



Evidence-Based Series 19-3

A Quality Initiative of the
Program in Evidence-Based Care (PEBC), Cancer Care Ontario
and the Psychosocial Oncology Program, Cancer Care Ontario
Developed by the Psychosocial Oncology Expert Panel

Psychosocial Health Care for Cancer Patients and Their Families

*G. Turnbull, F. Baldassarre, P. Brown, J. Hatton-Bauer, M. Li,
S. Lebel, L. Durkin, E. Green, and the Psychosocial Oncology Expert Panel*

Report Date: October 12, 2010

An assessment conducted in June 2016 put Evidence-based Series (EBS) 19-3 in the Education and Information Section. This means that the recommendations will no longer be maintained but may still be useful for academic or other information purposes. The PEBC has a formal and standardized process to ensure the currency of each document ([PEBC Assessment & Review Protocol](#))

EBS 19-3 is comprised of two sections and is available on the [CCO Website](#) on the PEBC [Cancer Screening](#) page.

Section 1: Framework Domains and Recommendations
Section 2: Adaptation and Internal and External Review

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EDUCATION AND INFORMATION



Evidence-Based Series 19-3: Section 1

Psychosocial Health Care for Cancer Patients and Their Families: A Framework to Guide Practice in Ontario and Guideline Recommendations

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PURPOSE

The Cancer Care Ontario (CCO) Psychosocial Program created this report for two purposes:

- To create a psychosocial care framework that can be used to direct improvements in the quality of comprehensive cancer care for patients and their families in Ontario.
- To provide recommendations on the best strategies for meeting the psychosocial health care needs of cancer patients and their families at both the provider level (psychosocial health services) and the system level (psychosocial health interventions).

TARGET POPULATION

Adult cancer patients and their families.

INTENDED USERS

Practitioners and planners who care for cancer patients and their families: 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.

DEVELOPMENT OF THIS REPORT

The Psychosocial Oncology Working Group (see Section 2, Appendix 1) was convened to develop this document. The Group used the methods of the Practice Guidelines Development Cycle (1) and the ADAPTE process (2) to inform its strategy. The 2008 Institute of Medicine (IOM) standard *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs* (3) served as a foundation document upon which the Group created the framework and recommendations. The IOM document was chosen for its comprehensive coverage, quality, currency, content, and consistency.

The Working Group assessed the acceptability and applicability of each IOM recommendation to the Ontario context and adapted eight of the IOM recommendations to Ontario, adding a new feature, and reframing the adapted content into eight key defining domains within a framework. The Group adapted the IOM evidence to create 31 actionable recommendations aimed to implement high-quality psychosocial care services. Since this is not a de novo guideline but rather an adaptation of the IOM standard, the content of this document reflects the original from which it was drawn. For this reason, some important aspects of psychosocial care (e.g., highlighting in the framework aspects of the cancer care continuum, expanding the research section, prioritizing psychosocial needs) that were not included in the original IOM document have not been included here. 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 expertise of the Group, and recommendations for the development of future guidelines were constructed as needed.

Introduction: Cancer Care Ontario Psychosocial Oncology Framework

The eight key domains that define the CCO psychosocial oncology framework are adaptations of recommendations from the IOM report that have been integrated with the expert opinion of the Working Group to make them specific to the context in Ontario.

Section 1 of this document contains the framework domains and the summary recommendations. Section 2 contains the framework domains and their original source; the recommendations, along with links to the existing evidence, and their justification; and examples of specific interventions for their implementation.

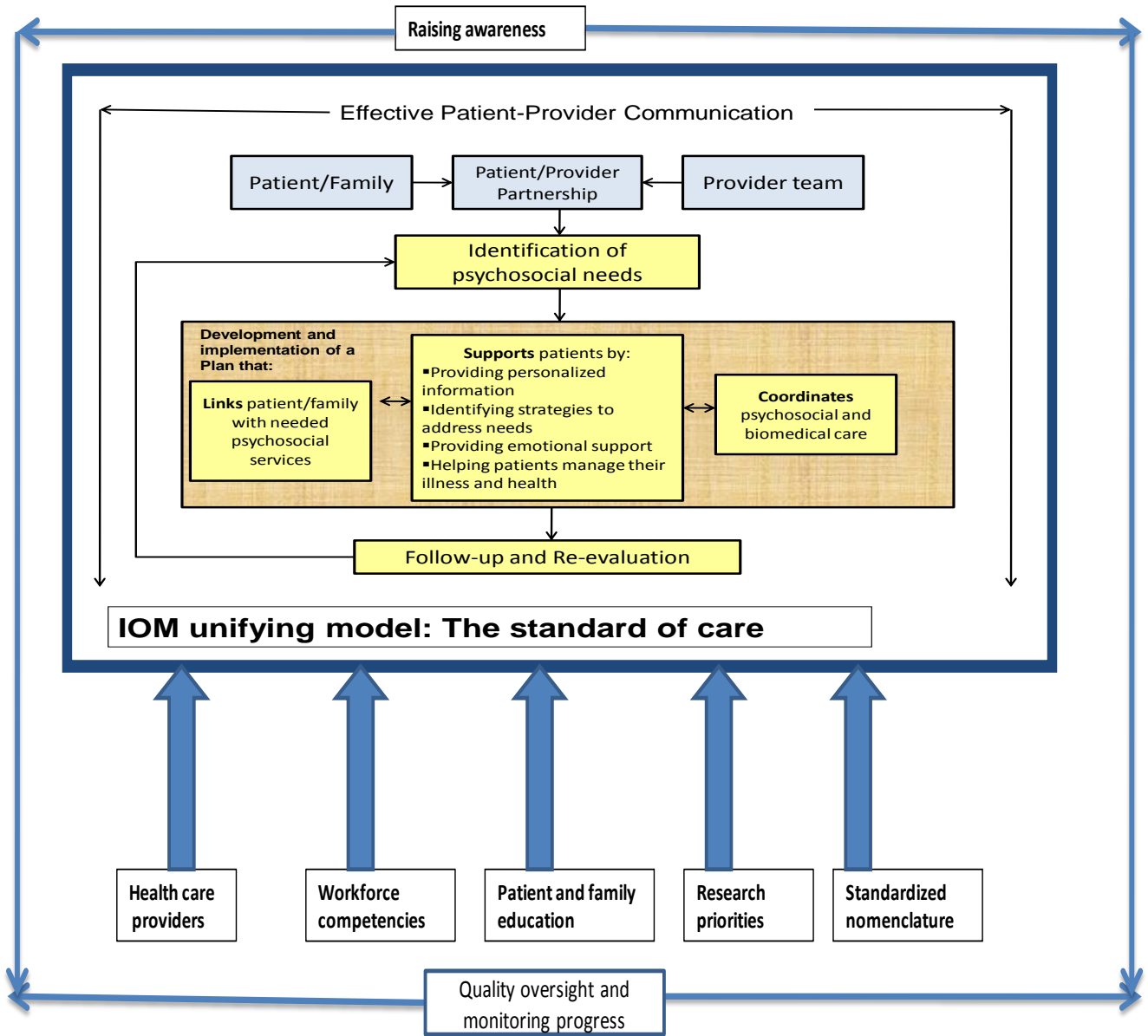
Table 1 lists the eight domains of the framework and is an easy reference, hyperlinked with the text of Sections 1 and 2 to help navigate this document.

Figure 1 is a pictorial representation of the psychosocial oncology framework, and of the interactions between and among its eight domains. The IOM unifying model (3) is at the centre of the framework, and is complemented by the other domains of the framework. The Raising Awareness and the Quality Oversight domains encompass the entire process, while the other domains underpin the unifying model.

Table 1. Framework domains and recommendations in Section 1 and Section 2.

Domains	Section 1 Framework and summary recommendations	Section 2 Development and review
A. Raising Awareness: Understanding and Defining Psychosocial Health Care.	Page 5	Page 6
B. Standard of Care	Page 6	Page 7
• <i>Facilitating effective communication</i>	Page 6	Page 8
• <i>Identifying psychosocial health needs</i>	Page 6	Page 8
• <i>Designing and implementing a plan</i>	Page 6	Page 9
• <i>Systematically monitoring, evaluating, and re-adjusting plans</i>	Page 7	Page 12
C. Health Care Providers	Page 8	Page 13
D. Patient and Family Education	Page 8	Page 14
E. Quality Oversight and Monitoring Progress	Page 8	Page 16
F. Workforce Competencies	Page 9	Page 18
G. Standardized Nomenclature	Page 9	Page 19
H. Psychosocial Research	Page 10	Page 20

Figure 1. Psychosocial oncology framework.



Note: Adapted from the Institute of Medicine (3), p. 158.

Framework Domains and Recommendations

Domain A. 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.

Recommendation

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

Psychosocial Oncology is a professional subspecialty [*sic*] 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 (4).

Domain B. Standard of Care

Comprehensive cancer care should ensure the provision of appropriate psychosocial health services by:

- facilitating effective communication between patients, their families and care providers;
- identifying psychosocial health needs of patients and families;
- designing and implementing a plan that:
 - links the patient/family with needed psychosocial health care services,
 - coordinates biomedical and psychosocial health care,
 - engages and supports patients/families in managing their illness and health; and
- systematically monitoring, evaluating, and re-adjusting plans.

Recommendations

Facilitating Effective Communication

- 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 develop formal strategies to teach communication techniques to patients.

The Working Group invites interested readers to refer to the PEBC Evidence-based Series (EBS) #19-2: *Provider-patient communication: a report of evidence-based recommendations to guide practice in cancer* (5) for more information, which is available from: <http://www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=44425>

Identifying Psychosocial Health Needs

- 3) All patients/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 (e.g., remission, progression, recurrence).

- 4) Screening should be performed with validated tools encompassing a comprehensive range of health-related psychosocial problems, including physical symptoms, emotional or spiritual distress, logistical 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.

Designing and Implementing a Plan

- 7) Health care providers should work with the patient and family to develop a plan of care that contains clear goals, aims at assisting in managing the illness and complex functional abilities (e.g., swallowing, communication, ambulation), and maintains the highest possible level of functioning and well-being.
- 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 (e.g., cognitive-behavioural therapy, supportive psychotherapy, family/couples therapy) and/or pharmacotherapy, as indicated.
- 13) Health care organizations should develop interprofessional 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 provide information about community resources that can help patients with changing these 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.

Systematically Monitoring, Evaluating, and Readjusting Plans

- 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

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.

Recommendations

- 19) All cancer care providers should participate in education and training programs to increase their awareness of the significance of psychosocial care and 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 these 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

Cancer patients and their families should be educated to expect, and request when necessary, cancer care that meets psychosocial health care needs.

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

For more specific recommendations, the Working Group invites readers to refer to the following PEBC publications:

- Special Report: *Establishing comprehensive cancer patient education services; a framework to guide Ontario cancer education services* (6), available from <http://www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=14324>
- EBS #20-2: *Effective teaching strategies and methods of delivery for patient education* (7), available from: <http://www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=60065>.

Domain E. 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. These findings could be used to inform an evaluation of the impact of this report.

Recommendations

- 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

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 them as fully as possible in accordance with a model that integrates biomedical and psychosocial care.

Recommendations

- 24) Workforce planning for cancer services should include planning for all psychosocial specialists (i.e., 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 the psychosocial service planning.
- 26) Cancer programs should support additional education for health care professionals, given they may not have specialized credentials in psychosocial oncology. Relevant courses such as the Inter-professional Psychosocial Oncology Distance Education Program (IPODE, <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

There is a need to develop a standardized, trans-disciplinary, taxonomy and nomenclature for psychosocial health services.

Recommendations

27) CAPO, the Canadian Partnership Against Cancer (CPAC), and CCO should collaborate with provincial, national, and international bodies to develop a standardized, trans-disciplinary taxonomy and nomenclature for psychosocial health services.

This initiative should aim to incorporate this taxonomy and nomenclature into an organization of practices and education, as well as into databases such as the National Library of Medicine Medical Subject Headings (MeSH), PsycINFO, the Cumulative Index to Nursing and Allied Health Literature (CINAHL), and the Excerpta Medica Database (Embase).

Domain H. Psychosocial Research

Organizations sponsoring research in oncology care should include the following areas among their funding priorities:

- 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:
 - 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; and
 - approaches for effectively linking patients with services and coordinating care, and for the uptake of psychosocial health services.
- At the provider level, the identification of 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. This effort should include:
 - 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 different types and levels of distress; and
 - developing standard outcome measures for assessing the effectiveness of these services.

Research on the use of these tools, strategies, and services should also focus on barriers to patient referral, and how best to ensure the delivery of appropriate psychosocial services to vulnerable populations such as those with low literacy, older adults, the socially isolated, those living in remote areas, and those who are members of cultural minorities.

