apply to immigrate to Canada and first take up residency in Ontario[12]. The Activity Level Reporting database captures patient activity within the cancer system and was used to define regional CCs and affiliates.

Ethics approval for this study was obtained from the Sunnybrook Health Sciences Centre Research Ethics Board, and all analyses adhered to the data confidentiality and privacy policies of ICES.

Measuring Participation in Symptom Screening

Symptom screening to improve symptom management was initiated by CCO in 2007. The program started with lung cancer patients and was expanded to other cancer sites during subsequent years, with an estimated 61% of Ontario's cancer patients being screened with the revised Edmonton Symptom Assessment System (ESAS-r) in 2015[30,31]. Currently, all regional CCs and nearly 80 non–regional CC health centres in the province systematically collect ESAS-r scores at cancer outpatient visits. Conversely, the ESAS-r is not routinely collected in physician offices, non–regional CC oncology clinics, patient homes, or other locations where care occurs. The ESAS-r is a valid and reliable screening tool developed to elicit a patient's assessment of 9 common cancer-associated symptoms[33–39]. Symptom screening is offered primarily in English and French at dedicated electronic kiosks in outpatient clinics, although paper forms are available and are entered manually into the symptom management database when needed. The paper version has been translated into 35 different languages, including many Indigenous languages.

We evaluated access to the symptom assessment program in the year after a cancer diagnosis. Follow-up was complete to 31 December 2015[40,41]. A dichotomous symptom screening variable (yes, no) was created from the PRO records. Patients with 1 or more ESAS-r records in the year after diagnosis were considered positive for symptom screening participation.

Patient-, Disease-, and System-Level Predictors

Variables were identified from the international cancer disparities literature and national cancer care equity frameworks[42–44]. We compared symptom screening uptake for groups potentially vulnerable to cancer care disparities, including elderly people, women, people with multiple physical or mental comorbidities, people living in materially deprived and rural communities, people who were immigrants, and people who were not referred for care at a regional CC or affiliated institution. We hypothesized that patients in those groups would have a lower likelihood of completing symptom screening.

Age at diagnosis and sex were obtained from the Registered Persons Database[32]. Age was categorized into five groups: 18–50, 51–60, 61–70, 71–80, and 81 years or older to explore potential nonlinear relationships. Comorbidity was defined using the Johns Hopkins (Baltimore, MD, U.S.A.) Adjusted Clinical Groups (ACG) system based on health care use in the 24 months preceding the cancer diagnosis[30,31]. The 32 individual aggregated diagnosis groups were summed to create a total score, which was dichotomized (0–9 vs. 10–32 diagnosis groups) to indicate low and high comorbidity[45,46]. Rurality of primary residence was defined for each patient using the Rurality Index for Ontario. Municipalities are assigned a score (0–100) based on total population, population density, and travel times to health care centres[47]. The Rurality Index for Ontario was operationalized as a nominal categorical variable and adapted categories from the developers and previously published work[47–51]. Community-level material deprivation was measured using census data linked to postal code information according to the Ontario Marginalization Index, a measure of marginalization that incorporates household income, education, quality of housing, and family structure characteristics[52]. Immigration status was categorized as a dichotomous (yes, no) variable using the database maintained by Immigration, Refugees and Citizenship Canada, which contains information from 1985. Individuals with a record in the database were classified as being immigrants to Canada. The identified individuals had been in Canada for various lengths of times and had immigrated from various countries and for varying reasons (including being refugees). Registration with a regional CC or affiliate during the study period was measured as a dichotomous variable. An "affiliate" is an associated hospital where cancer care is delivered as part of a formal relationship with the regional CC. Cancer site, regional CC or affiliate, and year of diagnosis were considered covariates in understanding receipt of symptom screening. Province-wide implementation of the screening program was performed by cancer site and was expanded across the province over time, and therefore those variables might be strong predictors of symptom screening receipt. Cancer site and year of diagnosis were abstracted from the OCR. Cancer sites were classified according to the World Health Organization's *International Classification of Diseases for Oncology* (3rd edition)[53]. Year of diagnosis was obtained from the OCR. Receipt of care from a regional CC or affiliated institution was defined as the presence of any record in the Activity Level Reporting database.

Statistical Analysis

Descriptive statistics are reported. Frequencies are used to describe categorical variables, and chi-square tests of independence were used to compare distributions in the screened and non-screened groups. To understand variation in follow-up time, patients were categorized as surviving 90 days or fewer, 91–180 days, 181–270 days, 271–365 days, and more than 365 days. The cumulative incidence function for symptom screening risk was plotted stratified by registration at a regional CC, and likelihood of screening was compared using the log-rank test.

