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 admissions1–5. Patients from ethnic minority populations, those living in low-income neighborhoods, and those who are female, experience inequalities in symptom burden, severity, and management6–11. Studies in the United States have outlined racial and ethnic differences in the severity and management of pain in cancer patients10,11. 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
sociation with symptom burden at end of life. 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. Physician preferences and attitudes influence the use of routine symptom screening data in the clinic. However, it is unclear whether symptom screening occurs uniformly for all patient groups in the province.

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. 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. Community-level information about marginalization and rural residence were provided by the 2006 census and Postal Code Conversion File databases. 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. 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. 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. 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. 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. 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 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. 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. 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. 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. The Rurality Index for Ontario was operationalized as a nominal categorical variable and adapted categories from the developers and previously published work. 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. 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 time and had immigrated from various countries and for varying reasons (including being refugees). Registration with a regional 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. Cancer site, regional 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). Year of diagnosis was obtained from the OCR. Receipt of care from a regional 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 or, 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. Age, sex, comorbidities, material deprivation, rurality of residence, immigration status, cancer site, referral for care at a regional or, 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 or. 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 or 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 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 or, 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 1 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      |         |
|                                       | 262,295                     | 163,610 |         |

**Implementation factors**

| Characteristic                        | None | ≥1    | p Value |
|---------------------------------------|------|-------|---------|
| 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) |       |
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 endocrine cancer were 57% less likely to have a symptom screening record (95% CI: 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% CI: 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% CI: 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.

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 cancer centre (RCC) or a regional cancer centre–affiliated institution (data not shown).

| 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.
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 cc 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 cc to screen all cancer patients starting in 2008. However, cco does not monitor the uptake of symptom screening in regional cc affiliates; uptake might therefore be even higher among regional cc 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 cc55,56. For example, a study in Ontario found that regional cc 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 cc. 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\textsuperscript{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\textsuperscript{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\textsuperscript{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\textsuperscript{64}. Symptom screening tools should be validated specifically for elderly populations to identify potential barriers and to create alternative implementation strategies where necessary\textsuperscript{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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