Recommendations

- 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 (i.e., levels of distress, natural course of symptoms, availability of social supports, temperamental traits, demographics), as well as theory-guided examinations of mechanisms for the obtained effects.
- 29) The development of more effective treatments for mental health problems in cancer particularly through randomized controlled trials (RCTs) testing collaborative care and multicomponent interventions and comparing the effectiveness of non-pharmacologic and pharmacologic treatments alone and combined.
- 30) An increased focus on the effects of receipt of psychosocial health services on physiological (i.e., endocrine and immunological functioning) and clinical outcomes, including nutritional and functional status.
- 31) Provincial and federal cancer research funding agencies should increase their support for psychosocial research. This can be accomplished either through dedicated funding priority calls for psychosocial care or by increasing funding allocation for psychosocial research in grant competitions.

FUTURE DIRECTIONS

The Working Group identified several important areas of clinical focus that were not included in the IOM document. In the Framework, Domain A. Raising Awareness is an essential prerequisite for uptake of this advice document. However, at the present time a clear understanding of the barriers to accessing psychosocial care and the best strategies for overcoming these barriers is lacking. The impact of financial strain and occupational disability faced by cancer patients is an important direction for future focus that will strengthen our ability to effect changes to the current structure of disability and extended health insurance coverage in Ontario. In accordance with the CCO definition of psychosocial oncology (8), this advice document advocates for a more multidisciplinary emphasis on cancer care. Further evaluation of the effectiveness of, and best strategies for, coordinating interprofessional care that includes practitioners from the biomedical and psychosocial sectors is required. Increased attention in these areas will provide a foundation for the development of needed future psychosocial guidelines addressing the needs of cancer patients and their families.

RELATED GUIDELINES

- PEBC EBS #19-2: *Provider-patient communication: report of evidence-based recommendations to guide practice in cancer.* (Available from: <http://www.cancercare.on.ca/pdf/pebc19-2s.pdf>)
- PEBC Special Report: *Multidisciplinary cancer conference standards.* (Available from: URL: <http://www.cancercare.on.ca/pdf/pebcmccs.pdf>)
- PEBC Special Report: *Establishing comprehensive cancer patient education services a framework to guide Ontario cancer education services.* (Available from: <http://www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=14324>)
- PEBC EBS #20-2: *Effective teaching strategies and methods of delivery for patient education.* (Available from: <http://www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=60065>)

- Canadian Association of Psychosocial Oncology: *Standards of psychosocial health services for persons with cancer and their families.* (Available from: <http://capo.ca/eng/CAPOstandards.pdf>)
- Canadian Partnership Against Cancer (Cancer Journey Action Group) and the Canadian Association of Psychosocial Oncology: *A Pan-Canadian clinical practice guideline: assessment of psychosocial health care needs of the adult cancer patient.* (Available from: <http://capo.ca/eng/AdultAssesmentGuideline122109.pdf>)

Further practical guidance tools can also be found in:

- Canadian Partnership Against Cancer: *Person-centred care toolkit.* (Available from: http://www.partnershipagainstcancer.ca./cjag_toolkit)
- Cancer Care Ontario: *Symptom management tools.* (Available from: <http://www.cancercare.on.ca/toolbox/symptools>) (Guidelines for responding to anxiety and depression will be available soon in this site.)

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Psychosocial Health Care for Cancer Patients and Their Families: Adaptation and Internal and External Review

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INTRODUCTION

Cancer is an increasing concern for the Canadian health care system. On the basis of current incidence rates, almost 40% of Canadian women and 45% of men will develop cancer during their lifetime, and approximately 1 in 4 Canadians will die from the disease (1). In 2008, 166,400 new cases of cancer were estimated in Canada, 63,000 of which were estimated to occur in Ontario. With advances in disease treatment, cancer is increasingly becoming a survivable illness. In 2004, approximately 853,400 Canadians (2.7% of the overall population) were cancer survivors (1), and this figure is destined to increase in future years (2).

Cancer patients, throughout the trajectory of their illness from diagnosis through treatment and beyond, may live for many years with the consequences of the disease or the side effects of its treatment. The consequences of the disease or the treatment can include permanent damage to physical health, alteration to normal development, emotional or mental health problems (3), or social problems (e.g., financial problems, reduced employment opportunities, the stigma of disability, and social/spiritual support concerns).

Cancer has thus become an illness that has all the hallmarks of a chronic condition needing continuing, long-term management in psychological, behavioural, and social, as well as strictly biomedical, arenas. Psychosocial care is a whole person approach to cancer care, addressing the social, psychological, emotional, spiritual, and functional aspects of the patient journey, through a team of care and service providers from various disciplines.

Cancer patients at all ages require psychosocial support. The elderly account for 42% of new cancer cases; 60% of deaths due to cancer occur among those who are at least 70 years old (1). For these individuals, the need for support is greater because of frequent co-morbidity and psychosocial issues that are intrinsically associated with aging. People who are young to middle-aged (20 to 59 years of age) are stricken in the most productive time of their lives (in Canada, 30% of new cancer cases and 18% of cancer deaths occur in this age group). Rates of cancer in children are lower and survival rates are higher than in adults, but the disruption to development and the long-term consequences can have an even greater impact for this group.

Families of cancer patients are also affected by the disease of their loved ones, often experiencing emotional distress, shifting of roles, financial burden, caregiver distress, and fear of losing their loved one, all of which can change their lives significantly (4,5).

Cancer patients experience a number of barriers to attaining optimal psychosocial health care. These barriers include: stigmatization; reduced awareness of available resources or inability to access them; lack of knowledge, skills and information necessary to manage the disease and the consequences of treatment; poor communication between patients and their health care providers; poor communication among health care professionals; and physical and financial barriers. These barriers can be exacerbated by a reduced knowledge and understanding on the part of health care providers of the key role psychosocial care plays in supporting the biomedical treatment of cancer patients. Legislative and regulatory constraints, health care professional education curricula with a primarily biomedical focus, and the structure of the clinical practice setting can further hinder access to psychosocial health care.

Failure to address these 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, both for cancer patients and their family members (4,6). In order to address these barriers, there is a need to provide coordinated psychosocial health services. In Ontario, legislation and some infrastructures for dealing with chronic diseases, even if not specific to cancer, do exist (7-9), both at the provincial and the regional level (8), but in practice they are primarily used for prevention and biomedical treatment rather than for the management of the larger array of psychosocial issues encountered by cancer patients. Services are often fragmented and underfunded (10). Many services that address the cancer patients' psychosocial needs, including mental health and behavioural, social, and spiritual services, exist in Ontario, but they are fragmented and not accessible to cancer patients to the same extent across the province, with rural areas being at the greatest disadvantage (11). Furthermore, the interprofessional nature of the services that has often been advocated in theoretical models and guidelines (7,12) is not always reflected in practice.

The CCO Psychosocial Oncology Program, headed by Esther Green, identified the need for an advice document to help address these issues. The 2008 Institute of Medicine standard *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs* (13) was identified as a document that could be adapted to produce an advice document relevant to the context of Ontario. The conceptual model presented by the IOM document is germane to the Ontario Chronic Disease Prevention and Management Framework (7), and the definition of

psychosocial health services brought forward by the IOM document matches the reality at both the provider and system level in Ontario. The CCO Psychosocial Oncology Program Panel worked at this project in collaboration with the Program in Evidence-based Care (PEBC).

The PEBC is an initiative of the Ontario provincial cancer system, CCO (14). The PEBC mandate is to improve the lives of Ontarians affected by cancer, through the development, dissemination, implementation, and evaluation of evidence-based products designed to facilitate clinical, planning, and policy decisions about cancer care. The PEBC produces evidence-based guidelines, known as Evidence-based Series (EBS) reports, using the methods of the Practice Guidelines Development Cycle (14,15). The EBS report consists of a comprehensive review of the evidence base for a specific cancer topic, an interpretation of and consensus agreement on that evidence by a working group or panel composed of relevant experts in the subject of the report, the resulting recommendations, and an external review by Ontario clinicians and other stakeholders in the province for whom the topic is relevant. The PEBC has a formal standardized process to ensure the currency of each document, through the periodic review and evaluation of the scientific literature and, where appropriate, the integration of that literature with the original guideline information.

In the following sections we present the methods relative to the adaptation process; to the internal and external review process; the results relative to the adaptation process; the feedback of the Internal Review Panel and our response to it, and the feedback from the External Review Panel and our response to it.

METHODS

Adaptation

A team comprised of experts in psychosocial oncology care and research methodologists was assembled at the start of the project (see Appendix 1). The Practice Guidelines Development Cycle (14) and the ADAPTE process (16) were the key methodological strategies used to create this document.

First, the ADAPTE process was used to adapt the recommendations provided in the IOM standard document to Ontario. The ADAPTE process is a systematic approach to the adaptation of guidelines produced in one context for use in another context (<http://www.adapte.org/>). The adaptation process involves three phases: A set-up phase, an adaptation phase, and a finalization phase. During the initial set-up phase the topic was selected, the necessary skills and resources were identified, the Psychosocial Oncology Working Group was established, the IOM document was selected for review, and feasibility for adaptation was assessed. Once the set up phase was completed, the Working Group assessed the IOM document for quality, currency, content, and consistency. Four members of the Working Group: a clinician, a manager, and two methodologists from the PEBC, evaluated the quality of the IOM standard using the AGREE instrument (17) (also available at <http://www.agreetrust.org/>). The AGREE instrument consists of 23 items organized in six domains that capture guideline quality. The six domains include: scope and purpose, stakeholder involvement, rigour of development, clarity and presentation, applicability, and editorial independence. Each item is rated on a 4-point scale described as: 4 = strongly agree, 3 = agree, 2 = disagree, and 1 = strongly disagree. A section for overall assessment is included at the end and provides the opportunity to make a judgement on the overall quality of the document. Inter-rater differences of more than one point were addressed among the group to achieve overall consensus. All members of the Working Group met and determined currency, content, and consistency of the IOM document. In order to check for currency, the developers of the IOM document were contacted, and the original search strategies were obtained. Consistency and content were evaluated with a series of questions which are part of the ADAPTE process (Appendix 3 A). Finally, the Working Group assessed the acceptability

and the applicability to Ontario of each one of the 10 recommendations presented in the IOM document according to the series of questions which are part of the ADAPTE toolkit (Appendix 3 B). The Working Group decided which of the 10 original recommendations should be adopted, which should be adopted with alterations, and which should either be rejected or require a new recommendation to be created. Finally, feedback was obtained from stakeholders impacted by the guideline and a process was established for the review and updating of the adapted guideline.

Internal Review

Prior to the submission of this EBS draft report for external review, the report was reviewed by the PEBC Report Approval Panel (RAP), which consists of two members, including an oncologist, with expertise in clinical and methodological issues, and by a panel of experts in the field of psychosocial oncology in Ontario.

External Review

The PEBC external review process is two-pronged and includes a targeted peer review that is intended to obtain direct feedback on the draft report from a small number of specified content experts and a professional consultation that is intended to facilitate dissemination of the final guidance report to Ontario practitioners. Following the review and discussion of Section 1: Framework and Summary Recommendations and Section 2: Development and Review of this report and the review and approval of the report by the PEBC Report Approval Panel, the Psychosocial Oncology Working Group circulated Sections 1 and 2 to external review participants in Ontario for review and feedback.

Targeted Peer Review: During the guideline development process, seven targeted peer reviewers from Ontario considered to be clinical and/or methodological experts on the topic of psychosocial oncology were identified by the Working Group. Several weeks prior to completion of the draft report, the nominees were contacted by e-mail and asked to serve as reviewers. Six agreed, and the draft report and a questionnaire were sent via e-mail for their review. The questionnaire consisted of items evaluating the methods, results, and interpretive summary used to inform the draft recommendations. The questionnaire also asked whether the draft recommendations should be approved as a guideline. Written comments were invited. The questionnaire and draft document were sent out on July 14, 2010. Follow-up e-mail reminders were sent at two weeks and four weeks. The Psychosocial Oncology Working Group met and reviewed the responses to the questionnaire.

Professional Consultation: Feedback was obtained through a brief online survey of health care professionals who are the intended users of the guideline, namely clinical nurse specialists, clinical leaders, clinical coordinators in the supportive care and genetic counselling area, 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 oncologists and psychiatrists.

Participants were asked to rate the overall quality of the guideline and whether they would use and/or recommend it. Written comments were invited. Participants were contacted by e-mail and directed to the survey website where they were provided with access to the survey, the guideline recommendations (Section 1), and the evidentiary base (Section 2). The notification e-mail was sent on July 14, 2010. The consultation period ended on August 13, 2010. The Psychosocial Oncology Working Group reviewed the results of the survey.

RESULTS

Adaptation and Initial Internal Review

The Working Group agreed that the IOM standard document was such that it could be recommended for adaptation in Ontario, because of its overall quality, currency and consistency, acceptability, and applicability. The detailed results of the assessment of content and consistency, currency, and validity of the IOM document, performed using the ADAPTE process, along with a brief summary of the supporting evidence gathered by the IOM Committee and the tools used during the adaptation process (<http://www.adapte.org/>) are presented in Appendix 2 (A). Appendix 2 (B) presents considerations about the acceptability and adaptability of each of the IOM recommendations to Ontario, and Appendix 2 (C) reports the results of the quality assessment performed on the IOM document using the AGREE instrument (<http://www.agreetrust.org/>).