We used multivariable modified Poisson regression with robust error variance to investigate independent predictors of symptom screening. This method of statistical modelling provides measures of relative risk and their 95% confidence limits (CLS) for common outcomes[54]. Age, sex, comorbidities, material deprivation, rurality of residence, immigration status, cancer site, referral for care at a regional CC, and year of cancer diagnosis were included as possible predictors. The TNM stage was not included in the model because staging data are not collected for all cancer types at the population level. Treatment variables such as chemotherapy and radiotherapy were not included given the complexity of measuring treatment for heterogeneous cancer sites and the overlap of those variables with referral for care at a regional CC. We performed two sensitivity analyses. In the first, we restricted the study population to a contemporary cohort of patients diagnosed between 2010 and 2014, which allowed for an uptake period after introduction and diffusion of the program across the province. In the second, we restricted the study population to patients with a regional CC registration.

RESULTS

During the study period, 425,905 patients with an incident cancer were registered to the OCR; of those patients, 163,610 (38%) had a record of at least 1 symptom screening in the year after diagnosis. Table I describes the characteristics of patients with and without at least 1 screening. Symptom screening increased significantly over time, from 10.7% in patients diagnosed in 2007 when the program was first implemented, to 54% in patients diagnosed in 2014 ($p < 0.001$). A significantly larger percentage of patients with a registration at a regional CC or affiliate than of those who had no such registration had at least 1 symptom screening record ($p < 0.001$). Figure 1 illustrates the cumulative incidence of symptom screening in those two patient subsets.

Table II presents, for each patient, disease, and system-level variable from the multivariable analysis, the adjusted relative likelihood of a patient receiving at least 1 symptom screening. Relative to patients who were not registered with a regional CC, those with such a registration in the study period were 5.68 times more likely to have at least 1 symptom screening record (95% CL: 5.59, 5.78). The likelihood of being screened also increased significantly over time: compared with patients diagnosed in 2007, those with a diagnosis in 2014 were 354% more likely to have at least 1 symptom screening record (95% CL: 4.43, 4.65).

Compared with breast cancer patients (the reference group), patients diagnosed with melanoma or with an

TABLE I Characteristics of 425,905 patients with and without at least 1 screening using revised Edmonton Symptom Assessment System in the year after an incident cancer diagnosis

Characteristic	Symptom screenings completed		*p* Value
	None	≥1	
Implementation factors			
Patients *(n)*	262,295	163,610	—
Registration at regional CC [*n* (%)]			<0.001
No	158,562 (91.4)	14,852 (8.6)	
Yes	103,733 (41.1)	148,758 (58.9)	
Year of diagnosis [*n* (%)]			<0.001
2007	45,886 (89.3)	5,525 (10.7)	
2008	40,923 (79.4)	10,644 (20.6)	
2009	35,147 (67.1)	17,268 (32.9)	
2010	31,311 (59.9)	20,953 (40.1)	
2011	29,843 (55.3)	24,158 (44.7)	
2012	27,437 (50.5)	26,843 (49.5)	
2013	26,619 (48.3)	28,477 (51.7)	
2014	25,129 (45.8)	29,742 (54.2)	
Cancer type [*n* (%)]			<0.001
Oral cavity or pharynx	4,749 (47.1)	5,326 (52.9)	
Gastrointestinal	53,866 (62.9)	31,815 (37.1)	
Respiratory system or thoracic	31,491 (54.8)	25,996 (45.2)	
Bones, joints, or soft tissue	1,994 (54.4)	1,671 (45.6)	
Melanoma	13,527 (73.8)	4,809 (26.2)	
Breast	23,288 (38.7)	36,953 (61.3)	
Gynecologic	12,341 (47.2)	13,826 (52.8)	
Genitourinary	65,136 (74.7)	22,094 (25.3)	
Nervous system and orbit	4,514 (60.0)	3,012 (40.0)	
Endocrine system	17,223 (89.9)	1,945 (10.1)	
Hematopoietic or lymphatic	19,600 (69.0)	8,818 (31.0)	
Other or unclear	14,566 (66.5)	7,345 (33.5)	
Survival from diagnosis [*n* (%)]			<0.001
0–90 Days	49,167 (89.1)	5,995 (10.9)	
91–180 Days	12,162 (58.8)	8,532 (41.2)	
181–270 Days	6,975 (48.2)	7,508 (51.8)	
271–365 Days	5,241 (42.8)	6,991 (57.2)	
≥366 Days	188,750 (58.4)	134,584 (41.6)	
Patient characteristics			
Age group at diagnosis [*n* (%)]			<0.001
≤50 Years	38,946 (57.4)	28,921 (42.6)	
51–60 Years	48,453 (56.2)	37,705 (43.8)	
61–70 Years	64,312 (57.2)	48,029 (42.8)	
71–80 Years	60,132 (63.1)	35,099 (36.9)	
>80 Years	50,452 (78.5)	13,856 (21.5)	
Sex [*n* (%)]			<0.001
Women	122,177 (57.2)	91,400 (42.8)	
Men	140,118 (66.0)	72,210 (34.0)	

