

Measuring patient-reported outcomes to improve cancer care in Canada: an analysis of provincial survey data

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ABSTRACT

Patient-reported outcomes measures (PROMS) are an important component of the shift from disease-centred to person-centred care. In oncology, PROMS describe the effects of cancer and its treatment from the patient perspective and ideally enable patients to communicate to their providers the physical symptoms and psychosocial concerns that are most relevant to them. The Edmonton Symptom Assessment System–revised (ESAS-r) is a commonly used and validated tool in Canada to assess symptoms related to cancer. Here, we describe the extent to which patient-reported outcome programs have been implemented in Canada and the severity of symptoms causing distress for patients with cancer.

As of April 2017, 8 of 10 provinces had implemented the ESAS-r to assess patient-reported outcomes. Data capture methods, the proportion of cancer treatment sites that have implemented the ESAS-r, and the time and frequency of screening vary from province to province. From October 2016 to March 2017 in the 8 reporting provinces, 88.0% of cancer patients were screened for symptoms. Of patients who reported having symptoms, 44.3% reported depression, with 15.5% reporting moderate-to-high levels; 50.0% reported pain, with 18.6% reporting moderate-to-high levels; 56.2% reported anxiety, with 20.4% reporting moderate-to-high levels; and 75.1% reported fatigue, with 34.4% reporting moderate-to-high levels.

There are some notable areas in which the implementation of PROMS could be improved in Canada. Findings point to a need to increase the number of cancer treatment sites that screen all patients for symptoms; to standardize when and how frequently patients are screened across the country; to screen patients for symptoms during all phases of their cancer journey, not just during treatment; and to assess whether giving cancer care providers real-time patient-reported outcomes data has led to appropriate interventions that reduce the symptom burden and improve patient outcomes. Continued measurement and reporting at the system level will allow for a better understanding of progress in PROMS activity over time and of the areas in which targeted quality improvement efforts could ensure that patient symptoms and concerns are being addressed.

Key Words Patient-reported outcomes, treatment

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INTRODUCTION

Patient-reported outcomes measures (PROMS) are an important component of the shift from disease-centred to person-centred care. In oncology, PROMS describe the effects of cancer and its treatment from the patient perspective and ideally enable patients to communicate to their providers the physical symptoms and psychosocial concerns that are most relevant to them. In clinical practice, the routine collection of PROMS—using, for example,

the Edmonton Symptom Assessment System–revised (ESAS-r) or other validated tools—provides real-time information about symptoms, helping providers to prioritize the concerns that matter most to patients, to standardize the symptom assessment process, and to facilitate appropriate follow-up to ensure that patient needs are being addressed. The information gathered from patients can enhance clinical management, enable comparisons of the performance of care providers, and contribute to program or service development. Research has shown that the

integration of PROMs into routine cancer care can improve patient–provider communication, satisfaction with care, symptom management, quality of life, and survival^{1–6}.

The ESAS-r is a commonly used, validated tool in Canada for assessing symptoms related to cancer^{7–9}. The tool captures information about physical symptoms (pain, tiredness, nausea, shortness of breath, drowsiness, and appetite), mental health (depression), emotional well-being (anxiety), and overall well-being¹⁰. Here, we describe the extent to which patient-reported outcome programs have been implemented in Canada and the severity of symptoms causing distress for patients with cancer. Such data can be used to identify areas that could benefit from improved measurement of patient-reported outcomes and to facilitate appropriate follow-up interventions and quality improvement efforts.

METHODS

The data of interest were obtained for period October 2016 to March 2017 from Alberta, Saskatchewan, Manitoba, Ontario, Quebec, Nova Scotia, Prince Edward Island, and Newfoundland and Labrador. British Columbia, New Brunswick, and the territories do not currently have standardized provincial or territorial programs to screen for symptoms at their cancer treatment sites. Provinces were provided with standardized data specifications and a data collection template. Provincial results that describe the extent to which the ESAS-r has been implemented and national results (combined data from 8 provinces) that describe the severity of symptoms causing distress (that is, low = scores 0–3; moderate = scores 4–6; high = scores 7–10) are reported.