After completing the adaptation process, eight of the ten recommendations from the IOM Standard were adapted for Ontario by the Working Group. Five of the IOM recommendations (The Standard of Care, Healthcare Providers, Patient and Family Education, Workforce Competencies, Standardized Nomenclature, and Psychosocial Research) were adapted with minor changes. Two of the IOM recommendations (Quality Oversight and Promoting Uptake and Monitoring Progress) were merged and heavily modified to constitute Domain E of the framework. Two recommendations from the IOM Standard were not adapted for Ontario (Support for Dissemination and Uptake and Support from Payers) because they did not fit the context of Ontario.

The document was submitted to the (RAP) for an initial review. Key issues raised by the RAP included:

- The scope of the document should be reconsidered because the target audience of the IOM committee and that of the Psychosocial Oncology Working Group are not the same.
- The document reads more like a framework than a guideline.
- The document does not present actionable recommendations (e.g., the interventions are not profiled).
- A suggestion was made to reframe the adapted recommendations into a framework, and for each one, based on the evidence provided by the IOM document and on the expert opinion of the Panel, create actionable recommendations or recommend the creation of new guidelines.

In response to the RAP review, the Psychosocial Oncology Working Group met several times in teleconference and reframed the nine adapted recommendations into an eight-domain framework (see Section 1). The evidence contained in the IOM standard was combined with the expert opinion of the members of the Working Group and was used to create actionable recommendations for psychosocial cancer care in Ontario. The document was significantly rewritten to incorporate the new framework organization and actionable recommendations.

To illustrate the development process from initial IOM recommendation to framework domain to actionable recommendation(s) that occurred during the initial drafting of the report and the revision in response to the RAP review, the opinion of the Working Group on the original IOM recommendations (with page numbers from the IOM document) is presented, with the adapted version of the recommendation transformed into a domain of the framework for psychosocial oncology in Ontario. The relative actionable recommendations and their justification, along with some example of strategies for implementation, follow.

IOM Recommendation: The Standard of Care

All parties establishing or using standards for the quality of cancer care should adopt the following as a standard:

All cancer care should ensure the provision of appropriate psychosocial health services by

- *facilitating effective communication between patients and care providers;**
- *identifying each patient's psychosocial health needs;*
- *designing and implementing a plan that*
 - *links the patient with needed psychosocial services,*
 - *coordinates biomedical and psychosocial care,*
 - *engages and supports patients in managing their illness and health; and*
- *systematically following up on, re-evaluating, and adjusting plans...*

...Although the language of this standard refers only to patients, the standard should be taken as referring to both patients and families when the patient is a child, has family members involved in providing care, or simply desires the involvement of family members (13) (p. 199).

Evidence

The evidence in support of this component of the framework had been collected by the IOM Committee through a multilayered systematic review intended to identify effective psychosocial health interventions and models of psychosocial care. Within each component of this domain, the IOM Committee searched for systematic reviews and single controlled and observational studies of interventions tested in cancer survivors, and in populations with other chronic conditions. Although some areas of this domain have been researched extensively and there is a strong body of evidence in support of them, sometimes the evidence for cancer populations is mixed or scarce, and some of the interventions are based on longstanding practice in health care rather than on evidence.

Opinion of the Working Group

The Working Group considered the recommendation *The Standard of Care* applicable to Ontario. It was noted that the IOM definition of psychosocial care is slightly different from what is used in Ontario. The IOM document does not appear to include the full range of health care disciplines that are made explicit in the Canadian definition (e.g., dietitians, speech language pathologists, physiotherapists, occupational therapists, spiritual care practitioners) and these professionals are part of the psychosocial team in Ontario. It was therefore determined that this recommendation be adopted with slight modifications.

The Working Group, in reviewing the IOM recommendations, decided that a new component was needed in the Ontario document, to reflect the all encompassing need to raise awareness and address the stigma around psychosocial care, and that this new element should form Domain A of the framework. The recommendation for “standard of cancer care” would then become Domain B.

Domain A. 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.

Psychosocial health care in oncology is defined as:

...a whole person approach to cancer care, addressing the social, psychological, emotional, spiritual and functional aspects of the patient journey through a team of care and service providers from various disciplines).¹

Psychosocial health care services are defined as:

...psychological and social services and interventions that enable patients, their families, and health care providers to optimize biomedical health care and to manage the psychological/behavioural and social aspects of illness and its consequences so as to promote better health (13) (p. 9).

This definition operates at both the provider level (psychosocial services, e.g., provision of information, peer support programs, psychiatric treatment, health promotion interventions, financial counselling) and the system level (psychosocial interventions, e.g., needs assessment, psychosocial referral, care coordination, follow-up evaluation).

Domain A. Raising Awareness contains a directive on how to place psychosocial care in the context of comprehensive cancer care in Ontario and ensures recognition of the importance of more interdisciplinary care for cancer patients and their families. This element was not originally part of the IOM document and is based on the Working Group's expert opinion. The Working Group felt this domain to be very important in Ontario where there is a need for more education and awareness among all providers about the psychosocial issues that cancer patients and their families experience. The definition of psychosocial health services from the IOM document (13) and the CCO definition of psychosocial health care in oncology¹ are presented as part of this domain.

Recommendation

- 1) That the definition put forward by CAPO be adopted to guide psychosocial oncology in Ontario:

Psychosocial Oncology is a professional subspecialty [sic] 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.²

Justification for the Recommendation: This definition is currently in use by CCO and should therefore be guiding psychosocial oncology in each of the Regional Cancer Programs.

¹ Cancer Care Ontario [Internet]. What's psychosocial oncology? Toronto (ON): Cancer Care Ontario; 2010 [cited 2010 Oct 10]. Available from: <http://www.cancercare.on.ca/cms/One.aspx?portalId=1377&pageId=8736>.

² Canadian Association of Psychosocial Oncology. Standards of psychosocial health services for persons with cancer and their families. Toronto (ON): Canadian Association of Psychosocial Oncology (CAPO); 2010 May 28 [cited 2009 Apr]. Available from: <http://capo.ca/eng/CAPOstandards.pdf>.

Domain B. Standard of Care

Comprehensive cancer care should ensure the provision of appropriate psychosocial health services by:

- facilitating effective communication between patients, their families, and care providers;
- identifying psychosocial health needs of patients and families;
- designing and implementing a plan that:
 - i) links the patient/family with needed psychosocial health care services,
 - ii) coordinates biomedical and psychosocial health care,
 - iii) engages and supports patients/families in managing their illness and health; and
- systematically monitoring, evaluating, and readjusting plans.

Domain B. Standard of Care indicates the strategies to be used for providing comprehensive psychosocial oncology services. This domain has been adapted from the most important of the IOM recommendations that was the basis for the IOM Committee model (13). The statements in the IOM document were germane to the experience of the Working Group in Ontario.

Recommendations

Facilitating Effective Communication

- 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 develop formal strategies to teach communication techniques to patients.

Examples of strategies include encouraging patients to write down their questions and concerns before meeting with clinicians, providing written “prompts” or reminders of key questions or issues, and providing information and decision aids about illness, treatment, and health by means of booklets, videos, coaching sessions, and diary keeping.

Justification for the recommendation: Evidence was presented in the IOM document on:

- The effectiveness of improving patients’ participation in their care (with prompts, audiotaping of visits, decision aids) in improving patient involvement in treatment decisions (18-20).

The Working Group invites readers interested in this aspect of the Standard of Care to refer to the PEBC Evidence-based Series (EBS) #19-2: *Provider-patient communication: A report of evidence-based recommendations to guide practice in cancer* (21).

Identifying Psychosocial Health Needs

- 3) All patients/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 (e.g., remission, progression, recurrence).
- 4) Screening should be performed with validated tools encompassing a comprehensive range of health-related psychosocial problems, including physical symptoms, emotional or spiritual distress, logistical 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.

In Ontario, the Edmonton Symptom Assessment System (ESAS) and the Canadian Problem Check List are the screening tools that have been recommended by CCO and the Screening for Distress initiative of the Cancer Journey Action Group, Canadian Partnership Against Cancer (CPAC). Additional practical guidance tools can be found in the Canadian Partnership Against Cancer Person-Centred Care Toolkit (http://www.partnershipagainstcancer.ca/cjag_toolkit); and in the Cancer Care Ontario Symptom Management Tools (<http://www.cancercare.on.ca/toolbox/symptools>). Guidelines for responding to anxiety and depression will be available soon on this site.

Justification for the recommendations: These recommendations are adapted from the National Comprehensive Cancer Network (NCCN) Distress Management Guidelines (22), combined with the expert opinion of the Working Group. The IOM document reports that:

- Relying on the patient to volunteer information and on the provider to ask questions for the detection of psychosocial needs has been shown to be ineffective (23-26);
- Strong evidence is available on the effectiveness of validated distress screening tools (24,27-33) and need assessment tools (34) in identifying psychosocial health needs;
- Recent critical reviews of psychosocial health screening in both primary care and cancer populations suggest that, in order to improve patient outcomes, such screening must necessarily be accompanied by an effective treatment and follow-up plan (35-38).

Designing and Implementing a Plan

- 7) Health care providers should work with the patient and family to develop a plan of care that contains clear goals, aims at assisting in managing the illness and complex functional abilities (e.g., swallowing, communication, ambulation), and maintains the highest possible level of functioning and well being.

Justification for the recommendation: According to the IOM document, this recommendation is based on longstanding practice, on the logic behind developing a plan for action, and on research studies which showed that case management and disease management programs that used a structured plan of care were more effective in improving patient outcomes and in reducing costs, and that preventive home visits were effective if they were based on multidimensional assessment (39,40).

i) Linking patient and family to psychosocial health services

- 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.

Justification for the recommendation: The IOM document reports that:

- Overall, evidence for the effectiveness of structured referral in linking the patient to services has been poor (41-44);

- Individual examples, however, show the value of referral (e.g., the American Cancer Society, which depends on referrals for their clients, indicated that referrals can successfully link patients with needed services);
- Case management has been effective in improving health outcomes (36,39,45-53).
- On-site collocation and the clinical integration of services are effective in linking patients with collocated services (54,55); improving treatment outcomes (56,57); ensuring that patients utilize the necessary services (43); and improving outcomes such as the easy exchange of expertise, easier collaboration, and effective, frequent and timely communication (58-63).
- Care/system navigators improved patient screening and follow-up after positive screening for the detection of cancer (64,65).

ii) Coordinating biomedical and psychosocial health care

9) At the system level, structures and mechanisms should be put into place to ensure the coordination of biomedical and psychosocial care.

The strategies that can be used to coordinate care include interprofessional teams, regularly scheduled interprofessional meetings, case management, disease management, in-person contact, patient support personnel (e.g., patient educators, system navigators), guidelines and protocols that incorporate attention to psychosocial issues, electronic health records, and personal health records, in order to meet patient and family psychosocial and biomedical needs.

Justification for the recommendations: The IOM report showed that:

- Evidence is limited on either the effectiveness of biomedical and psychosocial coordination or the various strategies for such coordination in the cancer population (40,62);
- Different coordination strategies in psychiatric populations were effective in facilitating the development of common goals and information sharing between medical and mental health providers (54);
- Multidisciplinary teams were effective in reducing mortality and rehospitalizations in populations other than cancer patients (66).

10) Health care providers and patient advocacy organizations should provide patients and their families with condition-specific information tailored to the individual patient's learning needs and style.

Justification for the recommendation: The IOM document reported on high-quality evidence showing that:

- Providing oral and written, condition-specific, information and fostering patient participation in their own care improved knowledge and recall of health information (67).
- Novel strategies were effective in increasing knowledge and satisfaction with decision making, reducing decisional conflict, increasing self-efficacy and task behaviour, and improving confidence in the doctor-patient encounter (68-70).
- Non-print formats are of greater benefit for underserved, low-literacy groups, where these formats have an impact on health behaviour (67).
- A Canadian multicomponent educational intervention was effective in facilitating surgical decision making among breast cancer patients (71).

- 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 (e.g., cognitive-behavioural therapy, supportive psychotherapy, family/couples therapy) and/or pharmacotherapy, as indicated.

Justification for the recommendations: One way to provide emotional support to cancer patients is through peer-led or professionally-led support groups. Although the evidence base for the effectiveness of cancer support groups has been hampered by methodological difficulties, overall the evidence supports their effectiveness in improving knowledge, coping skills, sense of self-efficacy, and interactions with others, particularly medical professionals (24,72-79). Similarly, the evidence for the effectiveness of both psychotherapeutic approaches and pharmacotherapy is mixed, arising from a lack of consistent taxonomy of interventions (see Framework Domain G. Standardized Nomenclature), appropriate outcomes measures, and adequately designed trials. The Working Group concludes that there is statistically significant, clinically relevant evidence to support the effectiveness of both psychotherapeutic and pharmacologic treatments in helping to manage anxiety or depression in adults with cancer (80-89).