TABLE I Continued

Characteristic	Symptom screenings completed		*p* Value
	None	≥1	
Patient characteristics continued			
Comorbidity [*n* (%)]			<0.001
0–9 ACGs	183,075 (59.5)	124,492 (40.5)	
10–32 ACGs	79,220 (66.9)	39,118 (33.1)	
Material deprivation [*n* (%)]			<0.001
Least marginalized	53,015 (59.6)	35,904 (40.4)	
2	51,365 (60.5)	33,486 (39.5)	
3	50,768 (61.6)	31,683 (38.4)	
4	51,285 (62.5)	30,791 (37.5)	
Most marginalized	52,205 (63.8)	29,589 (36.2)	
Missing	3,657 (62.9)	2,157 (37.1)	
Rurality (RIO score)			<0.001
0–9	179,774 (62.8)	106,308 (37.2)	
10–30	41,714 (58.2)	29,980 (41.8)	
31–50	27,099 (59.7)	18,295 (40.3)	
51–70	7,617 (61.2)	4,837 (38.8)	
≥71	3,906 (60.4)	2,559 (39.6)	
Unknown	2,185 (57.3)	1,631 (42.7)	
Immigration status			<0.001
Long-term resident	235,864 (61.2)	149,400 (38.8)	
Immigrant	26,431 (65.0)	14,210 (35.0)	

CC = cancer centre; ACG = Adjusted Clinical Groups (Johns Hopkins, Baltimore, MD, U.S.A.); RIO = Rurality Index for Ontario.

endocrine, genitourinary, hematopoietic, or lymphatic cancer were significantly less likely to have a symptom screening record in the year after diagnosis. For example, compared with breast cancer patients, patients diagnosed with an endocrine cancer were 57% less likely to have a symptom screening record (95% CL: 0.42, 0.45). Patients who immigrated to Ontario from outside Canada, elderly patients, patients with a greater number of comorbidities, and patients living in communities with the greatest material deprivation were significantly less likely to have a symptom screening record in the year after diagnosis. A U-shaped association with symptom screening was evident according to the rurality of the patient's residence. Compared with patients 50 years of age and younger, those 81 years of age and older were 30% less likely to have a symptom screening record (95% CL: 0.69, 0.71). Relative to longer-term residents of Ontario, patients who had immigrated to Ontario beginning in 1985 were 13% less likely to have 1 or more symptom screening records (95% CL: 0.86, 0.88). Compared with patients living in mid-level urban communities, those living in the most urban areas were significantly less likely to have at least 1 symptom screening record, as were those living in the most rural communities. Greater comorbidity and greatest community-level material deprivation were associated with significantly lower likelihoods of having at least 1 symptom screening record, but the magnitudes of effect in those cases were small.

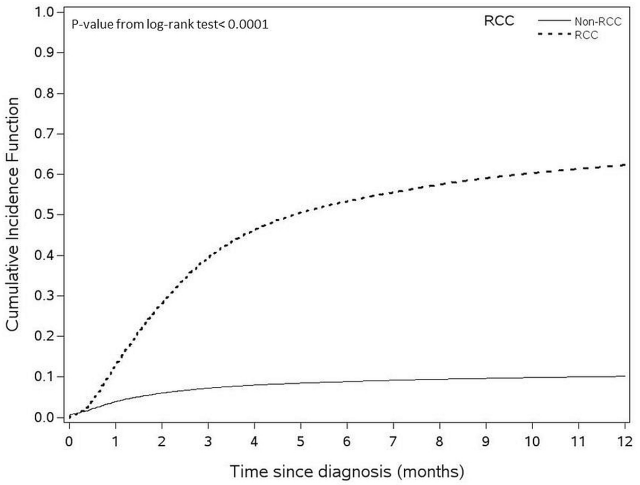

FIGURE 1 Cumulative incidence of patients having at least 1 symptom screening record in the year after a cancer diagnosis, stratified by registration at a regional cancer centre (RCC).