RESULTS

At April 2017, 8 of 10 provinces had implemented ESAS-r to assess patient-reported outcomes. Here, we report on the prevalence and severity of 4 symptoms—cancer pain, fatigue, anxiety, and depression—at provincial cancer treatment sites (Table 1). Capture methods for ESAS-r data (paper or electronic questionnaires), the proportion of cancer treatment sites that have implemented the ESAS-r (depending on the province, between 8% and 100% of cancer treatment sites have implemented the ESAS-r), and the time and frequency of screening (some provinces ask all cancer patients to complete the ESAS-r at every physician visit, and others screen at specific times or in specific patient populations) vary from province to province.

From October 2016 to March 2017, 88.0% of cancer patients (8 provinces reporting) reported symptoms causing distress. Of those patients,

- 44.3% reported depression, with 15.5% reporting moderate-to-high levels;
- 50.0% reported pain, with 18.6% reporting moderate-to-high levels;
- 56.2% reported anxiety, with 20.4% reporting moderate-to-high levels; and
- 75.1% reported fatigue, with 34.4% reporting moderate-to-high levels (Figure 1).

DISCUSSION AND CONCLUSIONS

The present work provides a snapshot of the current state of implementation of patient-reported outcome programs across Canada and the severity of symptoms among cancer patients. Most provinces (8 of 10) have implemented the ESAS-r in some or all of their cancer treatment sites, but findings suggest that the extent of implementation and the timing and frequency of screening varies widely province-to-province. The U.S. National Comprehensive Cancer Network has published standards of care for distress management and recommends that “ideally, patients should be screened for distress at every medical visit as a hallmark of patient-centred care. At a minimum, patients should be screened for distress at their initial visit, at appropriate intervals, and as clinically indicated”¹¹. Given the variation between provinces, further work is needed to increase, in some provinces, the number of cancer treatment sites that screen for symptoms causing distress and to standardize, across Canada, when and how often cancer patients are screened.

Of cancer patients who experience symptoms causing distress, between 15% and 34% report moderate-to-high distress levels, depending on the symptom: pain, fatigue, anxiety, or depression. For those patients, it is important that there be ongoing monitoring of symptoms and that symptoms be addressed through adequate follow-up and intervention, including further assessment, psychosocial and physical interventions as appropriate, a change in the care plan, or referral to another care provider^{11,12}. Timely and appropriate responses to symptoms can help to improve symptom management and the patient’s experience of care and quality of life. Further research is needed to assess whether adequate psychosocial services are available and to evaluate the effectiveness of patient-reported outcome programs in improving clinical management.

To advance measurement and reporting of patient-reported outcomes in Canada, the Canadian Partnership Against Cancer will work with jurisdictions that currently do not have standardized provincial programs to screen for symptoms to implement patient-reported outcome programs at their cancer treatment sites. In addition, the Partnership will work with partners to explore the use of data about symptoms and symptom severity (collected via the ESAS-r) to improve clinical practice and organizational effectiveness. Although other instruments are commonly used to measure patient-reported outcomes, the ESAS-r was selected because it is a validated tool that is short, easy for patients to complete, and useful in clinical practice. Efforts to expand the use of the ESAS-r will allow more clinicians to have, at the point of care, information that can be used to facilitate timely, person-centred cancer care, and to enhance patient–provider communication and patient experiences with care.

Our report has some limitations. Two provinces—British Columbia and New Brunswick—and the territories have not implemented the ESAS-r as a population-based symptom screening tool at their cancer treatment sites. The report’s findings might therefore not be generalizable to those jurisdictions. In addition, the extent of implementation of the ESAS-r varied with the province (that is, between

TABLE 1 Current state of implementation of patient-reported outcome programs, by province, at April 2017