- 13) Health care organizations should develop interprofessional collaborative care models for the delivery of comprehensive cancer care to ensure 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.

Justification for this recommendation: Illness self-management incorporates education and coaching tailored to the needs and learning styles of individual patients. Patients' active participation in their own care and lifestyle changes can significantly affect the severity of the disease and its impact on quality of life. Programs to enhance illness self-management usually contain interprofessional and multicomponent elements, including psychoeducation, self-care, self-management support, cognitive-behavioural interventions and problem solving. The IOM document presented good evidence of:

- The effectiveness of such programs in assisting cancer patients to cope with specific physical symptoms (e.g., fatigue, lymphedema, nausea), psychological distress, sexual dysfunction, and interaction with multiple providers (90-99);
- The pro-self program involves nurses coaching cancer patients and their families through the provision of basic disease and treatment information, approaches to symptom management, and problem-solving assistance. Pro-self is the most extensively studied strategy and has demonstrated significant reductions in pain intensity and more appropriate opioid use in several randomized trials (95,100-103);
- Nurse-led multicomponent home intervention helping lung cancer patients to maintain independence longer and reduce rehospitalization (104), improve mental health status in solid tumour patients (105), reduce caregiver distress in the palliative care of lung cancer patients (106), and improve survival among postsurgical cancer patients (49).

There is sufficient evidence in the literature for the effectiveness of such illness self-management programs to warrant further development and expansion of the collaborative care aspects of such programs.

- 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 provide information about community resources that can help patients with changing these 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.

Justification for the recommendations: The effect on health or health care of providing these material and logistical resources has been the focus of limited research. They are endorsed based on their long-standing and wide acceptance. Community organizations include not-for-profit cancer support programs such as Wellspring (<http://www.wellspring.ca/>) or the Canadian Cancer Society (<http://www.cancer.ca/>).

iii) Managing disruptions in family, school, and work life

- 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.

Examples of services for patients include personal care and homemaker services, cognitive testing, cognitive remediation, ecological/environmental interventions, pharmacotherapy, and the use of rehabilitation professionals (i.e., occupational therapists, speech language pathologists, and physiotherapists); examples of services for the family include education on how to respond to illness-related problems, caregiver support groups, and spousal and children's grief counselling.

Justification for this recommendation: This recommendation for assistance with activities of daily living is based on longstanding practice and acceptance, and research evidence in support of it was not reviewed. There has been little research on approaches to reducing cancer-related cognitive impairment (107,108). Evidence for the effectiveness of family and caregiver support in cancer is also limited and weak, suffering from an absence of standardized outcome measures, difficulties with randomization, and methodological problems such as the lack of longitudinal designs and failure to account for selective attrition (109-113). However, the absence of research is not evidence of an intervention's ineffectiveness, and these services are being endorsed based on their clinical significance and the expert opinion of the Working Group.

- 17) Health care providers should take into account the financial constraints of patients and support their access to appropriate services.

Justification for the recommendation: This recommendation is based on the expert opinion of the Working Group.

Systematically Monitoring, Evaluating, and Readjusting Plans

- 18) Health care professionals should systematically follow up on the uptake of services by patients, any problems encountered, and patient satisfaction with care.**

Telephone calls to patients to monitor their status, home visits by care managers or other personnel, scheduled outpatient visits, use of the Internet or web-based technology are examples of strategies that can be used to perform follow up.

Justification for the recommendation: The IOM report presented evidence of the effectiveness of the above-mentioned strategies for follow up of patient care (39,40,46,114,115).

IOM Recommendation: Healthcare Providers

All cancer care providers should ensure that every cancer patient within their practice receives care that meets the standard for psychosocial health care. The National Cancer Institute should help cancer care providers implement the standard of care by maintaining an up-to-date directory of psychosocial services available at no cost to individuals/families with cancer (13) (p.237).

Evidence

This recommendation is based on evidence supporting the IOM recommendation *The Standard of Care*, examples of how the standard has been implemented by some oncology practices in the US, and examples of how it can be implemented by others such as primary care physicians. The IOM Committee, in drafting this recommendation, expects that oncology providers will lead the way in the implementation of the recommendation, although it acknowledges that some of the psychosocial health services might be in scarce supply.

Opinion of the Working Group

The Working Group felt that this recommendation was acceptable and should be applied, with minor changes. In the smaller reality of Ontario, it would be more useful to patients and their families to have directories describing the resources available at the local level as opposed to a national list of services available. The recommendation adapted to Ontario with slight modifications is presented below.

Domain C. 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.

Domain C. Health Care Providers addresses the responsibility of all health care providers to make psychosocial care available to cancer patients and their families. A specification of the health care providers involved has been added, according to the reality in

Ontario, and to keep within the CAPO definition of psychosocial oncology adopted by the Working Group.

Recommendations

- 19) All cancer care providers should participate in education and training programs to increase their awareness of the significance of psychosocial care and 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 these areas

Examples of strategies to effectively enhance communication skills in health care professionals are programs carried out over a long period of time, using multiple teaching methods, allowing for practice, providing timely feedback, and allowing clinicians to work in groups with skilled facilitators.

Training in communication skills in Ontario is available through the *Maximizing your Patient Education Skills Workshop*³ offered by CCO's Patient Education Committee.

Justification for the recommendations: Evidence was presented in the IOM document on:

- The effectiveness of the tools and strategies for communication skill building in increasing patients' knowledge and satisfaction with decision making and in reducing decisional conflict (68).

- 21) Health care providers should maintain a directory of resources available to patients and their families at no cost.

Justification for the recommendation: These recommendations are based on the expert opinion of the IOM Committee and have been adapted to the reality of Ontario by the Working Group.

IOM Recommendation: Patient and Family Education

Patient education and advocacy organizations should educate patients with cancer and their family caregivers to expect, and request when necessary, cancer care that meets the standard for psychosocial care. These organizations should also continue their work on strengthening the patient side of the patient-provider partnership. The goals should be to enable patients to participate actively in their care by providing tools and training in how to obtain information, make decisions, solve problems, and communicate more effectively with their health care providers (13) (p. 237).

Evidence

This recommendation is based on the evidence supporting the IOM recommendation *The Standard of Cancer Care*, on examples of how the standard has been implemented by some oncology practices, and on examples of how it can be implemented by others such as primary care physicians.

³ Jones JM, Papadakos J, Bennett C, Blacker S, Catton P, Harth T, et al. Maximizing your Patient Education Skills (MPES): A multi-site evaluation of an innovative patient education skills training course for oncology health care professionals. Patient Educ Couns. Epub 2010 Sept 3.

Opinion of the Working Group

The Working Group considered this recommendation as a very good quality initiative, acceptable and applicable to Ontario. The IOM recommendation has been adapted with minor modifications.

Domain D. Patient and Family Education

Cancer patients and their families should be educated to expect, and request when necessary, cancer care that meets their psychosocial health care needs.

Domain D. Patient and Family Education broadens the domain of patient and family education to consider the importance of empowering patients to self-manage their disease and to consider how education informs and provides psychosocial support to patients.

Recommendation

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

Justification for the recommendation: This recommendation is based on the expert opinion of the Working Group and on the evidence contained in the CCO framework *Establishing Comprehensive Cancer Patient Education Services; a Framework to Guide Ontario Cancer Education Services* (116) and in the CCO guideline *Effective Teaching Strategies and Methods of Delivery for Patient Education* (117). Interested readers can refer to the above documents for more specific recommendations.

IOM Recommendation: Support for Dissemination and Uptake

The National Cancer Institute, the Centers for Medicare & Medicaid Services (CMS), and the Agency for Healthcare Research and Quality (AHRQ) should, individually or collectively, conduct a large-scale demonstration and evaluation of various approaches to the efficient provision of psychosocial health care in accordance with the standard of care. This program should demonstrate how the standard can be implemented in different settings, with different populations, and with varying personnel and organizational arrangements (13) (p. 239).

Evidence

The IOM recommendation is based on the evidence supporting the IOM *The Standard of Cancer Care*, on examples of how it has been implemented by some oncology practices and by others such as primary care physicians, and on the expert opinion of the IOM Panel.

Opinion of the Working Group

The Working Group decided that this recommendation cannot be adapted to the Ontario context. The Group opinion is that at the present time the focus needs to be on raising awareness of the need for psychosocial care, increasing knowledge and skills in psychosocial care providers, decreasing the stigma around psychosocial care, and addressing the need for effective, efficient services. The timing is too early for implementing a large-scale demonstration project, and it would be hard to find appropriate resources for it.

IOM Recommendation: Support from Payers

Group purchasers of health care coverage and health plans should fully support the evidence-based interventions necessary to deliver effective psychosocial health services:

- *Group purchasers should include provisions in their contracts and agreements with health plans that ensure coverage and reimbursement of mechanisms for identifying the psychosocial needs of cancer patients, linking patients with appropriate providers who can meet those needs, and coordinating psychosocial services with patients' biomedical care.*
- *Group purchasers should review cost-sharing provisions that affect mental health services and revise those that impede cancer patients' access to such services.*
- *Group purchasers and health plans should ensure that their coverage policies do not impede cancer patients' access to providers with expertise in the treatment of mental health conditions in individuals undergoing complex medical regimens such as those used to treat cancer. Health plans whose networks lack this expertise should reimburse for mental health services provided by out-of-network practitioners with this expertise who meet the plan's quality and other standards (at rates paid to similar providers within the plan's network).*

Group purchasers and health plans should include incentives for the effective delivery of psychosocial care in payment reform programs, such as pay-for-performance and pay-for-reporting initiatives-in which they participate (13) (p. 275).

Evidence

The IOM recommendation is based on a review that was, in turn, based on the five components of the model that underlies *The Standard of Care* (i.e., communication, identification of needs, care planning and linking patients to services, supporting patients in managing their illness, and coordinating psychosocial and biomedical care), on existing payment mechanisms and policies relevant to psychosocial health care services for cancer in the US, and on the IOM committee expert opinion.

Opinion of the Working Group

The Working Group decided that this recommendation cannot be adopted because it is incompatible with the culture, values, legislation, and health insurance policy in Ontario. The financing of the US health care system is almost entirely a commercial enterprise and is completely different from that of Canada. In Ontario, cancer care programs are not commercial enterprises, and are based primarily in provincially funded hospitals, with follow-up care being provided by primary care physicians. Many of the expenses patients incur for their treatment are covered by the Canadian universal health care system. This has vast implications for reimbursement systems, for the organization of care, and for the dissemination and uptake of recommendations.

IOM Recommendation: Quality Oversight

The National Cancer Institute, CMS, and AHRQ should fund research focused on the development of performance measures for psychosocial cancer care. Organizations setting standards for cancer care (e.g., National Comprehensive Cancer Network, American Society of Clinical Oncology, American College of Surgeons' Commission on Cancer, Oncology Nursing Society, American Psychosocial Oncology Society) and other standards-setting organizations (e.g., National Quality Forum, National Committee for Quality Assurance, URAC, Joint Commission) should

- *Create oversight mechanisms that can be used to measure and report on the quality of ambulatory oncology care (including psychosocial health care).*
- *Incorporate requirements for identifying and responding to psychosocial health care needs into their protocols, policies, and standards.*

Develop and use performance measures for psychosocial health care in their quality oversight activities (13) (p. 277).

Evidence

This recommendation is based on the expert opinion of the IOM committee.

Opinion of the Working Group

The Working Group deemed this recommendation acceptable because it meets the values and goals of all parties within Ontario. However, at this time, it would be difficult to identify funding bodies in Ontario to address this recommendation. Therefore, the Working Group decided that this recommendation should be adopted with major modifications.

Domain E. 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. These findings could be used to inform an evaluation of the impact of this report.

Domain E. Quality Oversight and Monitoring Progress was adapted by merging two recommendations in the IOM document, Quality Oversight and Promoting Uptake and Monitoring Progress, with major modifications to allow applicability in the Ontario context. The original recommendations were based on the expert opinion of the IOM committee, and the Working Group believes that this merged recommendation meets the values and goals of all parties in Ontario.

Recommendation

- 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.**

Justification for the recommendation: CCO has a provincial oversight role to determine and report on the quality of the cancer system, which includes monitoring and reporting on the performance of cancer programs intended to meet the needs of individuals at risk for, or living with, cancer.

