



Psychosocial care for cancer: a framework to guide practice, and actionable recommendations for Ontario

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ABSTRACT

Objectives

We set out to create a psychosocial oncology care framework and a set of relevant recommendations that can be used to

- improve the quality of comprehensive cancer care for Ontario patients and their families.
- meet the psychosocial health care needs of cancer patients and their families at both the provider and system levels.

Data Sources and Methods

The ADAPTE process and the practice guideline development cycle were used to adapt the 10 recommendations from the 2008 U.S. Institute of Medicine standard *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs* into the psychosocial oncology care framework. In addition, the evidence contained in the original document was used, in combination with the expertise of the working group, to create a set of actionable recommendations. Refinement after formal external review was conducted.

Data Extraction and Synthesis

The new framework consists of 8 defining domains. Of those 8 domains, 7 were adapted from recommendations in the source document; 1 new domain, to raise awareness about the need for psychosocial support of cancer patients and their families, was added. To ensure high-quality psychosocial care and services, 31 actionable recommendations were created. The document was submitted to an external review process. More than 70% of practitioners rated the quality of the advice document as high and reported that they would recommend its use.

Conclusions

This advice document advocates for a multidisciplinary approach to cancer care in response to the distress experienced by cancer patients and their families. The recommendations will be useful in future to measure performance, quality of practice, and access to psychosocial services.

KEY WORDS

Guideline, framework, cancer, psychosocial oncology, patient-centred care

1. INTRODUCTION

The economic and quality-of-life burden of cancer is an increasing concern worldwide^{1,2}. Throughout the trajectory of their illness, from diagnosis through treatment and beyond, cancer patients are increasingly living with the consequences of their disease or the side effects of its treatment. Concerns with their physical health, alterations to their normal development, emotional or mental health problems, and social problems (for example, financial concerns, reduced employment opportunities, the stigma of disability, and social and spiritual support concerns) are increasingly being identified³. Families of cancer patients are also affected by the disease, often experiencing emotional distress, shifting of roles, financial burden, caregiver stress, and fear of losing their loved one^{4,5}.

Cancer has thus become an illness that has all the hallmarks of a chronic condition needing continuing, long-term management not only in the biomedical arena, but in the psychological, behavioural, and social arenas as well. Psychosocial care is a whole-person approach to cancer care, addressing the social, psychological, emotional, spiritual, and functional aspects of the patient journey with an interdisciplinary team of care and service providers.

Despite the need, cancer patients experience a number of barriers to attaining optimal psychosocial health care. Those barriers include stigmatization^{6,7}; reduced awareness of available resources, or an inability to access them⁸; lack of knowledge, skills, and information necessary to manage the disease and its treatment; poor communication between patients and their health care providers; poor communication among health care professionals; and physical and financial barriers^{9–13}. Barriers can be exacerbated by reduced knowledge and understanding on the part of health care providers of the key role that psychosocial care plays in supporting the biomedical treatment of cancer patients. Legislative and regulatory constraints, professional health care education curricula primarily with a biomedical focus, and the structure of the clinical practice setting can further hinder access to psychosocial health care. Failure to address barriers may lead to increased mortality and morbidity, decreased functional status, reduced adherence to therapies, decreased ability to cope with many aspects of the disease, decreased ability to access care and to implement healthy behaviours, and reduced ability to work for both cancer patients and their family members^{4,14}.

To address those barriers, there is a need to provide coordinated psychosocial health services. Ontario has many services that address the psychosocial needs of cancer patients, including mental health and behavioural, social, and spiritual services, but they are fragmented¹⁵ and not accessible to cancer patients to the same extent across the province, with rural areas being at the greatest disadvantage¹⁶. Furthermore, the inter-professional nature of the services that often has been advocated in theoretical models and guidelines^{17,18} is not always reflected in practice. The Cancer Care Ontario (CCO) Psychosocial Oncology Program identified the need for guidance to help address the foregoing issues and promoted the development of the present advice document (Table 1).

2. METHODS

2.1 Adaptation

The Psychosocial Oncology Working Group was convened and worked in collaboration with the

Program in Evidence-based Care to develop the present document. The membership of the Working Group represented the disciplines of nursing, psychiatry, psychology, management, dietetics, and speech language pathology. The 2008 U.S. Institute of Medicine (IOM) standard *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*¹⁹ was identified as an appropriate foundation document upon which the Working Group created the framework and recommendations. The authors of the IOM document conducted an extensive multilayered review of the literature in the field. They also conducted a search for existing models of effective delivery of psychosocial health services. Based on the existing effective models they designed a model for the delivery of psychosocial health services. That model formed a foundation for their recommendations.

