

A Pan-Canadian Clinical Practice Guideline: Assessment of Psychosocial Health Care Needs of the Adult Cancer Patient

May 2009

Production of this guideline has been made possible through a financial contribution from Health Canada, through the Canadian Partnership Against Cancer.

This guideline was developed through a collaborative partnership between the Canadian Partnership Against Cancer and the Canadian Association of Psychosocial Oncology (CAPO). CAPO is the steward of this guideline.

This practice guideline is editorially independent of the funding sources. The views and interests of the funding sources have not influenced the recommendations in this document.

The views expressed herein represent the views of the National Advisory Working Group (acting as the Expert Panel), a sub-group of the Standards, Guidelines and Indicators Working Group of The Cancer Journey Action Group, Canadian Partnership Against Cancer (the Partnership).

All reviewers are acknowledged for their participation and valuable contribution to the development of this guideline.



Canadian Association of Psychosocial Oncology
Association Canadienne d'Oncologie Psychosociale



Referencing of the guideline should be as follows:

Howell, D., Currie, S., Mayo, S., Jones, G., Boyle, M., Hack, T., Green, E., Hoffman, L., Simpson, J., Collacutt, V., McLeod, D., and Digout, C. A Pan-Canadian Clinical Practice Guideline: Assessment of Psychosocial Health Care Needs of the Adult Cancer Patient, Toronto: Canadian Partnership Against Cancer (Cancer Journey Action Group) and the Canadian Association of Psychosocial Oncology, May 2009.

Access to the Guideline is available on cancerview.ca and the Canadian Association of Psychosocial Oncology website (www.capo.ca).

Guideline Steward Contact information:

Canadian Association of Psychosocial Oncology
189 Queen Street East, Suite 1
Toronto, Ontario
Canada
M5A 1S2

Phone: 416-968-0207

Fax: 416-968-6818

E-mail: capo@funnel.ca

www.capo.ca

Scheduled for update:

April 2014

Copyright

This guideline is copyrighted by the Canadian Association of Psychosocial Oncology (CAPO). The guideline and the illustrations herein may not be reproduced without the express written permission of CAPO. CAPO reserves the right at any time, and at its sole discretion, to change or revoke this authorization.

Disclaimer

Care has been taken in the preparation of the information contained in this practice guideline document. Nonetheless, any person seeking to apply or consult the practice guideline is expected to use independent clinical judgment and skills in the context of individual clinical circumstances or seek out the supervision of a qualified clinician. The Partnership and the Canadian Association of Psychosocial Oncology (CAPO) make no representation or warranties of any kind whatsoever regarding the content, use or application of this practice guideline and disclaim any responsibility for their application or use in any way.

Conflict of Interest Disclosures

Each member of the National Advisory Working Group acting in the role of the guideline expert panel completed a Conflict of Interest Document. No conflicts of interest were identified by members of the practice guideline writing team that could have compromised the recommendations contained within this document.

Contents

| | |
|---|----|
| Psychosocial Health Care Needs Assessment for Adults Substantive Recommendations | 4 |
| 1.0 Purpose of the Guideline | 6 |
| 2.0 Summary of the Issue | 6 |
| 3.0 Scope and Target Population | 8 |
| 4.0 Guideline Objectives and Questions Addressed..... | 10 |
| 5.0 Methods and Procedures | 11 |
| 6.0 Recommendations | 15 |
| 7.0 Implementation Considerations..... | 30 |
| 8.0 Research Implications..... | 31 |
| 9.0 Conclusion | 33 |
| 10.0 Acknowledgements | 34 |
| 11.0 Glossary..... | 37 |
| 12.0 References..... | 38 |
| Appendix A: ADAPTE Methodology | 45 |
| Appendix B: Guideline Search and AGREE Review | 46 |
| Appendix C: Summary of External Review..... | 53 |
| Appendix D: Psychosocial Health Care Needs Assessment for Adults with Cancer - Randomized/Quasi-Randomized Trials and Prospective Comparative Cohort Studies | 55 |
| Appendix E: Tools for Psychosocial Health Care Needs Assessment in Adults with Cancer..... | 59 |
| Appendix F: Example Instruments for Psychosocial Health Care Needs Assessment | 64 |
| Appendix G: Screening for Distress: Symptoms, Problems and Concerns..... | 67 |

Psychosocial Health Care Needs Assessment for Adults

Substantive Recommendations*

Essential Domains of Assessment

Recommendation 1: A routine, systematic and standardized assessment of psychosocial health care needs common across cancer populations is recommended as a critical first step in the provision of appropriate, and relevant psychosocial and supportive care interventions and/or services.

Recommendation 2: Routine, standardized, psychosocial health care needs assessment should include physical, informational, emotional, psychological, social, spiritual, and practical domains that are common across cancer populations.

Screening for Distress and Assessment

Recommendation 3: Screening for distress is recommended for use as an initial “red flag” indicator of psychosocial health care needs that should be followed by a more comprehensive and focused assessment to ensure that interventions are targeted, appropriate, and relevant to the needs and specific problems identified by the individual and family.

Recommendation 4: Screening for distress should not be limited to depression and anxiety symptoms alone but also include identification of physical, informational, psychological, social, spiritual, and practical domains of psychosocial health care needs or concerns that contribute to distress of cancer and treatment.

Critical Assessment Time Points

Recommendation 5: Routine psychosocial health care needs screening for distress and assessment is recommended at critical time points in the cancer continuum. These include: initial diagnosis, start of treatment, regular intervals during treatment, end of treatment, post-treatment or at transition to survivorship, at recurrence or progression, advanced disease, when dying, and during times of personal transition or re-appraisal (e.g., in a family crisis, during survivorship, when approaching death).

Recommendation 6: Disease, treatment, or phase-specific psychosocial health care needs assessments should be added to routine, standardized assessment across populations (generic), in order to tailor assessments to problems that are unique to a specific type of cancer, treatment modality, or phase in the cancer continuum (e.g., post-treatment survivorship or incontinence after pelvic surgery).

Screening for Distress and Assessment Is Recognized as a Therapeutic Interpersonal Process

Recommendation 7: Routine psychosocial health care needs screening for distress and assessment is recommended as an interpersonal process to elicit comprehensive information regarding patients’ needs for psychosocial and support interventions. Assessment may involve a combination of self-report questionnaires and interview approaches and is dependent on effective communication as part of a therapeutic relationship between patient and clinician.