IOM Recommendation: Workforce Competencies

- 1. Educational accrediting organizations, licensing bodies, and professional societies should examine their standards and licensing and certification criteria with an eye to identifying competencies in delivering psychosocial health care and developing them as fully as possible in accordance with a model that integrates biomedical and psychosocial care.*
- 2. Congress and federal agencies should support and fund the establishment of a Workforce Development Collaborative on Psychosocial Care during Chronic Medical Illness. This cross-specialty, multidisciplinary group should comprise educators, consumer and family advocates, and providers of psychosocial and biomedical health services and be charged with*
 - identifying, refining, and broadly disseminating to health care educators information about workforce competencies, models, and preservice curricula relevant to providing psychosocial services to persons with chronic medical illnesses and their families;*
 - adapting curricula for continuing education of the existing workforce using efficient workplace-based learning approaches;*
 - drafting and implementing a plan for developing the skills of faculty and other trainers in teaching psychosocial health care using evidence-based teaching strategies; and*
 - strengthening the emphasis on psychosocial health care in educational accreditation standards and professional licensing and certification exams by recommending revisions to the relevant oversight organizations.*
- 3. Organizations providing research funding should support assessment of the implementation in education, training, and clinical practice of the workforce competencies necessary to provide*

psychosocial care and their impact on achieving the standard for such care set forth in recommendation 1 (13) (p. 320).

Evidence

This recommendation is based on a narrative review of studies on health professional (i.e., physicians, nurses, social workers, mental health providers including psychologists, counsellors, and pastoral counsellors) educational programs in regard to their psychosocial content, their required qualifications, and the continuing education requirements in the US.

Opinion of the Working Group

The Working Group felt that this recommendation should be adopted, with modifications, because it meets the culture and values of practice settings in Ontario. At the present time in Ontario, some committees and infrastructures already exist, (e.g., Registered Nurses Association of Ontario, Ontario Association of Social Workers). The Group felt that this recommendation should be adjusted to fit the context of Ontario and emphasis should be put on interprofessional education. Advocating multidisciplinary, interdisciplinary education and training is in line with the mandate of CCO and of the Ontario Ministry of Health and Long-Term Care. The Working Group also noted that an emerging body of literature on the effectiveness of collaborative, multidisciplinary psychosocial care (118-121) supports the addition of this focus to the recommendation as part of Domain F of the framework.

Domain F. Workforce Competencies

Professional competencies in the delivery of psychosocial health care should meet the requirements of educational 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 them as fully as possible in accordance with a model that integrates biomedical and psychosocial care.

Domain F. Workforce Competencies was adapted from the corresponding IOM recommendation with major modifications. Changes have been made to put more emphasis on interprofessional education that is relevant to Ontario.

Recommendations

- 24) Workforce planning for cancer services should include planning for all psychosocial specialists (i.e., 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 the psychosocial service planning.
- 26) Cancer programs should support additional education for health care professionals, given they may not have specialized credentials in psychosocial oncology. Relevant courses such as the Interprofessional Psychosocial Oncology

Distance Education Program (IPODE, <http://www.ipode.ca/>) should be made available to all health care professionals who care for cancer patients and their families.

Justification for the recommendations: These recommendations come from the expertise of the Working Group.

IOM Recommendation: Standardized Nomenclature

To facilitate research on and quality measurement of psychosocial interventions, the National Institutes of Health (NIH) and AHRQ should create and lead an initiative to develop a standardized, transdisciplinary taxonomy and nomenclature for psychosocial health services. This initiative should aim to incorporate this taxonomy and nomenclature into such databases as the National Library of Medicine's Medical Subject Headings (MeSH), PsycINFO, CINAHL (Cumulative Index to Nursing and Allied Health Literature), and EMBASE (13) (p. 85).

Evidence

This recommendation is based on the difficulties that the IOM committee found in searching for psychosocial health services in the electronic databases of published literature.

Opinion of the Working Group

The Working Group considered this a very important recommendation because it meets the values and culture of practice settings in Ontario, and because there is a strong need to have a common language around issues of psychosocial health care. It can therefore be adopted with modifications.

Domain G. Standardized Nomenclature

There is a need to develop a standardized, transdisciplinary taxonomy and nomenclature for psychosocial health services.

Domain G. Standardized Nomenclature addresses the need for a common taxonomy in both the clinical and research areas of psychosocial oncology. It has been adapted from the corresponding IOM recommendation with minor changes.

Recommendations

- 27) CAPO, the Canadian Partnership Against Cancer (CPAC), and CCO should collaborate with provincial, national, and international bodies to develop a standardized, transdisciplinary taxonomy and nomenclature for psychosocial health services.

This initiative should aim to incorporate this taxonomy and nomenclature into an organization of practices and education, as well as into databases such as the National Library of Medicine Medical Subject Headings (MeSH), PsycINFO, the Cumulative Index to Nursing and Allied Health Literature (CINAHL), and the Excerpta Medica Database (Embase).

Justification for the recommendations: These recommendations derived directly from the domain of the framework and from the expertise of the Working Group.

IOM Recommendation: Research Priorities

Organizations sponsoring research in oncology care should include the following areas among their funding priorities:

- Further development of reliable, valid, and efficient tools and strategies for use by clinical practices to ensure that all patients with cancer receive care that meets the standard of psychosocial care set forth in recommendation 1. These tools and strategies should include
 - approaches for improving patient-provider communication and providing decision support to cancer patients;
 - screening instruments that can be used to identify individuals with any of a comprehensive array of psychosocial health problems;
 - needs assessment instruments to assist in planning psychosocial services;
 - illness and wellness management interventions; and
 - approaches for effectively linking patients with services and coordinating care.
- Identification of 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 change. This effort should include
 - identifying populations for whom specific psychosocial services are most effective, and psychosocial services most effective for specific populations; and
 - development of standard outcome measures for assessing the effectiveness of these services.
- Creation and testing of reimbursement arrangements that will promote psychosocial care and reward its best performance.

Research on the use of these tools, strategies, and services should also focus on how best to ensure delivery of appropriate psychosocial services to vulnerable populations, such as those with low literacy, older adults, the socially isolated, and members of cultural minorities (13) (p. 337).

Evidence

This recommendation is based on the findings of the systematic review that was done for *The Standard of Cancer Care* and on the expert opinion of the IOM Committee.

Opinion of the Working Group

The Working Group decided that this recommendation should be adopted with slight modifications because it is compatible with the values and culture of and is applicable to Ontario. However, reimbursement arrangements refer to a US-specific setting and do not apply to Ontario. Furthermore, the recommendation should be made more comprehensive to include all types of health care providers included in the CCO definition of psychosocial oncology².

Domain H. Psychosocial Research

Organizations sponsoring research in oncology care should include the following areas among their funding priorities:

- 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:
 - 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; and
- approaches for effectively linking patients with services and coordinating care, and for the uptake of psychosocial health services.
- At the provider level, the identification of 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. This effort should include:
 - 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 different types and levels of distress;
 - developing standard outcome measures for assessing the effectiveness of these services.

Research on the use of these tools, strategies, and services should also focus on the barriers to patient referral, on how best to ensure the delivery of appropriate psychosocial services to vulnerable populations such as those with low literacy, older adults, the socially isolated, those living in remote areas, and those who are members of cultural minorities.

Evidence

Opinion of the Working Group

Domain H. Psychosocial Research addresses the need for future research and more targeted funding in psychosocial oncology. This final domain was adapted from the IOM document with major modifications and was felt by the Working Group to be appropriate to the Ontario context.

Recommendations

- 28) Future research on the effectiveness of psychosocial health services should consider variables that moderate the treatment effects, such as a priori consideration of the nature of the samples (i.e., levels of distress, natural course of symptoms, availability of social supports, temperamental traits, demographics), as well as theory-guided examinations of the mechanisms for the obtained effects.
- 29) The development of more effective treatments for mental health problems in cancer, particularly through RCTs testing collaborative care and multicomponent interventions, and comparing the effectiveness of non-pharmacologic and pharmacologic treatments alone and combined.
- 30) An increased focus on the effects of receipt of psychosocial health services on physiological (i.e., endocrine and immunological functioning) and clinical outcomes, including nutritional and functional status.
- 31) Provincial and federal cancer research funding agencies should increase their support for psychosocial research. This can be accomplished either through dedicated funding priority calls for psychosocial care, or by increasing funding allocation for psychosocial research in grant competitions.

Justification for the recommendations: Uncontrolled variables that may moderate treatment effects are one confounding factor contributing to the mixed evidence base for the

effectiveness of psychosocial interventions. Manageable levels of psychological distress are common after cancer and naturally resolve over time without intervention (122). Other research shows that patients with the highest levels of distress show the greatest response to interventions, but most psychosocial research has been conducted without regard to the amount of distress experienced (80,123). It has also been demonstrated that the availability of social supports and the patient's capacity to utilize social supports moderates the level of cancer-related distress and their response to psychosocial interventions (87, 124). The theory-guided mechanistic tailoring of psychosocial services to patient characteristics will enhance effectiveness according to psychosocial health research results (125).

Given the mixed evidence base for the effectiveness of both non-pharmacologic and pharmacologic treatments in cancer and the paucity of large, RCTs of such interventions in cancer, this should be a priority area of research. The complexity of problems faced by cancer patients, limited availability of psychosocial resources, and the need for individual tailoring of treatments to address specific needs or patient characteristics, argues for intervention designs which are interprofessional and multicomponent. Furthermore, pharmacologic and non-pharmacologic therapies are each associated with relative risks and benefits. Pharmacologic treatments carry the risk of physical side effects and drug interactions, while the use of non-pharmacologic treatments may be limited in patients with significant pain, fatigue, cognitive impairment, or more severe illness, or when there is a lack of motivation on the part of the patient. The same multicomponent intervention designs can address the important question of their combined and relative efficacies.

Elucidation of physiological pathways mediating the health benefits of psychosocial health services in cancer will help build the conceptual framework underpinning those services, increase awareness of the significance of psychosocial health care, and point the way to new intervention targets. This is a new and rapidly expanding area of multidisciplinary research that warrants increased research focus.

Psychosocial research is currently the lowest funding priority and receives the fewest funding dollars among operating grants from most cancer research funding agencies. Given the multiple negative health outcomes and systemic costs associated with inadequate psychosocial care, increased funding in the area is warranted.

IOM Recommendation: Promoting uptake and monitoring progress

The National Cancer Institute/NIH should monitor progress toward improved delivery of psychosocial services in cancer care and report its findings on at least a biannual basis to oncology providers, consumer organizations, group purchasers and health plans, quality oversight organizations, and other stakeholders. These findings could be used to inform an evaluation of the impact of this report and each of its recommendations. Monitoring activities should make maximal use of existing data collection tools and activities (13) (p. 338).

Evidence

This recommendation is based on the expert opinion of the IOM committee.

Opinion of the Working Group

The Working Group considered this recommendation applicable because the public reporting of measures is a mechanism that can promote uptake and that is already in place in Ontario. CCO produces annual public reports; regional cancer programs may report more frequently. The Group also thinks that it is appropriate to suggest more indicators for reporting. This recommendation has been adopted and merged with the IOM recommendation Quality Oversight, with modifications, to create Domain E. Quality Oversight and Monitoring Progress.

Further Internal Review

The document was submitted to the RAP a second time. RAP approved the new version of the document with the suggestion to improve readability. The Working Group met again and made editing changes aimed to improve readability, although the content of the recommendations remained unchanged.

The Expert Panel then approved the report and provided suggestions for further improvement. Along with suggestions aimed at improving readability, there were others that focussed on philosophical issues, including the apparent lack of priority setting of the document, the need for considering the various phases of the cancer trajectory while making recommendations, the need for expanding the psychosocial oncology research section, and the need for being more explicit in the inclusion of all health care professionals involved in the care of cancer patients and their families. Suggestions were also made about implementation issues, but the nature and scope of this document did not allow for and was never intended to address implementation issues. It is important to establish that this was an adaptation of an existing document, rather than a de novo guideline, and therefore, the Working Group was restricted on the topics that could be addressed and on the structure of the framework. Changes to specific recommendations in response to Expert Panel comments are highlighted below:

Table 2. Comments from the Expert Panel and responses.

Comment	Change
We need to be sensitive to the cultural environment where the guidelines were developed, and adapt to the context of use and its culture.	<ul style="list-style-type: none"> • We used the CAPO definition of “psychosocial oncology,” which is more inclusive than the US definition, so that the Canadian context was the focus in recommendation 1. • We added “nutritional and functional status” to recommendation 31. • We made explicit who are the health care professionals involved in the care of cancer patients and their families in recommendation 24. • We made specific reference to cultural and language barriers, and we added rehabilitation specialists in the examples of recommendation 16. • We included “spiritual distress” in recommendation 4. • We added “nutritional services” to recommendation 13. • We worded the section Future Directions so that more emphasis is given to the multidisciplinary nature of cancer care.
The ESAS and the Canadian Problem Checklist are the two tools endorsed by CPAC to screen for distress in Canada.	We changed the justification of recommendation 5 to acknowledge this.
Recommendation #7 presents a very important point. The justification could be expanded to highlight the relevance of this point.	We expanded the justification by adding the description of the cited studies.
Peer led and professionally led	We added the specification of both to the justification for

support groups are different.	recommendation 12.
Wording of third bullet in Domain H Psychosocial Research needs to be changed.	We changed the wording so that the focus is more on “cancer types that are less studied” than on “cancers other than breast.”