The 10 recommendations issued in the IOM document were directed to macro-level stakeholders such as the U.S. National Library of Medicine and the U.S. National Institutes of Health. Notably, the IOM definition of psychosocial care is slightly different from that used in Ontario (available at <http://www.capo.ca/pdf/CAPOstandards.pdf>). In fact, the IOM document does not appear to include the full range of health care disciplines that are made explicit in the Canadian definition (for example, dietitians, speech language pathologists, physiotherapists, occupational therapists, spiritual care practitioners), all of whom are part of the psychosocial team in Ontario.

The document for Ontario is directed to a different audience of micro-level stakeholders, such as practitioners and administrators in individual institutions. For that reason, the recommendations in the IOM document were first adapted to the reality of Ontario and then transformed into a framework. The framework was then used to support actionable recommendations created by the Working Group based on the evidence contained in the IOM document.

The Working Group used the methods of the practice guidelines development cycle²⁰ and the ADAPTE process²¹ to inform its strategy. As part of the ADAPTE process, the Working Group assessed the quality, currency, content, and consistency of the original document, and the acceptability and applicability of each

TABLE 1 Purpose of the present work

What is already known in the area of psychosocial oncology?

Psychosocial oncology programs across Canada are designed in different ways and the resources assigned to each program depend on the funding approach, thus the uneven availability of psychosocial oncology care to the patients across the country. The Canadian Association of Psychosocial Oncology established new standards in 2009 and has partnered with the Canadian Partnership Against Cancer on guidelines related to psychosocial health assessment, depression, and anxiety.

What does this paper add?

This paper adds an overall framework informed by evidence to define and outline the ways in which the psychosocial health needs of cancer patients need to be addressed. The work calls out the areas related to clinical practice and the organizations and system elements that are required to provide quality psychosocial care to meet the needs of cancer patients and their families.

IOM recommendation to the Ontario context. Those methods are described in further detail in Section 2 of the cco Evidence-Based Series #19-3, available online at <https://www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=83597>.

2.2 Internal and External Review

The advice document was peer-reviewed by an internal panel of 2 experts in research methodology and by 35 practitioners in the clinical area of interest. The document was also reviewed by a panel of 6 Ontario practitioners who were external to the adaptation process. Those 6 targeted peer reviewers had an opportunity to review the document in detail and gave feedback by responding to a 7-item survey (100% response rate). With the aim of disseminating the document before its full publication, a copy was also sent to 488 practitioners who had a chance to review the document and to give feedback by responding to a 3-item survey (13% response rate). Participants in the review panels covered the disciplines of interest for the document—namely, clinical nurse specialists, clinical leaders, clinical coordinators in supportive care and genetic counselling, clinical consultants in palliative care, clinical managers, administrative managers, social workers, counsellors, registered dietitians, specialists in psychosocial oncology and palliative care, physiotherapists, spiritual care practitioners, psychologists, and physicians in various specialties, including oncology and psychiatry. The 7-item and 3-item surveys asked participants to rate the overall quality of the guideline and to state whether they would use it. Most survey respondents rated the quality of the advice document as high (83%) and reported that they would recommend its use (74%). Further refinements were made to the document in response to feedback from the external reviewers.

3. RESULTS

The Working Group adapted 8 of the IOM recommendations to Ontario, added a new feature, and reframed the adapted content into 8 key defining domains of the framework (Table II). Two of the IOM recommendations were not applicable to Ontario and were not adapted. In addition, the Working Group used the evidence base contained in the original document to create 31 actionable recommendations for implementing high-quality psychosocial care services.

Figure 1 is a pictorial representation of the psychosocial oncology framework and of the interactions between and among its 8 domains. The IOM unifying model¹⁹ is at the centre of the framework and is complemented by the other domains of the framework. The Raising Awareness and Quality Oversight domains encompass the entire process; the other domains underpin the unifying model. The results of the internal and external review process—and

more information about the recommendations, with examples and links to other resources—are reported in detail in the cco Evidence-Based Series #19-3. The description of each domain in the framework is provided in Table II; recommendations for practice are reported next.