Recommendation 8: Routine psychosocial health care needs screening for distress and assessment should be followed by evidence-based interventions and targeted care processes appropriate to the identified need in order to improve patient outcomes including relief of symptoms, emotional well-being and quality of life.

Tools that Support Comprehensive and Focused Assessment

Recommendation 9:

(a) A comprehensive assessment tool with sound psychometric properties that addresses all domains of psychosocial health care needs is recommended for use in routine clinical practice. A number of valid and reliable tools that can support a systematic approach to identify the broad range of psychosocial and support needs (i.e., Cancer Rehabilitation Evaluation System: CARES and the Supportive Care Needs Survey) are listed in Table 1.

(b) Focused assessments using a valid and reliable tool should follow a comprehensive assessment and be targeted to identification of the parameters of a specific problem (e.g., pain) and dimensions of a specific problem. For instance, use of the Memorial Symptom Assessment or similar tool to assess all dimensions of symptoms (frequency, severity, distress) amenable to intervention or a specific tool to assess parameters of pain (location, severity, quality, timing, aggravating or alleviating factors).

Tools that Support Screening for Distress

Recommendation 10: Screening for distress tools used as part of routine screening should be brief so as to minimize patient burden and maximize ease of uptake into clinical practice; and should possess adequate sensitivity and specificity and established cut-offs for rapid identification of high risk populations.

Recommendation 11: Problems and concerns checklists for use as part of “red flag” screening for distress should include all dimensions of psychosocial health care needs using valid and reliable tools where they exist. Problems and concerns checklists should be recognized as “indicators” of a need or concern only and should trigger a therapeutic dialogue between patient and clinician to obtain a more comprehensive and/or focused understanding of the problem or concern.

Preparation of Providers and the Care System

Recommendation 12:

(a) Ongoing education of all members of the health care team is critical to ensure competent psychosocial health care needs assessment and appropriate clinician response to findings of “red flag” screening for distress, and comprehensive and focused assessments.

(b) Interdisciplinary collaboration is recommended for routine, standardized psychosocial health care needs assessment and screening for distress and targeting of interventions consistent with practice scope to effectively address multidimensional domains of need and/or facilitate appropriate referral to discipline-specific and/or psychosocial oncology specialists and services.

**The recommendations are based on the expert consensus of an inter-professional panel, after a review of available evidence, guidelines from other groups and current clinical practice in Canada.*

Referencing of the guideline should be as follows: Howell, D., Currie, S., Mayo, S., Jones, G., Boyle, M., Hack, T., Green, E., Hoffman, L., Simpson, J., Collacutt, V., McLeod, D., and Digout, C. A Pan-Canadian Clinical Practice Guideline: Assessment of Psychosocial Health Care Needs of the Adult Cancer Patient, Toronto: Canadian Partnership Against Cancer (Cancer Journey Action Group) and the Canadian Association of Psychosocial Oncology, May 2009.

1.0 Purpose of the Guideline

Assessment is a critical first step to the identification of appropriate interventions and/or referral to relevant psychosocial and supportive care services (IOM, 2008). This guideline provides professional health care providers with recommendations regarding routine, systematic and standardized assessment of psychosocial health care needs for adult populations (age 18 years and older) affected by cancer. Recommendations are informed by empirical evidence embedded in international guidelines, systematic reviews, and consensus of interdisciplinary psychosocial experts.

2.0 Summary of the Issue

Extensive research shows that individuals with cancer experience an array of psychosocial and supportive care needs. These needs span physical, informational, emotional, psychological, social, spiritual, and practical domains (Ashbury et al., 1998; Boberg et al., 2003; Fitch, 1994; Gustafson et al., 1993; Richardson et al., 2005; Richardson et al., 2007; Sanson-Fisher et al., 2000). Domains of need are common across the cancer continuum, but phase-specific needs are more prominent at certain time points (Fitch, 2000). Critical transitions include the time prior to diagnosis for at-risk populations or those with a suspicion of cancer, as well as at time of diagnosis, during treatment, post-treatment or survivorship, recurrence, palliative care, end-of-life, and family bereavement (IOM, 2008; Richardson et al., 2005; Veach, Nicholas, & Barton, 2002). Critical transition points are times when patients (and their families) may be most vulnerable to unmet psychosocial needs and emotional distress and are the basis for timing of psychosocial health care needs assessment and re-assessment.

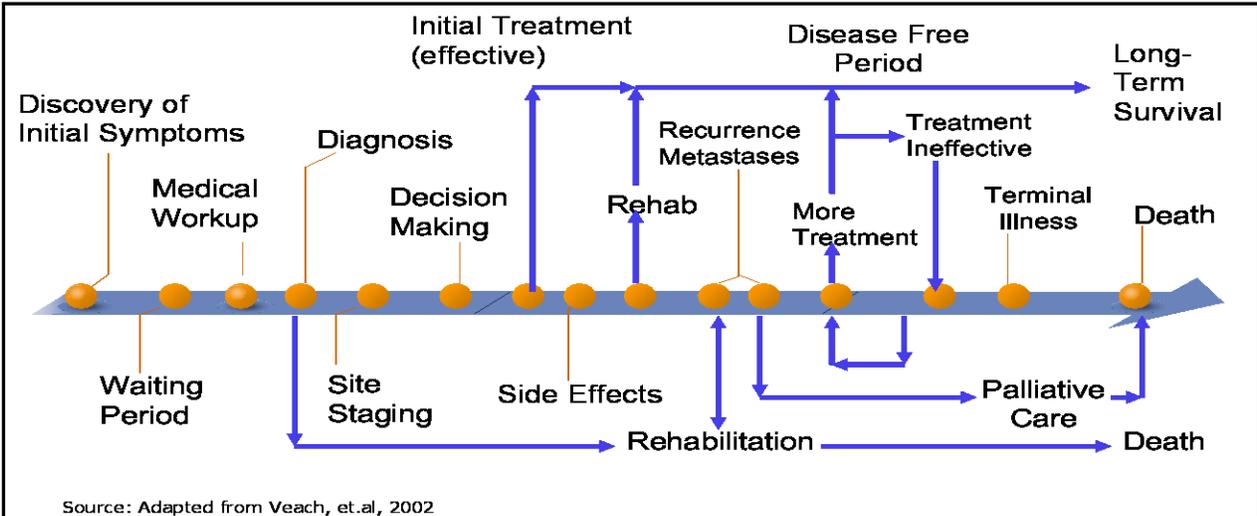


Figure 1: Cancer Care Continuum: Points of Assessment
(adapted from Veach, Nicholas, & Barton, 2002 - reprinted with permission from M. Boyle)