External review by Ontario Clinicians

Box 1 summarizes the draft framework and recommendations that were sent to the external reviewers.

Box 1.

Domain A. 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 any stage of the illness trajectory. Strategies to promote awareness of the significance of psychosocial healthcare needs and uptake of psychosocial health services should be encouraged.

Recommendation:

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

“Psychosocial Oncology is a professional sub-specialty 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” (<http://www.capo.ca/eng/finalstandards.asp#S2>)

Domain B. Standard of Care

Comprehensive cancer care should ensure the provision of appropriate psychosocial health services by

- facilitating effective communication between patients, their families and care providers;
- identifying psychosocial health needs of patients and families;
- designing and implementing a plan that
 - links the patient/family with needed psychosocial healthcare services,
 - coordinates biomedical and psychosocial healthcare,
 - engages and supports patients/families in managing their illness and health; and

systematically monitoring, evaluating, and re-adjusting plans.

Recommendations:

Facilitating effective communication.

- 2) To improve the patient end of the patient-provider communication dyad, organizations should provide and facilitate the use of tools to support communication and develop formal strategies to teach communication techniques to patients.

The Working Group invites interested readers to refer to the CCO guideline: “Provider-patient communication: A report of evidence-based recommendations to guide practice in cancer” (4) available at <http://www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=44425> for more information.

Identifying psychosocial health needs.

- 3) All patients/families should be screened for psychosocial healthcare needs at their initial oncology visit and at intervals throughout their cancer care trajectory, particularly with changes in disease status (e.g., remission, progression, recurrence).
- 4) Screening should be performed with validated tools encompassing a comprehensive range of health-related psychosocial problems - including physical symptoms, emotional or spiritual distress, logistical or material needs, inadequate social supports, and behavioural risk factors.

- 5) Results of screening should be shared with the patient and the healthcare team.
 - 6) Significant screening results should be followed up with an assessment by the most appropriate healthcare provider to confirm needs and develop a care plan.
Designing and implementing a plan.
 - 7) Healthcare providers should work with the patient and family to develop a care plan that contains clear goals, is aimed at assisting in managing the illness, and maintains the highest possible level of functioning and well-being.
 - 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) Healthcare providers and patients' advocacy organizations should provide patients and families with condition-specific information tailored to the individual patient's learning needs and style.
 - 11) All healthcare 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 referred to a mental health professional and treated with specific psychotherapies (e.g., cognitive-behavioural therapy, supportive psychotherapy, family/couples therapy) and/or pharmacotherapy, as indicated.
 - 13) Healthcare organizations should develop inter-professional collaborative care models for the delivery of comprehensive cancer care to ensure 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 organizations should assume responsibility for educating patients about the impact that some health risk behaviours can have on the disease and its treatment, and provide information about community resources that can help patients with changing these behaviours.
 - 15) Cancer programs and community 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 organizations should provide assistance in accessing services to address cancer-related disabilities, cognitive impairment, culture and language barriers, and family and caregiver support.
 - 17) Healthcare providers should take into account the financial constraints of patients, and support access to appropriate services.
- Systematically monitoring, evaluating, and re-adjusting plans.*
- 18) Healthcare 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. Healthcare 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 providers, administrators (e.g. managers), volunteers, community organizations, and other healthcare providers, have a responsibility to ensure that cancer patients and their families receive the psychosocial standard of care.

Recommendations:

19) All cancer care providers should participate in education and training programs to increase their awareness of the significance of psychosocial care and enhance their skills in the assessment and management of psychosocial issues.

20) Communication and patient education skills are critical for all healthcare providers and they should seek training in these areas.

21) Healthcare providers should maintain a directory of resources available to patients and their families at no cost.

Domain D. Patient and Family Education

Cancer patients and their families should be educated to expect, and request when necessary, cancer care that meets psychosocial health care needs.

Recommendation

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

For more specific recommendations the Working Group invites readers to refer to the CCO framework: “Establishing comprehensive cancer patient education services; a framework to guide Ontario cancer education services”, (5) available at <http://www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=14324>, and to the CCO guideline: “Effective teaching strategies and methods of delivery for patient education” (6) at <http://www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=60065>.

Domain E. Quality Oversight and Monitoring Progress

Oversight mechanisms should be created that can be used to measure and report on the quality of ambulatory psychosocial health care. These findings could be used to inform an evaluation of the impact of this report.

Recommendation:

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

Professional competencies in the delivery of psychosocial health care should meet the requirements of educational 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 them as fully as possible in accordance with a model that integrates biomedical and psychosocial care.

Recommendations:

24) Workforce planning for cancer services should include planning for all psychosocial specialists (i.e., social workers, psychologists, psychiatrists, advanced practice nurses, spiritual care providers, rehabilitation professionals such as occupational therapists, physiotherapists, speech language pathologists, and dietitians), to meet the growing needs/demands for care.

25) Volunteers as well as patient education and information specialists have unique roles to inform, support, and navigate cancer patients through their experience. Human health resource planning should take into consideration the need for such providers as part of the psychosocial service planning.

26) Cancer programs should support additional education for healthcare professionals, given they may not have specialized credentials in psychosocial oncology. Relevant courses such as the Inter-professional Psychosocial Oncology Distance Education Program (IPODE) should be made available to all health care professionals who care for cancer patients and their families.

Domain G. Standardized Nomenclature

There is a need to develop a standardized, trans-disciplinary, taxonomy and nomenclature for psychosocial health services.

Recommendations:

27) The Canadian Association of Psychosocial Oncology (CAPO), the Canadian Partnership Against Cancer (CPAC), and CCO, should collaborate with provincial, national, and international bodies to develop a standardized, trans-disciplinary, taxonomy and nomenclature for psychosocial health services.

28) This initiative should aim to incorporate this taxonomy and nomenclature into organization of practices and education as well as databases such as the National Library of Medicine's Medial Subject Headings (MeSH), PsychINFO, the Cumulative Index to Nursing and Allied Health Literature (CINAHL), and EMBASE.

Domain H. Psychosocial Research

Organizations sponsoring research in oncology care should include the following areas among their funding priorities:

- 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 by the intended users as set forth in the Standard of Care. These tools and strategies should include:
 - approaches for improving patient-provider communication and providing decision support to cancer patients;
 - screening instruments that can be used to identify individuals with any of a comprehensive array of psychosocial health problems;
 - needs assessment instruments to assist in planning psychosocial services;
 - illness and wellness management interventions; and
 - approaches for effectively linking patients with services and coordinating care, including research on barriers to patient referral, and uptake of psychosocial health services.
- At the provider level, identification of 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. This effort should include:
 - identifying populations for whom specific psychosocial services are most effective;
 - increased focus on understudied populations such as men, children, and understudied cancer types across the cancer trajectory and in patients experiencing different types and levels of distress; and
 - development of standard outcome measures for assessing the effectiveness of these services.

Research on the use of these tools, strategies, and services should also focus on how best to ensure delivery of appropriate psychosocial services to vulnerable populations, such as those with low literacy, older adults, the socially isolated, those living in remote areas, and members of cultural minorities.

Recommendations:

29) 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 (i.e., levels of distress, natural course of symptoms, availability of social supports, temperamental traits, demographics), as well as theory-guided examinations of mechanisms for the obtained effects.

30) The development of more effective treatments for mental health problems in cancer particularly randomized controlled trials testing collaborative care, multi-component interventions and comparing the effectiveness of non-pharmacologic and pharmacologic treatments alone and combined.

31) An increased focus on the effects of receipt of psychosocial health services on physiological (i.e., endocrine and immunological functioning) and clinical outcomes including nutritional and functional status.

32) Provincial and federal cancer research funding agencies should increase their support for psychosocial

research. This can be accomplished either through dedicated funding priority calls for psychosocial care, or by increasing funding allocation for psychosocial research in grant competitions.

- 33) CCO should annually review the funding portfolios of provincial and federal cancer research funding agencies to assess whether they include the suggested psychosocial research priorities and funding allocation targets

Targeted Peer Review: Six responses were received for the six surveys sent (100% response rate). The responses include returned completed surveys as well as phone, fax, and email responses. The key results of the feedback survey are summarized in Table 3.

Table 3. Responses to nine items on the targeted peer reviewer questionnaire.

Item	Number (%)*				
	Lowest quality (1)	(2)	(3)	(4)	Highest quality (5)
1. Rate the development methods			1 (17)	2 (33)	3 (50)
2. Rate the guideline recommendations			2 (33)	3 (50)	1 (17)
3. Rate the completeness of reporting			1 (17)	2 (33)	3 (50)
4. Does the document provide sufficient information to inform your decisions?				3 (50)	3 (50)
5. What are the barriers or enablers to the implementation of this guideline report?				3 (50)	2 (33)*
	Strongly Disagree (1)	(2)	(3)	(4)	Strongly Agree (5)
6. I would make use of this guideline in my professional decisions				3 (50)	2 (33)*
7. I would recommend this guideline for use in practice		1 (17)	1 (17)	1 (17)	2 (33)*

* One response was missing

Summary of written comments

Guideline development methods

- One reviewer requested clarification of the appropriateness of stakeholders involved in this guideline development. In response, the professional background of the Working Group members and of internal and external reviewers has been added to the methods of external review and to Appendix 1.

Guideline recommendations

- A few reviewers commented on the complexity of this document and suggested adding a table of contents and an explanation about the structure of the report at the beginning. In response, a description of the structure of the document; a table with framework domains and subdomains, with page numbers for where they can be found in Section 1 and in Section 2; and a hyperlink to relevant document sections was provided.

Completeness of reporting/Barriers to implementation/Other comments

- One reviewer suggested that recommendation 12 in Domain B needed clarification. In response the recommendation has been reworded.
- Three reviewers commented on the existence of other recently released guidelines on this topic and that it would be useful to have practical guidance on how to implement it. In

response, references to other guidelines and practical guidance tools were added with hyperlinks to Section 1. In Section 2, the examples were added to recommendation 6.

Professional consultation: Key results of the feedback survey are presented in Table 2. Of the 488 individuals to whom the survey was sent, 65 completed the survey (13%). The responses to individual questions are reported in Table 4 below.

Table 4. Responses to three items on the professional consultation survey.

Overall guideline assessment	Number (%)				
	Lowest quality (1)	(2)	(3)	(4)	Highest quality (5)
1. Rate the overall quality of the guideline report	1 (1.5)	1 (1.5)	9 (14)	30 (46)	24 (37)
	Strongly Disagree (1)	(2)	(3)	(4)	Strongly Agree (5)
2. I would make use of this guideline in my professional decisions	2 (3)	4 (6)	15 (23)	24 (38)	19 (30)*
3. I would recommend this guideline for use in practice	3 (5)	1 (1.5)	13 (20)	26 (41)	21 (33)*

* One response was missing

Summary of Written Comments

Comment	Response/Modifications
I believe that the use of some words such as "should" and "felt" are over used and do not give a strong enough expectation. Some words that are stronger and could replace 'should' I suggest would be more action oriented i.e. 'are', 'expected', 'needs to be' etc. I think 'felt' can be replaced by 'believed' which is a stronger word.	These are guidelines and not standards; therefore, stronger wording is not appropriate.
Practitioners may require some more practical directions on how to assess for the psychosocial needs of cancer patients	Reference to related guidelines and practical guidance tools has been added at the end of Section 1 and to Section 2, recommendation 6.
Many reviewers raised issues related to implementation of the guideline such as budget constraints, lack of resources etc.	Our guideline did not include tools for implementation, because the group responsible for implementation would be the Cancer Program. However we made reference to some practical guidance tools at the end of Section 1 and in Section 2 after recommendation 6.
Domain of documentation of psychosocial care not discussed and is essential so care is not fragmented and all work to common goal(s) that were cited in report -- how can something be measured if not documented.	No changes were made because documentation is a professional practice requirement.
Paragraph re: Intended users, P.2 shared include APNs - to be consistent across	Advanced Practice Nurses were not added among the intended users because the

Comment	Response/Modifications
document.	category “nurses” was intended to include all nurses.
I think it would be helpful to add one more recommendation into the Patient Education domain. It speaks to educating patients and families to expect a particular level of care, but I think it would good to further speak to the expectation of staff to provide patient education.	Recommendation 20 was reworded in response to this comment. No other recommendations were added.
"Intended users" suggest adding "health care" before administrators and dropping the "eg managers/"	Change was made.
Domain A pg 4 I would suggest that you state "all stages" rather than "any stage of" to be more emphatic about the recommendation.	Change was made.
Recommendation 3 refers to the assessment of psychosocial healthcare needs at the "initial oncology visit." The first visit is almost always to a surgeon where this will never occur. It might be realistic to say at their initial visit "to a cancer treatment facility" where these resources are more likely to be available.	Change was made to recommendation 3.
Domain F I think the wording is wrong -- "educational accrediting organization." These are two different functions. The accrediting organizations are not necessarily in the educational business so I would separate the concepts and insert educational institutions as a separate category.	Actually, educational organizations must be accredited as well; therefore, the Group is not sure that this change would be appropriate.
Recommendation 28 cannot stand alone. It is really a part of recommendation 27 and I would merge them.	Recommendations 27 and 28 were merged.
Domain H Suggest deleting some excessive words that get in the way of clear communication: delete "by the intended users (redundant) delete "any of a comprehensive array" - extra words that detract from the meaning of the bullet Move the reference to research (including research on barriers...and insert it into the sentence at the bottom of the box on research "...should also focus on barriers to patient referral..., and on how to best ensure..."	Changes were made.
Recommendation 31 is very specific and then is followed by a general recommendation re	The last recommendation has been deleted (33 is now 32, after merging 27 with 28). The

Comment	Response/Modifications
funding and then a recommendation (33) on what CCO should do to monitor the amount of funding for psychosocial research at the provincial and federal levels. I don't agree that this is CCO role and would delete this recommendation. Far better that CCO work with the psychosocial group provincially to better measure distress and the interventions that reduce it.	actionable recommendations are now 31 in total.
I would like to see more consistent inclusion of "complex functional abilities" or rehabilitation-type abilities/ parameters, including communication, swallowing, ambulation. These are more complex than pure physical aspects of care and somehow fall at the periphery of "psychosocial", thus tending to get lost. They are broadly incorporated in "functional", in the CAPO def (Recommendation 1), but are omitted just a few paragraphs later on the same page (Recommendation 4).	"...complex functional abilities such as swallowing, communication, ambulation," has been added to recommendation 7.
Instead of 'care plan' I might have suggested the wording 'plan of care.'	Plan of care was substituted to care plan in recommendations 6 and 7.
I do not understand why the oversight mechanisms are limited to ambulatory care when the guideline is to be applied to the entire cancer trajectory.	The word "ambulatory" was deleted from Domain E.