The results did not change when the analysis was restricted to the most contemporary cohort of patients for whom screening rates were more stable, or when the analysis was restricted to patients with a registration at a regional CC or a regional CC–affiliated institution (data not shown).

TABLE II Factors associated with the likelihood of having at least 1 record of screening using the revised Edmonton Symptom Assessment System in the year after a cancer diagnosis

Factor	Adjusted RR[a]	95% CL	*p* Value
Registration at regional CC			<0.001
No	Reference		
Yes	5.68	5.59, 5.78	
Year of diagnosis			<0.001
2007	Reference		
2008	1.89	1.84, 1.95	
2009	2.97	2.90, 3.05	
2010	3.67	3.58, 3.77	
2011	4.05	3.95, 4.16	
2012	4.45	4.34, 4.56	
2013	4.57	4.46, 4.69	
2014	4.54	4.43, 4.65	
Cancer type			<0.001
Oral cavity or pharynx	0.91	0.90, 0.93	
Gastrointestinal	0.85	0.84, 0.86	
Respiratory system or thoracic	0.97	0.96, 0.98	
Bones, joints, or soft tissue	0.92	0.89, 0.95	
Melanoma	0.64	0.62, 0.65	
Breast	Reference		
Gynecologic	0.99	0.98, 1.00	
Genitourinary	0.68	0.67, 0.69	
Nervous system and orbit	0.73	0.71, 0.74	
Endocrine system	0.43	0.42, 0.45	
Hematopoietic or lymphatic	0.79	0.77, 0.80	
Other or unclear	0.84	0.82, 0.85	
Age group at diagnosis			<0.001
≤50 Years	Reference		
51–60 Years	0.98	0.97, 0.99	
61–70 Years	0.96	0.96, 0.97	
71–0 Years	0.91	0.90, 0.92	
>80 Years	0.70	0.69, 0.71	
Sex			<0.001
Women	0.98	0.97, 0.99	
Men	Reference		
Comorbidity			
0–9 ACGs	Reference		
10–32 ACGs	0.96	0.95, 0.97	<0.001
Immigration status			<0.001
Long-term resident	Reference		
Immigrant	0.87	0.86, 0.88	
Material deprivation			<0.001
Least marginalized	Reference		
2	0.98	0.97, 0.99	
3	0.96	0.96, 0.97	
4	0.95	0.94, 0.96	
Most marginalized	0.93	0.92, 0.94	
Rurality (RIO score)			<0.001
0–9	Reference		
10–30	1.10	1.09, 1.11	
31–50	1.06	1.05, 1.07	
51–70	1.04	1.02, 1.05	
≥71	1.05	1.02, 1.07	
Unknown	1.13	1.09, 1.17	

[a] Adjusted for all other variables in the model;
RR = relative risk; CL = confidence limits; CC = cancer centre; ACGs = Adjusted Clinical Groups (Johns Hopkins, Baltimore, MD, U.S.A.); RIO = Rurality Index for Ontario.

DISCUSSION AND CONCLUSIONS

The present study provides evidence that large-scale implementation of routine symptom screening to improve symptom management is feasible within a universal health care system over a short period of time. We describe the increased uptake of symptom screening within particular cancer site groups for whom the ESAS-r tool might be more beneficial or for whom targeted efforts were made. We identified particularly successful implementation within regional CCs and affiliates in which infrastructure, incentives, support, training, and leadership investments over 10 years were successfully leveraged. We also identified areas for improvement, where routine symptom screening could be made more equitable—for example, addressing lower rates of screening in the immigrant and elderly patient populations.

The strongest predictor of symptom screening was attendance at a regional CC. Compared with patients who never accessed a regional CC or affiliate, those registered for care with such a centre had a greater than 450% increased probability of receiving screening. That finding was expected, considering that provincial implementation strategies required all regional CCs to screen all cancer patients starting in 2008[28]. However, CCO does not monitor the uptake of symptom screening in regional CC affiliates; uptake might therefore be even higher among regional CCs than among their affiliate health care centres. Despite universal access to care and a common funding mechanism, variation in adherence to provincial standards in other sectors has been found within and between regional CCs[55,56]. For example, a study in Ontario found that regional CCs demonstrated variable uptake of CCO-recommended treatment for head-and-neck cancer (range: 39%–82%)[56]. Just as physician uptake and other factors influence geographic variation in practice, oncologist engagement and attitudes toward the standardized symptom screening process can cause variation between the regional CCs[28]. Similar variations in adherence to provincial standards for symptom screening uptake can therefore be expected. Further study is required to understand the effects of differential symptom screening uptake on patient outcomes.