Psychosocial and support needs also vary with type of cancer and treatment, life-stage of individuals and their families, and according to socio-demographic, environmental, and living circumstances (Fitch, 2008; Veach, Nicholas, & Barton, 2002). The critical points along the cancer continuum when patient's needs may vary are depicted in Figure 1. Veach, Nicholas and Barton (2002) suggest that the points of assessment along the Cancer Care Continuum are best considered in the social context of the patient's (and family's) stage in the Family Life Cycle. Stages of the Family Life Cycle include: the single young adult, the newly forming couple, the family with young children, the family with adolescents, the family launching children, and the family later in life. In addition, the needs of older single adults, divorced and remarried adults, childless couples, recently bereaved adults will also modify the clinician's response to the patient during the assessment phase. Ethnicity, Aboriginal status, gender, sexual orientation, mental or physical disability, and cultural, or linguistic and racial factors also must be taken into considerations (Section 15, Charter of Rights and Freedoms, Government of Canada, 2008-11-12). Most important is the expectation that re-assessment will occur along the continuum of care at critical time points in the cancer continuum (see Figure 1). This is necessary to ensure that psychosocial care needs are identified in a timely manner as they change and evolve along the cancer continuum.

The "Cancer Care for the Whole Person" report of the Institute of Medicine (IOM, 2008) and similar earlier reports specific to Canada (Vachon, 2006; Vachon, 1998) show that many psychosocial-supportive care needs are not fully acknowledged across cancer systems and care sectors. This failure contributes to physical and psychological morbidity, poor quality of life, and may lead to further disability (Sanson-Fisher et al., 2000; Wen & Gustafson, 2004). While a number of international guidelines exist that support health care professionals in the provision of psychosocial or supportive care (NICE, 2004; National Breast Cancer and National Cancer Control Initiative, 2003), there are few specific recommendations embedded in these guidelines regarding routine psychosocial health care needs assessment. Yet, a comprehensive understanding of patient-specific psychosocial health care needs is an essential precursor to appropriate interventions and for facilitating access to relevant psychosocial and supportive care services (IOM, 2008). Inconsistent, and often inadequate, assessment and intervention to address the psychosocial needs of the adult cancer patient point to an urgent need for an evidence- and consensus-based guideline for practice. Pan-Canadian leadership is necessary to ensure consistent clinical practice that will reduce the high prevalence of unmet needs at all levels of the cancer control system. The Canadian cancer control agenda, specifically the Cancer Journey Action Group, are targeting strategies to ensure a person-focused cancer system that is responsive to the full range of psychosocial and supportive care

needs common across cancer populations. This approach will ultimately improve quality of life for all Canadians and their families who are affected by cancer.

3.0 Scope and Target Population

Target Population: Adults with cancer (age 18 and older) and their identified support network, at any phase of the cancer continuum, and regardless of cancer type, disease stage, or treatment modality. It is acknowledged that psychosocial and supportive care needs are dynamic and typically change over time. This requires periodic re-assessment at critical time points. Further, specific needs may vary with the phase of cancer, as well as the type of cancer and treatment modalities.

Intended Users: All members of the inter-professional health care team. This includes, but is not limited to, primary care providers, oncologists, nurses, social workers, psychiatrists, psychologists, dietitians, rehabilitation professionals, counsellors, speech language pathologists, and spiritual care providers. The guideline may also inform the training of professionals and decisions regarding appropriate resource allocation for psychosocial services.

Scope of the Guideline: This guideline is limited to recommendations on the routine, standardized assessment of domains of person-centred, psychosocial health care needs that are common across cancer populations. It does not address needs specific to cancer type, treatment modality, or cancer phase, nor does it include specific assessments conducted by specialists (e.g., psychologists or psychiatrists) for the purpose of clinical diagnosis.

Operational definitions to clarify the scope of the guideline are as follows:

Definition of Psychosocial Needs: Generic psychosocial health care needs are defined as those needs arising in the physical, informational, emotional, psychological, social, spiritual, and practical domains as part of a patient's experience of cancer and treatment (Fitch, 2008). These domains of need have been identified in a number of systematic reviews, (Richardson et al., 2007) population based surveys, (Boberg et al., 2003; Fitch, 2008; Gustafson et al., 1993; Sanson-Fisher et al., 2000; Vachon 2006; Vachon, 1998), and in two major reports (IOM, 2008; The Ontario Cancer Treatment and Research Foundation, Supportive Care Program Committee, 1994). This understanding reflects the Canadian Association of Psychosocial Oncology's definition of psychosocial care (n.d.), which includes similar domains, as follows: (see Table 1 on page 17 for a more expansive list):

- Physical needs (e.g., physical comfort and freedom from pain and other symptoms, optimum nutrition, activities of daily living; may include assessment of complications such as late effects of treatment)
- Informational needs (e.g., to reduce confusion, anxiety and fear, to inform patient and family decision-making, and to assist in skill acquisition related to treatment or disease, system orientation)
- Emotional needs (e.g., sense of comfort, safety, understanding and reassurance in dealing with sadness, grief, and loss)
- Psychological needs (e.g., coping with illness experience and its consequences, personal control, self-esteem)
- Social needs (e.g., family relationships and social networks, community acceptance and involvement in one's relationships)
- Spiritual needs (e.g., hope, belonging, meaning and purpose of life, existential concerns)
- Practical needs (direct assistance to accomplish tasks or activities - e.g., homemaking services, financial assistance, system navigation)

Definition of Assessment: Different types of assessments may be conducted depending on the particular needs and priorities for care (Ahern & Philpot, 2002; White, 2003; Holmes, 2003). Effective communication and establishment of a therapeutic relationship are fundamental to the assessment process (Hack, Degner, & Parker, 2005) but are not specifically addressed in this guideline. For specific guidance on effective communication with patients and families, interested clinicians are encouraged to refer to Cancer Care Ontario's *Provider-Patient Communication: A Report of Evidence-Based Recommendations to Guideline Practice in Cancer* (Rodin et al., 2008). Three main types of assessment are: screening for distress, comprehensive assessment; and focused assessment.