DISCUSSION AND CONCLUSIONS

Cancer patients and their families, during their journey with a disease that can manifest itself as a life-changing and life-long condition, often experience distress. Psychological distress has been recognized as "the 6th vital sign" (126-128). It can impair normal functioning in psychological, emotional, and financial areas; roles and relationships; and work (118). The impact of cancer on the psychosocial aspects of the lives of patients and their families may affect their coping skills and their ability to receive appropriate treatment, and may eventually increase morbidity and mortality. Yet, despite their prevalence, significant health consequences, and impact on responsiveness to intervention, psychosocial health care needs currently remain inadequately addressed.

The current standard of care for psychosocial services in Ontario is the 1999 Canadian Association of Psychosocial Oncology *National Psychosocial Oncology Standards for Canada* (129). However, the health care system across Ontario is inconsistent in meeting the psychosocial needs of cancer patients and their families, especially for older patients, those experiencing hopelessness (120), or the more economically disadvantaged (130). In recent years, there has been a burgeoning literature in areas such as screening for distress (3,129,132) and the treatment of psychosocial problems (118-121,131), but these interventions are not yet applied in a consistent manner throughout the province (129). This may be due to a lack of agreement regarding appropriate tools and a lack of transparency regarding current practices and their effectiveness in Canada (129), or simply because of a

lack of acknowledgement in everyday practice of the psychosocial elements of cancer care (131). These inconsistencies can be addressed by making evidence-based psychosocial care a routine part of cancer care (130).

With this goal in mind, the IOM report (13) has been adapted to the Ontario context. A great deal of discussion went on during the adaptation process in regard to the differences between the IOM and the Cancer Care Ontario definitions of psychosocial care. The Working Group found that the IOM definition was not as comprehensive as the definition in use in Ontario, in terms of breadth and of the health care practitioners involved in the psychosocial care of cancer patients. Therefore, the Working Group endeavoured during the adaptation process to make the new recommendations for Ontario fit the CCO definition. However, some sections such as Psychosocial Research have not been broadened to the extent possible in a de novo guideline.

The IOM document recommendations, once adapted, constitute a conceptual framework supporting more specific, actionable recommendations for Ontario. One domain, Raising Awareness, was newly created by the Working Group. The Group felt that, in Ontario, cancer patients still suffer the double stigma of living with cancer and of having psychosocial needs, for example, requiring treatment for depression often unmet (133). Having psychosocial care as a routine part of cancer care and making all stakeholders aware of the importance of recognising and treating the psychosocial needs of cancer patients can be effective strategies to reduce stigma (133). However, more research on the barriers to accessing psychosocial care is needed. This includes research focussed not only on the stigma experienced by cancer patients and their families, but also on the predictors of referral by health care providers, on systemic biases and practical impedances, and on the evaluation of intervention effectiveness in reducing such barriers to psychosocial care (132, 134).

Although the Working Group felt the IOM Support from Payers recommendation was not applicable in the Ontario context, financial strain and disability and rehabilitative support coverage were recognized as high-priority areas for cancer patients and their families. Although it was beyond the scope of this document to ask new research questions and issue new recommendations in these areas, these could be the focus of future CCO evidence-based guidelines.

The IOM unifying theoretical model that forms the basis of the *Standard of Care* (as shown in the centre of Figure 1, Section 1, is already embodied in the Ontario Chronic Disease Prevention and Management Framework (7) and endorsed by the Local Health Integration Networks (LHINs) in their programs for the management of chronic illness (8).

The recommendations now adapted to Ontario from the IOM report and the evidence contained in this document can be used in the future to develop performance measures. These can be used to judge the quality of practice and will help render cancer care, including its routine psychosocial component, more homogeneous across the province. The promotion and updating of these recommendations will lead to more timely access to quality psychosocial oncology care and will help reduce psychosocial morbidity among cancer patients and their families.

CONFLICT OF INTEREST

The authors of this report declared that there was no conflict of interest. However, it may well be that the standard definition of conflict does not readily apply in this context. While the individual authors may not have any direct interest in the establishment of psychosocial health services in Ontario, it is acknowledged and duly declared that funding derived from the implementation of psychosocial health services or the possible benefit to centres that provide training for psychosocial health services could be construed as a possible conflict of interest.

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Appendix 1. Members of the Psychosocial Oncology Working Group.

<p>Ms. Gale Turnbull (Manager) Manager, Supportive Care & Education Regional Lead for Palliative Care London Regional Cancer Program 790 Commissioners Road East London, ON N6A 4L6</p>	<p>Ms. Fulvia Baldassarre (Registered Nurse) Research Coordinator Program in Evidence-based Care McMaster University 1280 Main Street West Hamilton, ON L8S 4L8</p>
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<p>Dr. Madeline Li (Psychiatrist) Psychosocial Oncology and Palliative Care University Health Network Princess Margaret Hospital 610 University Avenue Toronto, ON M5G 2M9</p>	<p>Dr. Sophie Lebel (Psychologist) Assistant Professor/ Professeure adjointe University of Ottawa School of Psychology/École de Psychologie 200 Lees Avenue E158 Ottawa, ON K1N 6N5</p>
<p>Ms. Lisa Durkin (Speech Language Pathologist) University Health Network Princess Margaret Hospital 610 University Avenue Toronto, ON M5G 2M9</p>	

The Expert Panel reviewers and the External Peer reviewers came from a variety of backgrounds, including clinical nurse specialists, clinical leaders, clinical coordinators in supportive care and genetic counselling, clinical consultants in palliative care, clinical managers, administrative managers, counsellors, registered dietitians, social workers, specialists in psychosocial oncology and palliative care, physiotherapists, spiritual care practitioners, physicians, oncologists, psychiatrists, and psychologists.

Appendix 2. The ADAPTE process.

A - Assessment of content and consistency of the Institute of Medicine standard *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*.

Search and selection of evidence

Overall was the search for evidence comprehensive?	Yes	Unsure	No
1. The authors had a clearly focused question?	X		
2. Appropriate databases were searched for source guidelines?	X		
3. Internet sites were searched for source guidelines?		X	
4. Years covered in search	X		
5. Language covered in search	X		
6. Keywords used	X		
7. Combination of keywords	X		
8. Detailed search strategies are provided	X		
9. Snowball methods were used		X	
10. A hand search of the reference lists was completed		X	
11. Local experts and/or societies were asked for guideline recommendations	X		
Overall, was bias in the selection of articles avoided?			
12. Inclusion and exclusion criteria reported	X		
13. The number of persons who selected and analyzed the data is documented	X		
14. The procedure to solve disagreement is described			X
15. The number of references analyzed is documented	X		
16. The number of excluded references is documented	X		
17. The reason for excluding references are given	X		

Content and Consistency

The Working Group agreed that the original developers had a clearly focused question, and that they searched appropriate sources of evidence. The studies included in the IOM document were limited to English-language literature. However, the Group decided to consider the search comprehensive enough.

The Working Group assessed the consistency of the IOM document between the search and selection of studies, and between the evidence presented and the recommendations. The Working Group examined the search strategies of the original document. Although a hand search of the reference lists of included studies had not been reported, experts in the field had been extensively consulted, and the Working Group considered the search for evidence reasonably comprehensive overall.

The inclusion and exclusion criteria, the number of people who selected the evidence, and the number of references (included and excluded, with the reason for exclusion) were reported in the IOM document. The document describes the relevant evidence, reporting the type of study design, yet it does not report a formal quality assessment of the included studies. The Working Group felt that there was coherence between the searches performed, the evidence reported, and the recommendations, meaning that the data supported the recommendations and were consistent with the Working Group's expert opinion and experience. The Group opinion was that the original authors were very critical in their

processes, and that the risk of bias in the literature presented was low. The outcomes reported in the IOM document were considered clinically sound.

Currency

The IOM document was published in 2008. The original developers performed their literature searches from October to December 2006, and an update was done in February and March 2007. The period covered by the review was 1980 to 2007 for the review of health services (provider level) and 2002 to 2007 for the validated models of clinical practice (systems level). Because the literature in the field of psychosocial care is rapidly expanding, the Working Group identified the possibility that there might be gaps in knowledge and that an update of the literature search in the IOM document might be considered. However, the Working Group was not aware of any published or unpublished studies that contradict the evidence presented in the IOM document, or that could potentially alter the nature of the recommendations. The more recent evidence, comprised mainly of studies of better quality and with same direction of effect as in the past, confirms and strengthens the existing recommendations.

Scientific validity of guidelines

Overall the evidence was valid?	Yes	Unsure	No
1. Given the search strategy, the risk that relevant evidence has been missed is low			X
2. The criteria for selecting the evidence is explicit	X		
3. Settings and protocols of selected studies fit with the health question	X		
4. Outcomes were clinically sound	X		
5. The criteria used for assessing the quality and validity of the selected studies are adequately reported			X
6. The risk that biased evidence has been reported is low	X		
7. The outcomes were considered clinically sound	X		
Coherence between the evidence and recommendations			
8. The evidence was direct. Patients and interventions included in the studies were comparable to those targeted by the recommendation	X		
9. Conclusions were supported by data and/or the analysis: results were consistent from study to study. When inconsistencies existed in data, considered judgment was applied and reported	X		
10. The conclusions are clinically relevant	X		
11. The conclusions derived from data point to effectiveness/ ineffectiveness of the intervention and the recommendation is written accordingly	X		
Coherence between the evidence and recommendations			
12. There is some justification to recommend/ not recommend the intervention even though the evidence is weak	X		
13. The hierarchy of strength of evidence is adequately described	X		
Overall, the scientific quality of this recommendation does not present risks of bias			
14. The strength of evidence attributed to the recommendation is adequately described and justified	X		
15. Risks and benefits have been weighed	X		

**B - Acceptability and adaptability to Ontario of the Institute of Medicine standard
Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs**

Recommendation 1

Overall the recommendation is acceptable	Yes	Unsure	No
1. The strength of evidence and the magnitude of effect adequately support the grade of the recommendation	X		
2. There is sufficient benefit of the intervention, compared with other available management	X		
3. The recommendation is compatible with the culture and values in the setting where it is to be used	X		
Overall the recommendation is applicable			
1. The intervention is applicable to the patients in Ontario	X		
2. The interventions/ equipment are available in Ontario		X	
3. The necessary expertise is available in the context of use	X		
4. There are no constraints, legislation, policies, or resources in the healthcare setting of use that would impede the implementation of the recommendation			X
Can recommendation 1 be adopted in Ontario?	Yes with slight modifications		

Evidence

The IOM evidence was obtained through a multi-layered systematic review (SR). First SRs, single controlled studies, or observational studies of health care psychosocial services tested on cancer patients and their families were selected; if none was available for a specific topic, SRs, single controlled studies, or observational studies of patients with other chronic diseases were selected. This review was intended to identify effective psychosocial health services of effective psychosocial health interventions (provider level). In order to identify empirically validated models for the delivery of health care psychosocial interventions (system level), the IOM Committee reviewed previous IOM studies and expert reports, gathered knowledge among Committee members, solicited other expert organizations and individuals, and searched the peer-reviewed literature. On the basis of the identified models, the authors recommended a unifying model for care delivery, including the components outlined below.