We found that, compared with Canadian-born cancer patients, patients born outside of Canada were 13% less likely to receive symptom screening. That observation is supported by the literature indicating that foreign-born populations use cancer screening and prevention services

less often[57–60]. Lower rates of symptom screening might be driven by language barriers and cultural differences. The electronic ESAS-r tool is available only in English and French, meaning that patients have to seek out a paper copy if they prefer to complete the symptom tool in a different language. More research is required to ensure that recent immigrants, who make up 30% of the Ontario population[61], and those speaking languages not currently captured by the CCO ESAS-r tool are adequately supported.

Older age was also identified as a risk factor for non-receipt of symptom screening. Compared with patients 50 years of age or younger, those more than 80 years of age were 30% less likely to receive symptom screening. That finding might be the result of electronic data entry, which could reduce use by some patients, particularly those of older age, who are less likely than patients in younger age groups to use technology[62,63]. Additionally, illiteracy, cognitive disorders, comorbidities, poor eyesight, and hearing difficulties are present in higher proportion in older patients and could affect symptom screening participation[64]. Symptom screening tools should be validated specifically for elderly populations to identify potential barriers and to create alternative implementation strategies where necessary[64,65].

Identifying the patients who do not receive symptom screening has important implications for researchers using the screening data to inform clinical practice or policy changes. Although the data represent a comprehensive and large-scale collection of PROs, they do not reflect the experience of all patients—particularly patients who do not receive their care at a regional CC. Refining study populations with a greater likelihood of being screened for symptoms will allow for internally valid study designs. For example, studies of PROs in populations treated with radiotherapy rather than with surgery alone would have a greater likelihood of covering the entire population, given that all radiotherapy in Ontario is provided at regional CCs. Similarly, restricting a study to contemporary cohorts or to patients registered at a regional CC would create internally valid study populations from which the researcher could evaluate the generalizability of the findings. Further consideration of who is not included in the study is also important when investigating cancer care disparities, given the lower likelihood of symptom screening for cancer patients in vulnerable circumstances.

The present study has limitations. Completed paper versions of the ESAS-r screening tool might not have been entered into the electronic database. Patients who were seen outside a regional CC, who were elderly, or who completed the ESAS-r screening in a language other than English or French might have been more likely to complete a paper copy and therefore to have been misclassified as not having been screened. In addition, patients managed completely outside the regional CC might still have been systematically screened for symptoms using other validated or non-validated scales. Although data for those patients would not have contributed to overall population statistics, the patients themselves could still be benefiting clinically from symptom screening. Given the heterogeneity of our cohort, we were unable to assess the influence of treatment on receipt of symptom screening. Compared with patients managed using surgery alone, or with those who received palliative non-oncologic-directed treatment only, those receiving chemotherapy or radiotherapy might have had more opportunity to access the screening tool. Finally, the length of follow-up from the time of diagnosis varied for individual patients. Only 10% of patients who lived for 3 months or less had at least 1 symptom screening; of those who lived longer than 3 months, almost half had at least 1 symptom screening.

Offering system-wide standardized collection of PROs is an important contribution to patient care and population-based research. Over time, the CCO program has demonstrated successful implementation to assess the intensity of the symptom burden and to improve symptom management. However, access to the program is not uniform across the province. Targeting non–regional CCs, foreign-born patients, and patients of older age is necessary to mitigate regional differences and broaden the equitable distribution of symptom screening across the province. Consideration of who has a greater likelihood of completing at least 1 symptom screening record is also important for research that will use this data resource in the future.

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CONFLICT OF INTEREST DISCLOSURES

We have read and understood *Current Oncology*'s policy on disclosing conflicts of interest, and we declare that we have none.

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REFERENCES

1. So W, Marsh G, Ling W, *et al.* The symptom cluster of fatigue, pain, anxiety, and depression and the effect on the quality of life of women receiving treatment for breast cancer: a multicenter study. *Oncol Nurs Forum* 2009;36:E205–14.
2. Coates A, Abraham S, Kaye SB, *et al.* On the receiving end—patient perception of the side-effects of cancer chemotherapy. *Eur J Cancer Clin Oncol* 1983;19:203–8.