- **Screening for Distress:** Assessment of the four vital signs, heart rate, blood pressure, respiratory rate, and temperature is considered a standard part of clinical care. Pain and emotional distress are highly prevalent in cancer and are now considered the 5th and 6th vital signs (Accreditation Canada, 2008). Screening for distress is a pro-active, rapid identification of key indicators using short or ultra-short psychometrically sound measures to identify patients at risk for poor health outcomes and enable targeting of further assessment and appropriate referral. Screening for distress provides a "snapshot" view of a patient's problems or concerns, but further elaboration using a more

comprehensive and focused assessment approach is essential in order to identify appropriate intervention strategies (IOM, 2008). Screening for Distress, the 6th Vital Sign is endorsed as the pan Canadian program for screening for distress.

- **Comprehensive Assessment:** A comprehensive assessment is an in-depth look at and appraisal of the patient's psychosocial health care needs, health status, coping skills, and risk factors. It considers the social and demographic factors, living circumstances, and pre-existing illness factors that might influence psychosocial needs. A generic comprehensive assessment will cover psychosocial and supportive care domains common to all cancer populations, but items may need to be added to identify problems specific to a disease site, treatment modality, or phase of cancer. A thorough psychosocial assessment covers the patient's values, preferences, and resilience in managing problems. A comprehensive assessment is typically followed by a more focused assessment, to identify factors associated with a particular problem.
- **Focused Assessment:** A focused assessment addresses specific domains, conditions, and problems identified through screening for distress. It aims to identify and manage a particular issue, such as pain or alterations in sexuality (Ahern & Philpot, 2002; White, 2003; Holmes, 2003). Recommended parameters for a focused problem assessment are usually synthesized in clinical practice guidelines specific to the problem.

It is recognized that patients will have other needs beyond the cancer experience. Co-morbidities and pre-existing deficits in cognitive functioning, or those resulting from cancer treatment, can complicate both medical treatment and psychosocial responses. Environmental context, social network, cultural beliefs, race, ethnicity, and personal life circumstances and experiences all play a role in determining and managing needs. Further, respect for patients' values and preferences are core principles in the provision of person-centered care, and critical in the assessment process (Gerteis et al., 1993).

4.0 Guideline Objectives and Questions Addressed

The following clinical questions guided the development of this guideline:

1. What patient and family parameters and aspects of psychosocial health care needs should be considered as part of standard assessment of persons with cancer?

2. What is the appropriate timing and frequency of assessments in the cancer continuum?
3. What impacts do assessments, as part of routine care, have on patient outcomes?
4. Are there any well-established, evidence-based tools, measures, or instruments that facilitate assessment?
5. Who should conduct psychosocial health care needs assessments?

5.0 Methods and Procedures

This guideline was developed through a collaborative partnership between the Canadian Partnership Against Cancer (the Partnership) and the Canadian Association of Psychosocial Oncology (CAPO). The purpose of this collaboration was to meet a shared goal of ensuring that patients receive the highest quality of psychosocial and supportive care across the cancer continuum. This guideline built upon two preceding reviews of psychosocial guidelines: (1) CAPO review with support of the BC Cancer Foundation (Stephen & Boyle, 2005); and (2) a scoping review and scan of existing guidelines conducted by the Partnership's Cancer Journey Action Group (CJAG) (Howell, 2007, 2009). Members of an existing CAPO guideline committee and a CJAG steering group for standards, guidelines, and indicators formed the inter-professional expert panel that completed this guideline (see Section 9.0 for a list of expert panel members and their disciplinary expertise).

Search for existing guidelines

ADAPTE methodology (ADAPTE Collaboration, 2007) was used to guide the guideline development process (Appendix A) combined with systematic reviews of the empirical evidence. First, electronic health science databases (HealthStar, Medline, CINAHL, Embase and PsychINFO) were searched for clinical guidelines. Internet searches of local, provincial, national and international guideline databases or organization websites were also performed for "grey" literature. (A complete list of databases, websites and search terms used are provided in Appendix B). Criteria for guidelines to be further reviewed were: (1) published 2003-2008, (2) focused on clinical practice and evidence-based, and (3) relevant to psychosocial health care needs assessment for adult cancer patients. Guidelines were excluded if they: (1) did not include reference to the evidence to inform recommendations, (2) focused strictly on assessment and management of individual physical symptoms (e.g., pain, oral mucositis, nausea/vomiting, dyspnea, etc.), or (3) focused solely on interpersonal processes (e.g., therapeutic relationships, communication). Identified guidelines were

assessed for inclusion by two trained and experienced reviewers (MJ, SM). Nine guidelines were identified for inclusion in the review process.

Second, each guideline was independently reviewed and scored by four panel members using the Appraisal of Guidelines for Research and Evaluation (AGREE) instrument (AGREE Collaboration, 2001). The AGREE instrument provides a framework for the evaluation of guideline quality on the basis of six domains: scope and purpose, stakeholder involvement, rigour of involvement, clarity and presentation, applicability, and editorial independence. Final decisions regarding the quality and appropriateness of the guidelines for adaptation were reached through panel consensus. (A detailed description of the AGREE review process is provided in Appendix B.)

Third, a consensus process was used for adopting specific recommendations in relevant guidelines and more specifically to use the Australian National Breast Cancer Centre and National Cancer Control Initiative (2003) guideline as a foundational document. National Comprehensive Cancer Network (NCCN, 2008) guidelines also informed recommendations in this guideline. Identification of specific parameters for psychosocial assessment was overall lacking in these guidelines. However, the few recommendations that did exist were adapted for this guideline. Several additional documents identified through this process were also used to guide the development of recommendations regarding the parameters of psychosocial health care needs. These included:

1. Institute of Medicine (IOM). (2008). *Cancer care for the whole patient: Meeting psychosocial health needs*. Nancy E. Adler and Ann E. K. Page, eds. Washington, DC: The National Academies Press.
2. Richardson, A., Sitzia, J., Brown, V., Medina, J., and Richardson, A. (2005). *Patients' needs assessment tools in cancer care: Principles and practice*. London: King's College London.
3. Wen, K-Y., and Gustafson, D. H. (2004). Needs assessment for cancer patients and their families. *Health and Quality of Life Outcomes*, 2, 11.