4. RECOMMENDATIONS

Domain A. Raising Awareness: Understanding and Defining Psychosocial Care

1. That the definition put forward by the Canadian Association of Psychosocial Oncology (CAPO)²² be adopted to guide psychosocial oncology in Ontario:

Psychosocial Oncology is a professional subspecialty in oncology. The domain of psychosocial oncology includes the formal study, understanding and treatment of the social, psychological, emotional, spiritual, quality of life and functional aspects of cancer as applied across the cancer trajectory from prevention through bereavement. It seeks to develop and integrate new knowledge and techniques of the psychosocial and biomedical sciences as it relates to cancer care.

Domain B. Standard of Care

2. To improve the patient end of the patient-provider communication unit, organizations should provide and facilitate the use of tools to support communication and should develop formal strategies to teach communication techniques to patients.
3. All patients and families should be screened for psychosocial health care needs at their initial visit to a cancer treatment facility and at intervals throughout their cancer care trajectory, particularly with changes in disease status (for example, remission, progression, recurrence).
4. Screening should be performed using validated tools that encompass a comprehensive range of health-related psychosocial problems, including physical symptoms, emotional or spiritual distress, logistic or material needs, inadequate social supports, and behavioural risk factors.
5. Results of screening should be shared with the patient and the health care team.
6. Significant screening results should be followed up with an assessment by the most appropriate health care provider to confirm needs and develop a plan of care.
7. Health care providers should work with the patient and family to develop a plan of care that contains clear goals, that aims to assist in managing the illness and complex functional abilities (for example, swallowing, communication, ambulation), and that maintains the highest possible level of functioning and well-being.

TABLE II The Psychosocial Care Framework

Domain A	<p>Raising Awareness: Understanding and Defining Psychosocial Care Psychosocial care should be considered an integral and standardized part of cancer care for patients and their families at all stages of the illness trajectory. Strategies to promote awareness of the significance of psychosocial health care needs and uptake of psychosocial health services should be encouraged.</p>
Domain B	<p>Standard of Care Comprehensive cancer care should ensure the provision of appropriate psychosocial health services by</p> <ul style="list-style-type: none"> • facilitating effective communication between patients, their families, and care providers. • identifying psychosocial health needs of patients and families. • designing and implementing a plan that <ul style="list-style-type: none"> – links the patient and family with needed psychosocial health care services. – coordinates biomedical and psychosocial health care. – engages and supports patients and families in managing their illness and health. • systematically monitoring, evaluating, and readjusting plans.
Domain C	<p>Health Care Providers All cancer care providers, including oncologists, palliative care physicians, family physicians, psychiatrists, psychologists, social workers, nurses, dietitians, occupational therapists, physiotherapists, speech language pathologists, spiritual care practitioners, health care administrators, volunteers, community organizations, and other health care providers, have a responsibility to ensure that cancer patients and their families receive the psychosocial standard of care.</p>
Domain D	<p>Patient and Family Education Cancer patients and their families should be educated to expect, and to request when necessary, cancer care that meets psychosocial health care needs.</p>
Domain E	<p>Quality Oversight and Monitoring Progress Oversight mechanisms should be created that can be used to measure and report on the quality of psychosocial health care. The findings could be used to inform an evaluation of the impact of the present report.</p>
Domain F	<p>Workforce Competencies Professional competencies in the delivery of psychosocial health care should meet the requirements of educational institutions and accrediting organizations, licensing bodies, and professional societies. Educational bodies should examine their standards and licensing and certification criteria with an eye to identifying competencies in delivering psychosocial health care and developing those competencies as fully as possible in accordance with a model that integrates biomedical and psychosocial care.</p>
Domain G	<p>Standardized Nomenclature There is a need to develop a standardized transdisciplinary taxonomy and nomenclature for psychosocial health services.</p>
Domain H	<p>Psychosocial Research Organizations sponsoring research in oncology care should include the following areas among their funding priorities:</p> <ul style="list-style-type: none"> • At the system level, further development of reliable, valid, and efficient tools and strategies for use by clinical practices to ensure that all patients with cancer receive appropriate psychosocial care as set forth in the Standard of Care. These tools and strategies should include <ul style="list-style-type: none"> – approaches for improving patient–provider communication and providing decision support to cancer patients. – screening instruments that can be used to identify individuals with psychosocial health problems. – needs assessment instruments to assist in planning psychosocial services. – illness and wellness management interventions. – approaches for effectively linking patients with services and coordinating care, and for the uptake of psychosocial health services. • At the provider level, more-effective psychosocial services to treat mental health problems and to assist patients in adopting and maintaining healthy behaviours such as smoking cessation, exercise, and dietary changes have to be identified. That effort should include: <ul style="list-style-type: none"> – identifying populations for whom specific psychosocial services are most effective. – increasing the focus on understudied populations such as men and children, and understudied cancer types across the cancer trajectory and in patients experiencing various types and levels of distress. – developing standard outcome measures for assessing the effectiveness of the foregoing services. <p>Research on the use of the tools, strategies, and services should also focus on barriers to patient referral and how best to ensure delivery of appropriate psychosocial services to vulnerable populations such as low literacy individuals, older adults, socially isolated individuals, people living in remote areas, and members of cultural minorities.</p>