3. Fiorentino L, Rissling M, Liu L, Ancoli-Israel S. The symptom cluster of sleep, fatigue and depressive symptoms in breast cancer patients: severity of the problem and treatment options. *Drug Discov Today Dis Models* 2011;8:167–73.
4. Barbera L, Sutradhar R, Howell D, *et al.* Does routine symptom screening with ESAS decrease ED visits in breast cancer patients undergoing adjuvant chemotherapy? *Support Care Cancer* 2015;23:3025–32.
5. Barbera L, Paszat L, Chartier C. Indicators of poor quality end-of-life cancer care in Ontario. *J Palliat Care* 2006;22:12–17.
6. Check DK, Reeder-Hayes KE, Zullig LL, Weinberger M, Basch EM, Dusetzina SB. Examining racial variation in antiemetic use and post-chemotherapy health care utilization for nausea and vomiting among breast cancer patients. *Support Care Cancer* 2016;24:4839–47.
7. Check DK, Reeder-Hayes KE, Basch EM, Zullig LL, Weinberger M, Dusetzina SB. Investigating racial disparities in use of NK1 receptor antagonists to prevent chemotherapy-induced nausea and vomiting among women with breast cancer. *Breast Cancer Res Treat* 2016;156:351–9.
8. Reyes-Gibby CC, Anderson KO, Shete S, Bruera E, Yennurajalingam S. Early referral to supportive care specialists for symptom burden in lung cancer patients: a comparison of non-Hispanic whites, Hispanics, and non-Hispanic blacks. *Cancer* 2012;18:856–63.
9. Fisch MJ, Lee JW, Weiss M, *et al.* Prospective, observational study of pain and analgesic prescribing in medical oncology outpatients with breast, colorectal, lung, or prostate cancer. *J Clin Oncol* 2012;30:1980–8.
10. Martinez KA, Snyder CF, Malin JL, Dy SM. Is race/ethnicity related to the presence or severity of pain in colorectal and lung cancer? *J Pain Symptom Manage* 2014;48:1050–9.
11. McNeill JA, Reynolds J, Ney ML. Unequal quality of cancer pain management: disparity in perceived control and proposed solutions. *Oncol Nurs Forum* 2007;34:1121–8.
12. Chochinov HM, Martens PJ, Prior HJ, Kredentser MS. Comparative health care use patterns of people with schizophrenia near the end of life: a population-based study in Manitoba, Canada. *Schizophr Res* 2012;141:241–6.
13. Berry DL, Blumenstein BA, Halpenny B, *et al.* Enhancing patient-provider communication with the electronic self-report assessment for cancer: a randomized trial. *J Clin Oncol* 2011;29:1029–35.
14. Chen J, Ou L, Hollis SJ. A systematic review of the impact of routine collection of patient reported outcome measures on patients, providers and health organisations in an oncologic setting. *BMC Health Serv Res* 2013;13:211.
15. Gilbert JE, Howell D, King S, *et al.* Quality improvement in cancer symptom assessment and control: the Provincial Palliative Care Integration Project (PPCIP). *J Pain Symptom Manage* 2012;43:663–78.
16. Ruland CM, Holte HH, Røislien J, *et al.* Effects of a computer-supported interactive tailored patient assessment tool on patient care, symptom distress, and patients' need for symptom management support: a randomized clinical trial. *J Am Med Inform Assoc* 2012;17:403–10.
17. Hassett MJ, O'Malley AJ, Pakes JR, Newhouse JP, Earle CC. Frequency and cost of chemotherapy-related serious adverse effects in a population sample of women with breast cancer. *J Natl Cancer Inst* 2006;98:1108–17.
18. Enright K, Grunfeld E, Yun L, *et al.* Population-based assessment of emergency room visits and hospitalizations among women receiving adjuvant chemotherapy for early breast cancer. *J Oncol Pract* 2015;11:126–32.
19. Basch E, Deal AM, Dueck AC, *et al.* Overall survival results of a trial assessing patient-reported outcomes for symptom monitoring during routine cancer treatment. *JAMA* 2017;318:197–8.