Given the absence of recommendations regarding psychosocial health care needs assessment, consensus was reached to also conduct a systematic review of the empirical literature regarding psychosocial health care needs assessment.

Search for applied studies of psychosocial health care needs assessments

To supplement the foundational documents, a literature search was conducted in May 2008 using the following electronic databases: CINAHL, EMBASE, HealthSTAR,

MEDLINE, PsycINFO, CDSR (Cochrane Database of Systematic Reviews), DARE (Database of Abstracts of Reviews of Effects), HTA (Health Technology Assessments), and CCTR (Cochrane Central Register of Controlled Trials). Search terms included cancer, neoplasm, psychosocial aspects of illness, psychosocial factors, psychosocial support, psychological stress, symptom distress, psychosocial care, distress syndrome, psychosocial readjustment, assessment and screening for distress. A search of reference lists in reviewed guidelines (those listed above) and in retrieved articles was also conducted.

Inclusion and exclusion criteria. Studies eligible for inclusion included systematic reviews, randomized trials, quasi-randomized trials, and prospective comparative cohort studies, published after 2002 and not already reviewed in the context of the chosen foundational documents. Eligible studies evaluated the effectiveness of routine assessment of psychosocial health care needs of the patient, including one or more of: physical, informational, emotional, psychological, social, spiritual and practical needs. Outcomes of interest were limited to those that reflected a focus on psychosocial well-being, including but not limited to: quality of life, symptom severity, improvement in coping, improved self-concept, improved communication with the healthcare team, and reduction in unmet needs. Studies were included if they focused on adults (age 18 and above) who have had suspicious findings on cancer screening (high risk for cancer) and/or had a cancer diagnosis. Studies were excluded if not published in English.

Results. The search yielded 421 references. These were independently reviewed for inclusion and exclusion criteria by two experienced research assistants with graduate-level training in research and systematic review methods (MJ, SM). Where there were discrepancies, consensus between reviewers was reached through discussion. No recent systematic review relating to the effectiveness of psychosocial needs assessment among cancer patients was identified. However, five randomized controlled trials, two quasi-randomized controlled trials, and two prospective comparative cohort studies were identified. Methodological characteristics and key findings from these studies were extracted into summary tables (MJ, see Appendix D). The tables and all full-text articles were presented to the panel, who participated in a consensus process to appraise the quality of these primary papers and to discuss the implications of these articles to the development of practice recommendations.

Search for assessment instruments

A literature search for tools that would enable a standardized, psychosocial health care needs assessment as part of routine care was conducted in July 2008. The following electronic databases were searched: MEDLINE, CINAHL, EMBASE, PsycINFO, EBR, Scopus, and Health and Psychosocial Instruments (HAPI). Search terms included

various known instrument names collected from the existing reports and panel expertise, such as Patient Care Monitor, Supportive Care Needs Survey, and Distress Thermometer. A hand search through reference lists of systematic reviews and reviewed guidelines (as listed above) was also conducted.

Inclusion and exclusion criteria. Studies of interest were systematic reviews published after August 2002, and primary studies not previously reviewed in the context of identified systematic reviews. Eligible studies evaluated instrument(s) used to assess the psychosocial health care needs (physical, informational, emotional, psychological, social, spiritual, and practical) of adult cancer patients, either as a broad set of needs or one class of needs only (e.g., information needs). Included studies provided data on instrument validity, reliability, or responsiveness. Studies were excluded if the method for evaluating the instrument was not documented, or if the evaluated instrument was not in English or French (except where a translated instrument was administered to Canadian patients).

Results. This second search yielded 119 references, which were independently reviewed for inclusion and exclusion criteria by two experienced research assistants with graduate-level training in research and systematic review methods (MJ, SM). Where there were discrepancies, consensus between reviewers was reached through discussion. In addition to the Wen and Gustafson (2004) systematic review, two further systematic reviews and fourteen primary studies were identified. These provided information on the validity, internal consistency, reliability and/or responsiveness for 40 different assessment instruments. Methodological characteristics and key findings from these studies were extracted into summary tables (MJ, see Appendices E and F). Subsequently, these tables and full-text articles were presented to the panel, who then participated in a consensus process to appraise the quality of the research, and to discuss the implications of this evidence for the development of practice recommendations.

Methods for formulating the recommendations

Guideline development panel members were provided all foundational documents and guidelines, full-text articles of included studies, and data summary tables for review. In September 2008, panel members convened for an all-day meeting to discuss the evidence in the context of the clinical questions (per Section 4.0). Where strong empirical evidence was not available, the panel employed a consensus process to develop a recommendation based on “best clinical practice”. **Overall, the final recommendations are based on expert consensus of the inter-professional panel, after review of the available evidence, guidelines from other groups, and current clinical practice in Canada.**

External review

A draft of the guideline was reviewed by a diverse panel of external reviewers, who were invited to participate on the basis of clinical, content, and/or methodological expertise. Effort was made to ensure that the external review panel reflected perspectives from a range of clinical settings and geographical locations. Twenty individuals (an 80% response rate) provided feedback in the context of this review process. The results of the review were discussed by the guideline development panel and, where appropriate, revisions were made to the guideline. Further detail regarding the external review process is provided in Appendix C.

6.0 Recommendations

Recommendation 1: A routine, systematic and standardized assessment of psychosocial health care needs common across cancer populations is recommended as a critical first step in the provision of appropriate, and relevant psychosocial and supportive care interventions and/or services.

Evidence-Based Rationale

Numerous clinical practice guidelines and substantive reviews have recognized the importance of psychosocial health care needs assessment as a precursor to the provision of quality psychosocial and supportive care (IOM, 2008; NCCN, 2008; NICE, 2004; Richardson et al., 2007; Wen & Gustafson, 2004).