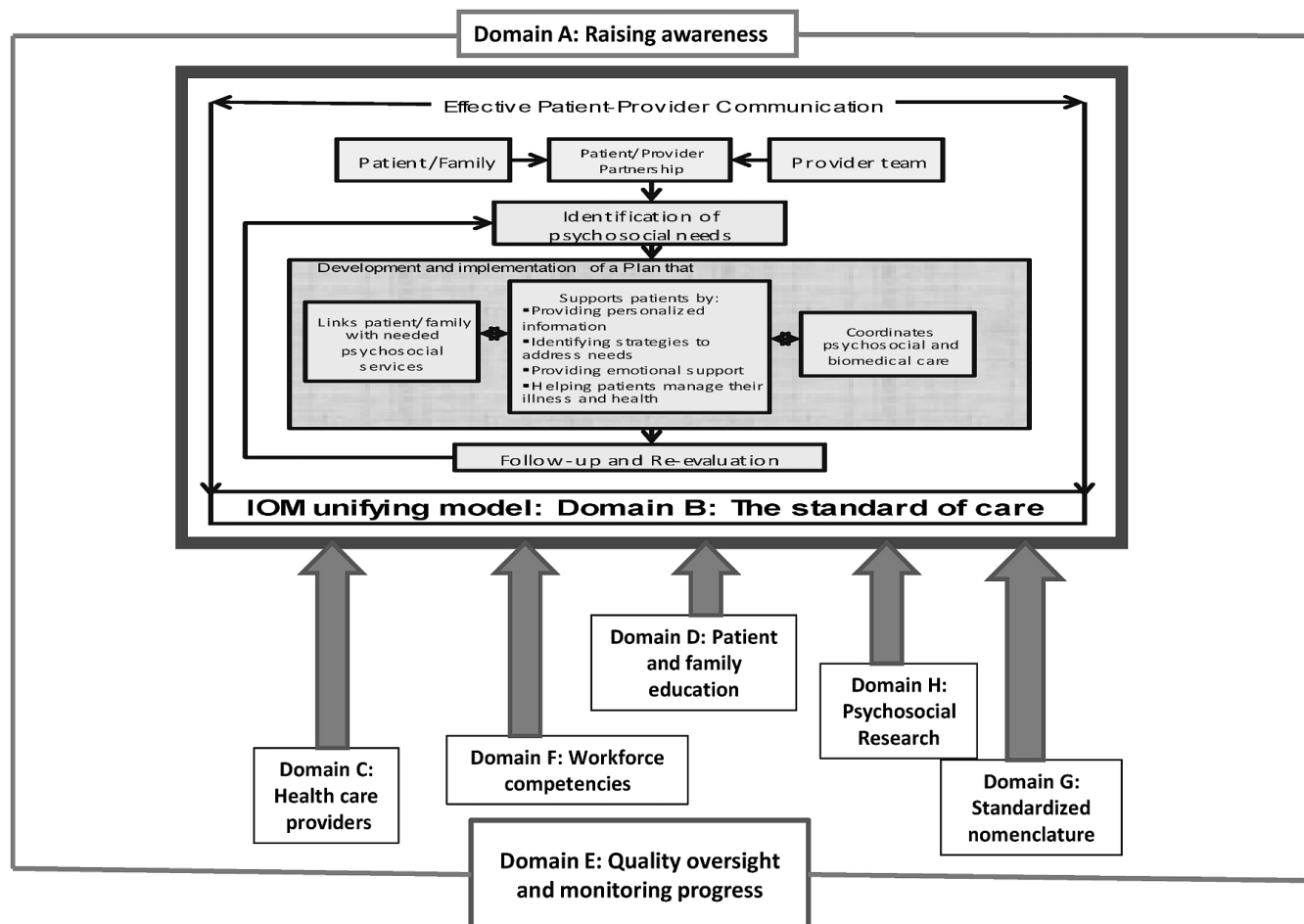


FIGURE 1 Psychosocial Oncology Framework. Adapted from *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*¹⁹ (p. 158).