20. Rocque GB, Pisu M, Jackson BE, *et al.* on behalf of the Patient Care Connect Group. Resource use and Medicare costs during lay navigation for geriatric patients with cancer. *JAMA Oncol* 2017;3:817–25.
21. Gotay CC, Kawamoto CT, Bottomley A, Efficace F. The prognostic significance of patient-reported outcomes in cancer clinical trials. *J Clin Oncol* 2008;26:1355–63.
22. Spoozak L, Seow H, Liu Y, Wright J, Barbera L. Performance status and symptom scores of women with gynecologic cancer at the end of life. *Int J Gynecol Cancer* 2013;23:971–8.
23. Barbera L, Atzema C, Sutradhar R, *et al.* Do patient-reported symptoms predict emergency department visits in cancer patients? A population-based analysis. *Ann Emerg Med* 2013;61:427–37.e5.
24. Barbera L, Seow H, Husain A, *et al.* Opioid prescription after pain assessment: a population-based cohort of elderly patients with cancer. *J Clin Oncol* 2012;30:1095–9.
25. Barbera L, Seow H, Howell D, *et al.* Symptom burden and performance status in a population-based cohort of ambulatory cancer patients. *Cancer* 2010;116:5767–76.
26. Bubis LD, Davis L, Mahar A, *et al.* Symptom burden in the first year after cancer diagnosis: an analysis of patient-reported outcomes. *J Clin Oncol* 2018;36:1103–11.
27. Howell D, Hack TF, Green E, Fitch M. Cancer distress screening data: translating knowledge into clinical action for a quality response. *Palliat Support Care* 12014;12:39–51.
28. Pereira JL, Chasen MR, Molloy S, *et al.* Cancer care professionals' attitudes toward Systematic Standardized Symptom Assessment and the Edmonton Symptom Assessment System after large-scale population-based implementation in Ontario, Canada. *J Pain Symptom Manage* 2016;51:662–72.e8.
29. Statistics Canada. Population estimates on July 1st, by age and sex [Web page]. Ottawa, ON: Statistics Canada; 2019. [Available at: https://www150.statcan.gc.ca/t1/tbl1/en/tv.action?pid=1710000501&pickMembers%5B0%5D=1.7&pickMembers%5B1%5D=2.1; cited 4 January 2019]
30. Reid RJ, MacWilliam L, Verhulst L, Roos N, Atkinson M. Performance of the ACG case-mix system in two Canadian provinces. *Med Care* 2001;39:86–99.
31. Reid RJ, Roos NP, MacWilliam L, Frohlich N, Black C. Assessing population health care need using a claims-based ACG morbidity measure: a validation analysis in the Province of Manitoba. *Health Serv Res* 2002;37:1345–64.
32. Wilkins R. *PCCF+ Version 3G User's Guide.* Cat. no. 82F0086-XDB. Ottawa, ON: Statistics Canada; 2009.
33. Bruera E, Kuehn N, Miller MJ, Selmser P, Macmillan K. The Edmonton Symptom Assessment System (ESAS): a simple method for the assessment of palliative care patients. *J Palliat Care* 1991;7:6–9.
34. Chang VT, Hwang SS, Feuerman M. Validation of the Edmonton Symptom Assessment Scale. *Cancer* 2000;88:2164–71.
35. Davison SN, Jhangri GS, Johnson JA. Longitudinal validation of a modified Edmonton Symptom Assessment System (ESAS) in haemodialysis patients. *Nephrol Dial Transpl* 2006;21:3189–95.
36. Hannon B, Dyck M, Pope A, *et al.* Modified Edmonton Symptom Assessment System including constipation and sleep: validation in outpatients with cancer. *J Pain Symptom Manage* 2015;49:945–52.
37. Nekolaichuk C, Watanabe S, Beaumont C. The Edmonton Symptom Assessment System: a 15-year retrospective review of validation studies (1991–2006). *Palliat Med* 2008;22:111–22.
38. Richardson LA, Jones GW. A review of the reliability and validity of the Edmonton Symptom Assessment System. *Curr Oncol* 2009;16:55.
39. Watanabe SM, Nekolaichuk C, Beaumont C, Johnson L, Myers J, Strasser F. A multicenter study comparing two