The IOM (2008) proposed a Model for Delivering Psychosocial Health Services, in which the first step is the identification of patients with psychosocial health care needs that are likely to affect their health and health care. Similarly, the National Institute for Clinical Excellence (NICE) guidance on *Improving Supportive and Palliative Care for Adults with Cancer* (2004) recommended that the assessment of individuals' needs be a critical first step in the provision of relevant support.

Needs may be identified through patients' voluntary provision of such information or through providers eliciting this information during structured or unstructured clinical conversations (IOM, 2008). However, various studies indicate that patients vary in their ability to volunteer information and providers vary in their ability to elicit information (IOM, 2008; Richardson et al., 2007). Indeed, needs may not be met because they are not recognized by providers or even by patients themselves (NICE, 2004). As a result, the use of routine, systematic, and standardized approaches to psychosocial health care needs assessment is regarded as vital to ensuring that such needs are identified and appropriately addressed.

The implications of identifying and addressing psychosocial health problems are significant. The NCCN (2008) suggests that early recognition and management of needs may have several benefits, such as: enhanced quality of care and satisfaction, increased patient-provider communication, increased trust, and increased patient adherence to treatment plan. Conversely, the failure to address psychosocial problems results in needless patient and family suffering, obstructs quality health care, and can potentially affect the course of the disease (IOM, 2008).

Recommendation 2: Routine, standardized, psychosocial health care needs assessment should include physical, informational, emotional, psychological, social, spiritual, and practical domains that are common across cancer populations.

Evidence-Based Rationale

This recommendation was developed based on empirical evidence synthesized in international guidelines regarding the parameters for effective, routine, psychosocial needs assessment. This base was affirmed and elaborated in light of the adopted conceptual framework (Table 1 on page 17) (The Ontario Cancer Treatment and Research Foundation, Supportive Care Program Committee, 1994), foundational documents (IOM, 2008; Australian National Breast Cancer Centre and National Cancer Control Initiative, 2003), and the diverse expertise and consensus of the guideline development panel, as well as the panel's systematic reviews (NCCN, 2008; Richardson et al., 2005; Richardson et al., 2007). Furthermore, these areas of need are consistent with those reflected in a number of national Canadian surveys of cancer patient needs (Ashbury et al., 1998; Fitch, 2008; Vachon 2006; Vachon, 1998).

Based on their systematic review of the evidence, the Australian National Breast Cancer Centre and National Cancer Control Initiative (2003) identified physical (e.g., pain, fatigue, fertility), emotional (e.g., intense unpleasant and distressing feelings of anger, fear and helplessness), psychological (e.g., depression, anxiety, self-concept, body image, sexuality, altered relationships), social (e.g., level and type of support), and practical and financial needs (e.g., access to home help and supportive treatment and services including cost, travel to clinics, financial concerns) as highly prevalent domains of need. Spiritual and existential issues were also identified as issues towards the end-of-life.

The NCCN (2008) distinguishes between practical problems (e.g., illness-related concerns, housing, employment) and psychosocial problems (e.g., adjustment to illness, family conflicts, bereavement). However, consistent with the operational definition of psychosocial health care needs as adopted for the present guideline, all of these problems have been considered and are embedded in the framework in Table 1.

| <i>Assessment Parameters</i> | <i>Examples of issues associated with needs</i> |
|--|--|
| <p>Physical needs</p> <ul style="list-style-type: none"> physical comfort and freedom from pain, optimum nutrition, activities of daily living; may include assessment of complications such as late effects of treatment | Nausea and vomiting, pain, fatigue, fertility, lymphoedema, respiratory issues, cognitive impairment, bowel difficulties, genitourinary difficulties, sleep disturbances, etc. |
| <p>Informational needs</p> <ul style="list-style-type: none"> information to reduce confusion, anxiety and fear, to inform patient and family decision-making, and to assist in skill acquisition | Cancer treatment and side effects, how to handle or manage side effects, care processes, patient education resources, system orientation, etc. |
| <p>Emotional needs</p> <ul style="list-style-type: none"> sense of comfort, safety, understanding and reassurance | Fear, distress, guilt, grief, anxiety and depression, hope and hopelessness, sadness etc. |
| <p>Psychological needs</p> <ul style="list-style-type: none"> coping with illness experience and its consequences, personal control, self-esteem | Changes in lifestyle, sexual problems, loss of personal control, fear of recurrence, self-image problems, body image problems, etc. |
| <p>Social needs</p> <ul style="list-style-type: none"> related to family relationships, community acceptance and involvement in relationships | Changes in social roles, coping with interpersonal problems, starting new social relationships, re-integration, return to work, social support available to the patient |
| <p>Spiritual needs</p> <ul style="list-style-type: none"> hope, belonging, meaning and purpose of life | Search for meaning, existential despair, examining personal values and priorities, hope and hopelessness |
| <p>Practical needs</p> <ul style="list-style-type: none"> direct assistance or resources to accomplish tasks or activities | Costs (diagnosis, treatment, prostheses, aids), daily home help, transportation, child care, elder care, loss of income, legal and financial issues, system navigation |

Table 1: Domains of Psychosocial Health Care Needs
(adapted from The Ontario Cancer Treatment and Research Foundation, Supportive Care Program Committee, 1994)
Published with permission.

Recommendation 3: Screening for distress is recommended for use as an initial “red flag” indicator of psychosocial health care needs that should be followed by a more comprehensive and focused assessment to ensure that interventions are targeted, appropriate, and relevant to the needs and specific problems identified by the individual and family.

Recommendation 4: Screening for distress should not be limited to depression and anxiety symptoms alone but also include identification of physical, informational, psychological, social, spiritual, and practical domains of psychosocial health care needs or concerns that contribute to distress of cancer and treatment.

Evidence-Based Rationale

Psychosocial health care needs assessment is considered a valuable adjunct to the assessment process (IOM, 2008; NCCN, 2008; Richardson et al., 2005). Given limited resources in ambulatory cancer centers and the limited time that each patient is present in a cancer centre, many organizations will choose to initially screen patients for distress as part of a triaging system. Screening for distress involves the administration of a test to individuals who are not known to have or do not necessarily perceive that they have or are at risk of having a particular condition or need (IOM, 2008). In the context of psychosocial care, a screening for distress program allows for a rapid identification of individuals who are at risk for having psychosocial health care needs and are likely to benefit from a comprehensive psychosocial health care needs assessment, tailored interventions, or referral to psychosocial services. Although a psychosocial health care needs assessment may be performed without a preceding screen (IOM, 2008), a positive screen for distress should always be followed with a comprehensive assessment.