8. As part of the health care plan, patients need to be linked to the most appropriate health care provider, either within the organization or within the broader community.
9. At the system level, structures and mechanisms should be put into place to ensure the coordination of biomedical and psychosocial care.
10. Health care providers and patient advocacy organizations should provide patients and families with condition-specific information tailored to the individual patient’s learning needs and style.
11. All health care providers and individuals working in community organizations should collaborate in the provision of emotional support for cancer patients and their families.
12. Patients diagnosed with clinically significant depression and anxiety should be treated or referred for treatment with specific psychotherapies (for example, cognitive-behavioural therapy, supportive psychotherapy, family or couples therapy) or with pharmacotherapy, or both, as indicated.
13. Health care organizations should develop inter-professional collaborative care models for the delivery of comprehensive cancer care that ensures access to the full range of psychological, physical, social, emotional, spiritual, nutritional, informational, and practical services needed by cancer patients and their families to support illness self-management.
14. Cancer programs and community-based not-for-profit cancer support organizations should assume responsibility for educating patients about the impact that health-risk behaviours can have on the disease and its treatment and should provide information about community resources that can help patients to change those behaviours.
15. Cancer programs and community-based not-for-profit cancer support organizations should provide information and assistance to patients regarding medication and disability coverage, transportation, lodging during outpatient therapy, child care, wigs and prostheses, and material medical supplies.
16. Cancer programs and community-based not-for-profit cancer support organizations should provide assistance in accessing services to address

cancer-related disabilities, cognitive impairment, cultural and language barriers, and family and caregiver support.

17. Health care providers should take into account the financial constraints of patients and support their access to appropriate services.
18. Health care professionals should systematically follow up on the uptake of services by patients, as well as any problems encountered and patient satisfaction with care.

Domain C. Health Care Providers

19. All cancer care providers should participate in education and training programs to increase their awareness of the significance of psychosocial care and should enhance their skills in the assessment and management of psychosocial issues.
20. Communication and patient education are expectations of clinical care. All health care providers should seek training in those areas.
21. Health care providers should maintain a directory of resources available to patients and their families at no cost.

Domain D. Patient and Family Education

22. Cancer programs should establish comprehensive cancer patient education programs.

Domain E. Quality Oversight and Monitoring Progress

23. Indicators to measure the effectiveness of psychosocial care and services should be identified and included in regional and provincial reporting, including, but not limited to, understanding the patient's experience with care.

Domain F. Workforce Competencies

24. Workforce planning for cancer services should include planning for all psychosocial specialists (that is, social workers, psychologists, psychiatrists, nurses, spiritual care practitioners, dietitians, and rehabilitation professionals such as occupational therapists, physiotherapists, and speech language pathologists), to meet the growing needs and demands for care.
25. Volunteers and patient education and information specialists have unique roles to inform, support, and help navigate cancer patients through their experience. Human health resource planning should take into consideration the need for such providers as part of psychosocial service planning.
26. Cancer programs should support additional education for health care professionals, given that those professionals may not have specialized credentials in psychosocial oncology. Relevant

courses such as CAPO's Interprofessional Psychosocial Oncology Distance Education Program (<http://www.ipode.ca/>) should be made available to all health care professionals who care for cancer patients and their families.

Domain G. Standardized Nomenclature

27. The Canadian Partnership Against Cancer, CAPO, and CCO should collaborate with provincial, national, and international bodies to develop a standardized, transdisciplinary taxonomy and nomenclature for psychosocial health services. The initiative should aim to incorporate the taxonomy and nomenclature into organizations of practice and education, and also into databases such as the National Library of Medicine Medical Subject Headings, PsycINFO, the Cumulative Index to Nursing and Allied Health Literature, and the Excerpta Medica database.

Domain H. Psychosocial Research

28. Future research on the effectiveness of psychosocial health services should consider variables that moderate treatment effects, such as *a priori* consideration of the nature of the samples (that is, levels of distress, natural course of symptoms, availability of social supports, temperamental traits, demographics) and theory-guided examinations of mechanisms for the effects obtained.
29. More-effective treatments for mental health problems in cancer should be developed, particularly through randomized controlled trials testing collaborative care and multicomponent interventions and comparing the effectiveness of nonpharmacologic and pharmacologic treatments, alone and combined.
30. An increased focus should be placed on the effects of receipt of psychosocial health services on physiologic (that is, endocrine and immunologic functioning) and clinical outcomes, including nutritional and functional status.
31. Provincial and federal cancer research funding agencies should increase their support for psychosocial research. Such increases can be accomplished either by calling for priority funding dedicated to psychosocial care or by increasing funding allocations for psychosocial research in grant competitions.