numerical versions of the Edmonton Symptom Assessment System in palliative care patients. *J Pain Symptom Manage* 2011;41:456–68.
40. Clarke E, Marrett L, Kreiger N. Cancer registration in Ontario: a computer approach. *IARC Sci Publ* 1991;:246–57.
41. Robles SC, Marrett LD, Clarke EA, Risch HA. An application of capture–recapture methods to the estimation of completeness of cancer registration. *J Clin Epidemiol* 1988;41:495–501.
42. Ward E, Jemal A, Cokkinides V, *et al.* Cancer disparities by race/ethnicity and socioeconomic status. *CA Cancer J Clin* 2004;54:78–93.
43. Jemal A, Bray F, Center MM, Ferlay J, Ward E, Forman D. Global cancer statistics. *CA Cancer J Clin* 2011;61:69–90.
44. DeMartino JK, Larsen JK. Equity in cancer care: pathways, protocols, and guidelines. *J Natl Compr Canc Netw* 2012;10(suppl 1):S1–9.
45. Kagedan DJ, Dixon ME, Raju RS, *et al.* Predictors of adjuvant treatment for pancreatic adenocarcinoma at the population level. *Curr Oncol* 2016;23:334–42.
46. Kagedan DJ, Goyert N, Li Q, *et al.* The impact of increasing hospital volume on 90-day postoperative outcomes following pancreaticoduodenectomy. *J Gastrointest Surg* 2017;21:506–15.
47. Kralj B. *Measuring Rurality—RIO2008_BASIC: Methodology and Results.* Toronto, ON: The Ontario Medical Association; 2009.
48. Hamilton L. *The Diagnostic Interval of Colorectal Cancer Patients in Ontario by Degree of Rurality* [MSc thesis]. Kingston, ON: Queen's Graduate Theses and Dissertations; 2015. [Available online at: https://qspace.library.queensu.ca/handle/1974/13760; cited 6 December 2018]
49. Kralj B. Measuring "rurality" for purposes of health-care planning: an empirical measure for Ontario. *Ont Med Rev* 2000;:33–52.
50. Jaakkimainen RL, Sood PR, Schultz SE. Office-based procedures among urban and rural family physicians in Ontario. *Can Fam Physician* 2012;58:e578–87.
51. Tepper JD, Schultz SE, Rothwell DM, Chan BTB. *Physician Services in Rural and Northern Ontario: ICES Investigative Report.* Toronto, ON: Institute for Clinical Evaluative Sciences; 2006.
52. Matheson FI, Dunn JR, Smith KL, Moineddin R, Glazier RH. Development of the Canadian Marginalization Index: a new tool for the study of inequality. *Can J Public Health* 2012;103(suppl 2):S12–16.
53. World Health Organization (WHO). *International Classification of Diseases for Oncology.* 3rd ed. 1st rev. Geneva, Switzerland: WHO; 2013.
54. Spiegelman D, Hertzmark E. Easy SAS calculations for risk or prevalence ratios and differences. *Am J Epidemiol* 2005;162:199–200.
55. Gray S, Bu J, Saint-Jacques N, Rayson D, Younis T. Chemotherapy uptake and wait times in early-stage non-small-cell lung cancer. *Curr Oncol* 2012;19:e308–18.
56. Hall SF, Irish JC, Gregg RW, Groome PA, Rohland S. Adherence to and uptake of clinical practice guidelines: lessons learned from a clinical practice guideline on chemotherapy concomitant with radiotherapy in head-and-neck cancer. *Curr Oncol* 2015;22:e61–8.
57. Hedeen AN, White E. Breast cancer size and stage in Hispanic American women, by birthplace: 1992–1995. *Am J Public Health* 2001;91:122–5.
58. Remennick L. The challenge of early breast cancer detection among immigrant and minority women in multicultural societies. *Breast J* 2006;12(suppl 1):S103–10.
59. Kobetz E, Menard J, Barton B, *et al.* Barriers to breast cancer screening among Haitian immigrant women in Little Haiti, Miami. *J Immigr Minor Health* 2010;12:520–6.
60. Vahabi M, Lofters A, Kumar M, Glazier RH. Breast cancer screening disparities among urban immigrants: a population-based study in Ontario, Canada. *BMC Public Health 2015;*15:679.
61. Ontario, Ministry of Finance. *2016 Census Highlights: Factsheet 8.* Toronto, ON: Government of Ontario; 2017. [Available online at: https://www.fin.gov.on.ca/en/economy/demographics/census/cenhi16-8.html; cited 2 February 2018]
62. Niehaves B, Plattfaut R. Internet adoption by the elderly: employing IS technology acceptance theories for understanding the age-related digital divide. *Eur J Inf Syst* 2014;23:708–26.
63. Lerouge C, Ma J, Sneha S, Tolle K. User profiles and personas in consumer health technologies. *Int J Med Inform* 2013;82:e251–68.
64. Di Maio M, Perrone F. Quality of life in elderly patients with cancer. *Health Qual Life Outcomes* 2003;1:44.
65. Wedding U, Pientka L, Hoffken K. Quality-of-life in elderly patients with cancer: a short review. *Eur J Cancer* 2007;43:2203–10.