Various substantive reviews have considered the issue of screening for distress within the context of psychosocial care (IOM, 2008; Mitchell, 2007; Mitchell, 2008; NCCN, 2008; Vodermaier, Linden, & Siu, 2009). Taken together, these works reflect a broad grouping of screening for distress tools into three categories: screening for distress; screening for symptoms; and screening for sources of distress such as related problems and concerns. Examples of commonly cited tools are provided in Appendix G. Although each of these approaches to screening for distress may provide valuable information with which to guide practice, narrowly focused screening for distress tools may fail to identify individuals who may be at risk for psychosocial health care needs across the domains of the guiding supportive care needs framework. For example, a tool developed for the purpose of screening for symptom distress may overlook the important issue of social support needs. Indeed, as recommended by the IOM (2008), psychosocial screening for distress instruments should be used to detect a

comprehensive range of psychosocial health care needs similar to those identified in the conceptual framework as outlined earlier in this report (Table 1 on page 17).

There is currently no gold standard instrument reflective of such a comprehensive approach to psychosocial health care needs screening. Moreover, there is little guidance with respect to which screening for distress instruments should be used for the different types of patients seen in various clinical settings (IOM, 2008). It was beyond the scope of the current guideline to review the properties of all screening tools for psychological distress, symptoms, and problems and concerns. However, based on the major reviews consulted and the consensus of the guideline development panel, the following are recommended as considerations in choosing an instrument for psychosocial health care needs screening (IOM, 2008; Vodermaier, Linden, & Siu, 2009):

- The instrument should be designed to screen for a comprehensive range of psychosocial health care needs that contribute to distress
- The instrument should be brief and feasible for routine use
- The length and burden of the instrument should be considered given the clinical setting and the patients' physical condition (e.g., cancer survivor populations, acutely ill patients, patients with advanced cancer)
- The instrument should have adequate sensitivity, specificity, and predictive value for the patient population to which it will be applied
- The instrument should have an internal consistency of 0.8 or greater, with content and criterion validity, and Receiver Operating Characteristic (ROC) analyses that indicate clinical value
- The instrument should provide empirically justified cut-offs to guide clinical decision-making and identification of level of risk

Recommendation 5: Routine psychosocial health care needs screening for distress and assessment is recommended at critical time points in the cancer continuum. These include: initial diagnosis, start of treatment, regular intervals during treatment, end of treatment, post-treatment or at transition to survivorship, at recurrence or progression, advanced disease, when dying, and during times of personal transition or re-appraisal (e.g., in a family crisis, during survivorship, when approaching death).

Recommendation 6: Disease, treatment, or phase-specific psychosocial health care needs assessments should be added to routine, standardized assessment across populations (generic), in order to tailor assessments to problems that are unique to a specific type of cancer, treatment modality, or phase in the cancer continuum (e.g., post-treatment survivorship or incontinence after pelvic surgery).

Evidence-Based Rationale

Specific empirical evidence to support appropriate timing of psychosocial health needs assessments was an identified gap in the literature. It is commonly recognized in clinical practice that patients have specific psychosocial and supportive care needs that change across the continuum and which differ, or emerge, in critical phases or at points of transition (called periods of increased vulnerability by the NCCN (2008)).

Figure 1 (page 6) depicts the points along the continuum representing points of transition and periods when patients (and their families) may experience increased vulnerability and psychosocial distress. At a minimum, these transition points should be considered for re-assessment of psychosocial health care needs.

The National Institute for Clinical Excellence (NICE) in their document entitled *Improving Supportive and Palliative Care for Adults with Cancer* (2004) recommended that systematic assessment should be a critical first step in the provision of relevant support. Such assessment should be ongoing and be focused at key points in the continuum (including diagnosis, start of treatment, completion of primary treatment, recurrence, and palliative care). The NCCN (2008) identified many periods of increased vulnerability, such as, finding a suspicious symptom, during workup, finding out diagnosis, awaiting treatment, change in treatment, end of treatment, discharge from hospital after treatment, survivorship, medical follow-up and surveillance, treatment failure, recurrence/progression, and advanced cancer. The Australian National Breast Cancer Centre and National Cancer Control Initiative (2003) identified a number of survivorship issues related to impairments in physical function, late or ongoing effects of treatment, altered sexual functioning, concerns about returning to work, negative adjustment, and fear of recurrence.

Following a generic assessment of psychosocial health care needs, different types of focused (e.g., disease specific or phase specific) assessments will be required, dependent upon identified needs and priorities of care (Ahern & Philpot, 2002; White, 2003; Holmes, 2003).

Recommendation 7: Routine psychosocial health care needs screening for distress and assessment is recommended as an interpersonal process to elicit comprehensive information regarding patients' needs for psychosocial and support interventions. Assessment may involve a combination of self-report questionnaires and interview approaches and is dependent on effective communication as part of a therapeutic relationship between patient and clinician.

Recommendation 8: Routine psychosocial health care needs screening for distress and assessment should be followed by evidence-based interventions and targeted care processes appropriate to the identified need in order to improve patient outcomes including relief of symptoms, emotional well-being and quality of life.

Evidence-Based Rationale

To supplement the evidence included in the Australian National Breast Cancer Centre and National Cancer Control Initiative (2003) and the Institute of Medicine (2008) reports, and to specifically address the question of effectiveness of psychosocial assessments on patient outcomes, a literature search was conducted for experimental studies that evaluated routine psychosocial health care needs assessment as compared to a control group. The literature search identified five randomized controlled trials (Detmar et al., 2002; McLachlan et al., 2001; Rosenbloom et al., 2007; Sarna, 1998; Velikova et al., 2004), two quasi-randomized controlled trials (Boyes et al., 2006; Kristeller et al., 2005), and two prospective comparative cohort studies (Bramsen et al., 2008; Taenzer et al., 2000) (Characteristics of these nine studies are provided in Appendix D).