5. DISCUSSION

The present advice document marks an important step forward for the cancer system in Ontario. It provides a guide from which to evaluate the current system and set improvement goals. Many of the original domains and recommendations from the IOM document were adopted, and any changes

required because of the differences in health care systems in the United States and Ontario were made. The adaptation is unique in identifying a distinct domain (Domain A, the need to raise awareness of psychosocial care) and broadening the definition of health care providers to include the multidisciplinary teams that are more reflective of the Ontario context (Domain C). Although programs have been implemented in cancer centres, a consistent approach to psychosocial health care by the patient care teams, and systematic approaches to implementation, such as the use of workload measures to plan the resources required to deliver psychosocial health care, are lacking. The low response rate from practitioners to whom the document was sent for external review might be interpreted as a sign of the need for the Raising Awareness domain of this framework for Ontario. In keeping with the comprehensive and holistic CAPO definition of psychosocial oncology, the categories of health care providers that are the intended users of this document have been expanded to include medical, psychosocial, and allied health professionals, plus volunteers and community partners. The document and the framework will not only prioritize areas for improvement in psychosocial care, given the current context in Ontario, but also identify where future work needs to be planned and implemented. Foremost in priority setting and planning is the need to raise awareness and recognition among all stakeholders that this area of cancer care is of utmost importance and that it sustains all the other areas of development to improve every patient's experience.

This document reflects the original IOM standard from which it was drawn. For that reason, some important aspects of psychosocial care that were not included in the original document (for example, highlighting in the framework aspects of the cancer care continuum, expanding the research section, prioritizing psychosocial needs, and addressing issues of equity and diversity) have not been included here. The present advice document differs from the original IOM document in the development of 31 specific actionable recommendations based on the evidence base in the IOM document. In some cases, when actionable recommendations were made for which the IOM document did not contain sufficient supportive evidence for intended users in Ontario, the existing evidence was integrated with the expert opinion of the Working Group, and recommendations for the development of future guidelines were constructed as needed.

The recommendations in the present advice document are consistent with, and complementary to, other Ontario and Canadian guidelines related to psychosocial care. They include guidelines for Canadian standards in

- psychosocial care (*Standards of Psychosocial Health Services for Persons with Cancer and*

Their Families, available at http://capo.ca/CAPO_standards.pdf).

- patient education (*Establishing Comprehensive Cancer Patient Education Services*, available at <https://www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=14324>; *Effective Teaching Strategies and Methods of Delivery for Patient Education*, available at <https://www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=60065>), communication (*Provider–Patient Communication*, available at <https://www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=44425>), and navigation (*Guide to Implementing Navigation*, available at http://www.partnershipagainstcancer.ca/wp-content/uploads/2.4.0.1.4.7-Guide_Implementation_Navigation.pdf).
- psychosocial screening (*Guide to Implementing Screening for Distress, the 6th Vital Sign*, available at http://www.partnershipagainstcancer.ca/wp-content/uploads/2.4.0.1.4.5-Guide_CJAG.pdf), assessment (*A Pan-Canadian Clinical Practice Guideline: Assessment of Psychosocial Health Care Needs of the Adult Cancer Patient*, available at <http://www.partnershipagainstcancer.ca/wp-content/uploads/AdultAssesmentGuideline122109.pdf>), and management (*Cancer Care Ontario Symptom Management Guides*, available at <https://www.cancercare.on.ca/cms/one.aspx?portalId=1377&pageId=58189>).

6. CONCLUSIONS

The framework for psychosocial care presented here provides regional cancer programs with a tangible set of recommendations upon which to review their services and to identify gaps. It advocates for a multidisciplinary approach to cancer care in response to the distress experienced by cancer patients and their families, and it encourages cancer programs to develop, review, and revise services to the standards now set out for Ontario. This work can be applied to cancer systems and organizations in all provinces, notwithstanding that each province might want to contextualize the recommendations for the specific issues that dominate the provincial cancer mandate. Many practitioners who reviewed this advice document raised concerns related to implementation of these recommendations such as budget constraints, scarcity of psychosocial resources, and challenges with engaging the medical community. Future work should focus on establishing the best methods and creating tools for such implementation to achieve optimal person-centred care.

7. CONFLICT OF INTEREST DISCLOSURES

The authors declare that no financial conflicts of interest exist.

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