Province	Disease site	Data capture method	Clinical sites (n)		Frequency of screening
			Collecting ESAS-r	Providing cancer therapy	
British Columbia	—	—	—	—	
Alberta	All	Paper (with electronic re-entry for 15 of 17 sites)	17	17	<ul style="list-style-type: none"> ■ New patient oncology visit ■ Follow-up visit ■ Once per cycle of chemotherapy; beginning, middle, and end of radiation therapy
Saskatchewan	All	Paper (with electronic re-entry)	18	18	<ul style="list-style-type: none"> ■ Once for every new patient at the new-patient consultation ■ Once per patient referred to the pain and symptom management clinic ■ Once for every radiation therapy patient while on radiation therapy
Manitoba	All (excluding head-and-neck cancers)	Paper (with electronic re-entry)	22	Unknown	<ul style="list-style-type: none"> ■ At every physician visit
Ontario	All [excluding <i>in situ</i> melanoma (malignant skin and malignant melanoma)]	Electronic (direct patient entry)	92	92	<ul style="list-style-type: none"> ■ All visits
Quebec	All	Electronic (direct patient entry)	7	92	<ul style="list-style-type: none"> ■ At every physician visit
New Brunswick	—	—	—	—	
Nova Scotia	All	Paper	9	11	<ul style="list-style-type: none"> ■ Newly diagnosed patients ■ Specific transition points in cancer care
Prince Edward Island	All	Paper	2	2	<ul style="list-style-type: none"> ■ New-patient oncology visits ■ Intravenous chemotherapy review appointments ■ End of treatment for all patients
Newfoundland and Labrador	All	Electronic (tertiary cancer treatment centre) Paper (with electronic re-entry for all other clinics)	13	Unknown	<ul style="list-style-type: none"> ■ New-patient oncology visit ■ Some follow-up screening at identified time points in treatment trajectory

ESAS-r = Edmonton Symptom Assessment System, revised version.
Data source: Patient-Reported Outcome Initiative partners.

8% and 100% of cancer treatment sites had implemented ESAS-r, depending on the province), and so national results might be skewed by provinces that screen more patients for symptoms causing distress.

There are some notable areas in which the implementation of PROMS could be improved in Canada. Findings point to a need to increase the number of cancer treatment sites that screen all patients for symptoms and to standardize when and how frequently patients are screened across the country. In addition, there is a need to screen patients for symptoms during all phase of their cancer journey, and not just during treatment. It is also important to assess whether providing cancer care providers with real-time patient-reported outcomes data has led to appropriate interventions that reduce the symptom burden and improve patient outcomes. Continued measurement and reporting at the system level will allow for a better understanding

of progress in PROMS activity over time and the areas in which quality improvement efforts could be targeted to ensure that the symptoms and concerns of patients are being addressed.

In 2018, the System Performance Initiative at the Canadian Partnership Against Cancer (<http://systemperformance.ca>) will be releasing two relevant pan-Canadian reports. *Living with Cancer: A Report on the Patient Experience* describes the patient experience with cancer care from suspicion to survivorship and points to provider- and system-level changes that have to be made to ensure that patients receive person-centred care. The *2018 Cancer System Performance Report* describes the extent to which the health care system is providing high-quality, seamless, equitable, and sustainable cancer care, and points to opportunities to improve data collection and reporting to maximize the utility of the resulting information.

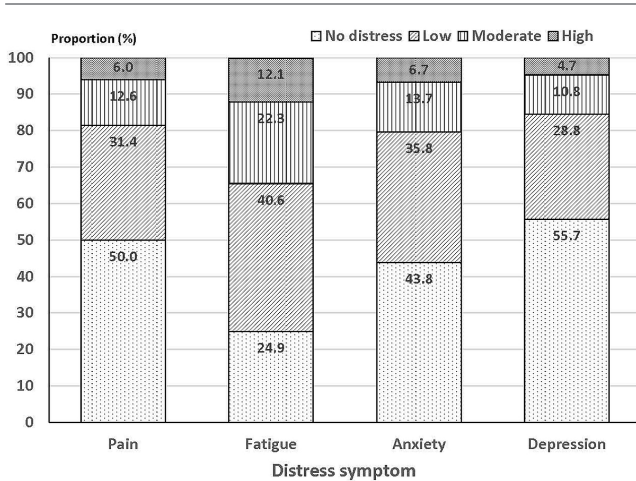


FIGURE 1 Severity of symptoms causing distress, Alberta, Saskatchewan, Manitoba, Ontario, Quebec, Nova Scotia, Prince Edward Island, and Newfoundland and Labrador combined, October 2016 to March 2017. The Edmonton Symptom Assessment System (revised version) asks patients to describe how they are feeling on a scale of 0–10. No distress = score of 0; low = scores of 1–3; moderate = scores of 4–6; high = scores of 7–10. Each symptom had a small number of missing responses that were excluded (pain, 0.4%; fatigue, 0.4%; anxiety, 0.5%; depression, 0.5%). Data source: Patient-Reported Outcome Initiative partners.

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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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