Communication

The importance of communication in improving outcomes, including patients' participation in their care, knowledge of their disease and treatment, physiological and functional outcomes, satisfaction with treatment and decision making, confidence in treatment, and decreasing decisional conflict, both in patients with cancer and with other chronic diseases, was supported by evidence from three SRs, two randomized controlled trials (RCTs), and fifteen observational studies. Various interventions to improve patient-provider communication have been shown to be effective in improving patient outcomes in seven RCTs and two SRs reported in the IOM document.

Identification of Needs

To identify patients who are at risk for having psychosocial health needs, the IOM document describes more than 13 screening tools measuring several aspects of cancer patients' risk for psychosocial health problems and makes reference to three SRs and meta-analyses, one RCT, eight observational studies, and five studies testing operating characteristics as well as their strengths and limitations. Needs assessment is a more in-depth evaluation than is screening and confirms the presence of psychosocial health problems. The IOM standard reports a list of needs assessment instruments used to ascertain the presence of psychosocial health problems (from an SR) and their effectiveness in improving access to services (from another SR of RCTs). The evidence in this area comes mainly from non-cancer patient populations, and the effectiveness of need assessment is shown to be linked to its combination with follow-up care and implementation.

Care Planning and Linking Patients to Services

Care planning was a component of most of the effective models for psychosocial health services delivery found by the IOM Committee. The IOM document states that this practice has not been the subject of much research in cancer care but is founded on longstanding practice in health care, the logic of planning before action, and some research from patients with chronic diseases other than cancer.

Several mechanisms to link patients with needed psychosocial health services have been shown to be effective, although the evidence in their support is of variable strength. These mechanisms include structured referrals, case management, collocation and clinical integration of services, and care and/or system navigators. The evidence on referrals found by the IOM team is mixed. Some studies show the ineffectiveness of referral mechanisms in connecting patients to providers and the failure of patients to follow through on these referrals, yet other organizations such as the American Cancer Society provide evidence of a high utilization of such services. Evidence of the effectiveness of case management was from six SRs of studies on chronic diseases other than cancer. Few RCTs of case management on cancer care have been conducted, and the effectiveness of case management in cancer care is still uncertain. The evidence for the effectiveness of on-site collocation and the clinical integration of services included four RCTs in populations with diseases other than cancer. The evidence in support of the effectiveness of system navigators consisted of two RCTs and an observational study and referred mostly to the screening phase of the cancer care continuum.

Supporting Patients in Managing Their Illness

The body of evidence presented by the IOM document on supporting patients in managing their illness comprises the evidence for the effectiveness of psychosocial health care services at the patient and provider level. The IOM document reports that research has shown some of these services to be effective, while others such as financial assistance and provision of transportation have not been studied much because of their longstanding and wide acceptance. The following psychosocial health services are discussed in the IOM document and evidence is presented for each: a) provision of information; b) services to help cope with emotions, including peer support programs, counselling and psychotherapy, and psychopharmacological services; c) help in managing illness comprehensively; d) assistance in changing behaviours, including smoking cessation, diet, and physical activity; e) provision of material and logistical resources; f) help in managing disruption in family, school, and work life, including assistance with activities of daily living, cognitive and educational assistance, family and caregiver support, and legal protections and services; g) help in managing financial demands and insurance.

Coordinating Psychosocial and Biomedical Care

In the IOM document, the evidence on the effectiveness of care coordination strategies to improve functional health status and satisfaction with care and hospitalization came from two reviews of reports on the effectiveness of care coordination for many chronic diseases other than cancer. One SR found that the use of multidisciplinary teams was effective in reducing mortality and hospitalizations for individuals with heart failure. However, two other SRs in the area of cancer showed that evidence for the effectiveness of multidisciplinary teams is scarce. The IOM Committee points out that care coordination in the area of cancer is more difficult because it entails coordination between psychosocial services and biomedical services and coordination among several biomedical services provided by multiple clinicians. The IOM Committee concluded that the effectiveness of care coordination mechanisms most likely depends upon matching these mechanisms with patient needs.

Following Up

Various forms of follow-up have been found by the IOM Committee to be important components in the effective models for the delivery of psychosocial health services (systems level). Evidence was found in an SR and in a book that looked at effective interventions for improving health care processes and outcomes.

Recommendation 2

Overall the recommendation is acceptable	Yes	Unsure	No
1. The strength of evidence and the magnitude of effect adequately support the grade of the recommendation	X		
2. There is sufficient benefit of the intervention, compared with other available management	X		
3. The recommendation is compatible with the culture and values in the setting where it is to be used	X		
Overall the recommendation is applicable			
1. The intervention is applicable to the patients in Ontario	X		
2. The interventions/ equipment are available in Ontario	X		
3. The necessary expertise is available in the context of use	X		
4. There are no constraints, legislation, policies, or resources in the healthcare setting of use that would impede the implementation of the recommendation	X		
Can recommendation 2 be adopted in Ontario?	Yes with slight modifications		

Recommendation 3

Overall the recommendation is acceptable	Yes	Unsure	No
1. The strength of evidence and the magnitude of effect adequately support the grade of the recommendation	X		
2. There is sufficient benefit of the intervention, compared with other available management	X		
3. The recommendation is compatible with the culture and values in the setting where it is to be used	X		

Overall the recommendation is applicable			
1. The intervention is applicable to the patients in Ontario	X		
2. The interventions/ equipment are available in Ontario	X		
3. The necessary expertise is available in the context of use	X		
4. There are no constraints, legislation, policies, or resources in the healthcare setting of use that would impede the implementation of the recommendation			X
Can recommendation 3 be adopted in Ontario?	Yes as is		

Recommendation 4

Overall the recommendation is acceptable	Yes	Unsure	No
1. The strength of evidence and the magnitude of effect adequately support the grade of the recommendation	X		
2. There is sufficient benefit of the intervention, compared with other available management	X		
3. The recommendation is compatible with the culture and values in the setting where it is to be used			X
Overall the recommendation is applicable			
1. The intervention is applicable to the patients in Ontario	X		
2. The interventions/ equipment are available in Ontario	X		
3. The necessary expertise is available in the context of use	X		
4. There are no constraints, legislation, policies, or resources in the healthcare setting of use that would impede the implementation of the recommendation	X		
Can recommendation 4 be adopted in Ontario?	No		

Recommendation 5

Overall the recommendation is acceptable	Yes	Unsure	No
1. The strength of evidence and the magnitude of effect adequately support the grade of the recommendation			X
2. There is sufficient benefit of the intervention, compared with other available management		X	
3. The recommendation is compatible with the culture and values in the setting where it is to be used			X
Overall the recommendation is applicable			
1. The intervention is applicable to the patients in Ontario			X
2. The interventions/ equipment are available in Ontario			X
3. The necessary expertise is available in the context of use			X
4. There are no constraints, legislation, policies, or resources in the healthcare setting of use that would impede the implementation of the recommendation	X		
Can recommendation 5 be adopted in Ontario?	No		

Recommendation 6

Overall the recommendation is acceptable	Yes	Unsure	No
1. The strength of evidence and the magnitude of effect adequately support the grade of the recommendation	X		
2. There is sufficient benefit of the intervention, compared with other available management	X		
3. The recommendation is compatible with the culture and values in the setting where it is to be used	X		
Overall the recommendation is applicable			
1. The intervention is applicable to the patients in Ontario	X		
2. The interventions/ equipment are available in Ontario		X	
3. The necessary expertise is available in the context of use		X	
4. There are no constraints, legislation, policies, or resources in the healthcare setting of use that would impede the implementation of the recommendation			X
Can recommendation 6 be adopted in Ontario?	Yes with major modifications		

Recommendation 7

Overall the recommendation is acceptable	Yes	Unsure	No
1. The strength of evidence and the magnitude of effect adequately support the grade of the recommendation			X
2. There is sufficient benefit of the intervention, compared with other available management	X		
3. The recommendation is compatible with the culture and values in the setting where it is to be used	X		
Overall the recommendation is applicable			
1. The intervention is applicable to the patients in Ontario	X		
2. The interventions/ equipment are available in Ontario	X		
3. The necessary expertise is available in the context of use	X		
4. There are no constraints, legislation, policies, or resources in the healthcare setting of use that would impede the implementation of the recommendation		X there are some constraints	
Can recommendation 7 be adopted in Ontario?	Yes with slight modifications		

Recommendation 8

Overall the recommendation is acceptable	Yes	Unsure	No
1. The strength of evidence and the magnitude of effect adequately support the grade of the recommendation	X		
2. There is sufficient benefit of the intervention, compared with other available management	X		
3. The recommendation is compatible with the culture and values in the setting where it is to be used	X		
Overall the recommendation is applicable			

1. The intervention is applicable to the patients in Ontario	X		
2. The interventions/ equipment are available in Ontario	X		
3. The necessary expertise is available in the context of use	X		
4. There are no constraints, legislation, policies, or resources in the healthcare setting of use that would impede the implementation of the recommendation			X
Can recommendation 8 be adopted in Ontario?	Yes with slight modifications		

Recommendation 9

Overall the recommendation is acceptable	Yes	Unsure	No
1. The strength of evidence and the magnitude of effect adequately support the grade of the recommendation	X		
2. There is sufficient benefit of the intervention, compared with other available management	X		
3. The recommendation is compatible with the culture and values in the setting where it is to be used	X		
Overall the recommendation is applicable			
1. The intervention is applicable to the patients in Ontario	X		
2. The interventions/ equipment are available in Ontario	X		
3. The necessary expertise is available in the context of use	X		
4. There are no constraints, legislation, policies, or resources in the healthcare setting of use that would impede the implementation of the recommendation	X		
Can recommendation 9 be adopted in Ontario?	Yes with slight modifications		

Recommendation 10

Overall the recommendation is acceptable	Yes	Unsure	No
1. The strength of evidence and the magnitude of effect adequately support the grade of the recommendation	Not applicable		
2. There is sufficient benefit of the intervention, compared with other available management	X		
3. The recommendation is compatible with the culture and values in the setting where it is to be used	X		
Overall the recommendation is applicable			
1. The intervention is applicable to the patients in Ontario	X		
2. The interventions/ equipment are available in Ontario	X		
3. The necessary expertise is available in the context of use	X		
4. There are no constraints, legislation, policies, or resources in the healthcare setting of use that would impede the implementation of the recommendation			X
Can recommendation 10 be adopted in Ontario?	Yes with slight modifications		

C - AGREE evaluation

Quality appraisal with the AGREE instrument

The aggregated score for each domain was:

Scope and purpose:	91.7%
Stakeholder involvement:	68.8%
Rigor of development:	67.9%
Clarity and presentation:	71.0%
Applicability:	58.0%
Editorial independence:	50.0%

The Working group noted that the AGREE tool, designed for clinical practice guidelines, at times did not fit perfectly to the IOM document. The table below reports the AGREE raw scores (Rating: Strongly Agree=4 to Strongly Disagree=1).

Reviewer Name:	Rater 1	Rater 2	Rater 3	Rater 4
Scope and Purpose				
1. The overall objective of the guideline is specifically described	4	4	4	4
2. The clinical question covered by the guideline is specifically described	3	3	4	3
3. The patients to whom the guideline is meant to apply are specifically described	4	4	4	4
Stakeholder involvement				
4. The guideline development group includes individuals from all relevant professional groups	3	4	4	3
5. The patients' views and preferences have been sought	3	4	3	4
6. The target users of the guideline are clearly defined	3	4	4	4
7. The guideline has been piloted among target users	1	2	1	2
Rigor of development				
8. Systematic methods were used to search for evidence	4	4	3	4
9. The criteria for selecting the evidence are clearly described	3	4	3	4
10. The methods for formulating the recommendations are clearly described	3	4	3	4
11. The health benefits, side effects, and risks have been considered in formulating the recommendations	3	3	3	4
12. There is an explicit link between the recommendations and the supporting evidence	2	3	2	3
13. The guideline has been	3	4	4	4

externally reviewed by experts prior to its publication				
14. A procedure for updating the guideline is provided	1	1	1	1
Clarity and presentation				
15. The recommendations are specific and unambiguous	3	4	3	4
16. The different options for the management of the condition are clearly presented	3	4	3	4
17. Key recommendations are easily identifiable	3	4	4	4
18. The guideline is supported with tools for application	1	2	2	2
Applicability				
19. The potential organizational barriers in applying the recommendations have been discussed	4	4	4	4
20. The potential cost implications of applying the recommendations have been considered	2	1	2	2
21. The guideline presents key review criteria for monitoring and/or audit purposes	2	3	2	3
Editorial independence				
22. The guideline is editorially independent from the funding body	4	4	3	4
23. Conflicts of interest of guideline development members have been recorded	2	1	1	1
Would you recommend these guidelines for use in practice?	Recommend with alterations	Strongly recommend, but needs adaptation to Ontario	Recommend (with provisos or alterations), I would recommend with changes for the Canadian context.	Recommends with alterations