The empirical evidence in this body of literature was challenging to synthesize, due to differences in the assessment parameters included, lack of clarity regarding the processes of assessment and subsequent care provision, and the primary outcomes of interest. The parameters of psychosocial assessment varied across studies and encompassed: overall and individual dimensions of quality of life (Detmar et al., 2002; McLachlan et al., 2001; Taenzer et al., 2000; Rosenbloom et al., 2007; Velikova et al., 2004), physical and psychological symptoms (Boyes et al., 2006; Sarna, 1998), and supportive care and/or spiritual care needs (Bramsen et al., 2008; Kristeller et al., 2005). The format of the studied psychosocial assessments included semi-structured interviews (Bramsen et al., 2008; Kristeller et al., 2005; Rosenbloom et al., 2007) and self-administered questionnaires (Boyes et al., 2006; Detmar et al., 2002; McLachlan et al., 2001; Sarna, 1998; Taenzer et al., 2000; Velikova et al., 2004). The primary outcomes of interest varied widely across studies, including one or more of: quality of life, psychological or physical symptoms, patient-clinician communication, and patient satisfaction. Overall, studies did not specifically address all components of psychosocial health care needs and so diversity of findings prevented synthesis of results. Even so, several related questions were addressed in these nine studies:

1. Do *un-interpreted* survey results have an impact on patient outcomes when they are disseminated without a specific focus on care process changes? Five studies (Detmar et al., 2002; McLachlan et al., 2001; Sarna, 1998; Taenzer et al., 2000; Velikova et al., 2004) investigated the effect of providing questionnaire results to the treatment team, particularly medical oncologists. Studies that directly measured patient outcomes report mixed results overall,

but do show improvement in emotional, physical, and functional well-being (Detmar et al., 2002; McLachlan et al., 2001; Sarna, 1998; Velikova et al., 2004). Improved communication regarding quality of life issues (Detmar et al., 2002; Taenzer et al., 2000; Velikova et al., 2004) and increased patient satisfaction with the level of emotional support received were also observed (Detmar et al., 2002). This finding is not consistent across studies. For instance, Velikova et al. (2004) found that improvements to emotional well-being and overall quality of life were not significantly different between the standardized assessment group and attention control group.

2. Does the provision of interpreted survey results to staff have an impact on patient outcomes? Two studies (Boyes et al., 2006; Rosenbloom et al., 2007) evaluated assessment protocols that involved an interpretation of self-administered questionnaire results prior to the provision of these results to the treatment team. In one study, computer software was used to score questionnaire responses and develop a feedback report. The report consisted of an overview of physical symptom, anxiety and depression scores; supportive care needs and suggested strategies for referral were provided to the treating oncologist (Boyes et al., 2006). In another approach, an interviewer met with the patient following completion of the questionnaire in order to elicit greater detail based on the patient's feedback, which was then relayed to the treatment nurse (Rosenbloom et al., 2007). Although Boyes et al. (2006) reported fewer debilitating symptoms in the intervention group at the 3rd clinic visit, there were no significant differences reported in either study across measures of physical, psychological, functional well being, quality of life, supportive care needs, or patient satisfaction. These two studies suggest that the provision of interpreted questionnaire data to the treating clinician is insufficient for changing clinical management to the effect of improving patient outcomes. Indeed, half of the physicians involved in the Boyes et al. (2006) study did not discuss the feedback report with their patients.
3. Does a direct, one-on-one interview by specialist psychosocial staff or front-line staff with a patient result in increased referral for psychosocial care and provide psychosocial benefit?
 - a. One study (Bramsen et al., 2008) demonstrated a greater referral rate, improved physical functioning and pain scores, and better role functioning in a group who were interviewed by a psychologist or social worker regarding their psychosocial issues. In light of the aforementioned studies, a more direct approach with patients may be better than an

indirect strategy through the front-line staff in regard to some outcomes. In composite, perhaps direct and indirect strategies are complementary.

- b. Though limited to the assessment of spiritual concerns, Kristeller et al. (2005) reported that an assessment interview led by the treating oncologist showed an improvement in the relationship between the patient and oncologist, but had no impact on symptoms, spirituality, or religiosity.

Across these studies, the use of instruments differed, as did the targeted outcomes resulting from standardized assessment (Appendix D, Table 3). Due to the diversity in study design and intervention, it was not possible to carry out a meta-analysis to statistically summarize findings across studies (e.g., to calculate an average effect size) or to generate a conclusion of benefit or harm. Of all the outcomes measured, only one study reported a harmful impact secondary to providing questionnaire findings to staff, and this was limited to the spiritual domain (McLachlan et al., 2001).

The overall conclusion from these nine studies is that, although the care interventions that brought about the change are unclear, psychosocial health care needs assessments have a positive, yet modest, clinical impact on reducing symptoms and emotional distress and improving quality of life.

Our independent findings were consistent with that reported in the Cancer Care for the Whole Person report as follows: “There is very little high quality evidence of the impact of using assessment tools on clinical practice or patient outcomes” (IOM, 2008, p. 47). The difficulty of interpreting research results is increased by the failure of existing studies to provide an understanding of the processes of care and specific interventions that were implemented.

Although the current evidence fails to establish the effectiveness of psychosocial health care needs assessment, two major factors were also considered in the development of this recommendation. First, psychosocial assessment appears to be highly acceptable to both patients and clinicians, particularly as a means of enhancing the communication of clinically relevant information (Boyes et al., 2006; Detmar et al., 2002). Studies that have demonstrated a positive impact of psychosocial assessment on patient outcomes highlight the significance of communication to the assessment process. Second, notwithstanding the one negative outcome reported (McLachlan et al., 2001), psychosocial assessment is considered to be a safe and practical means by which to elicit valuable information regarding patients’ psychosocial health and concerns. **Overall, psychosocial health care needs assessment does not appear to place a significant burden on patients and has many potential clinical benefits with regard to facilitating communication and guiding psychosocial and supportive care interventions.**

Lastly, assessment alone does not automatically lead to improved outcomes; it must be followed by appropriate interventions and effective management of the problem identified. Assessment may lead to better outcomes by three possible mechanisms: (1) leading directly to the implementation of new care processes (i.e., psychosocial interventions or team based care planning), (2) providing more information to guide appropriate referral to psychosocial services, or (3) enhancing the patients' experience of the care received (e.g., communication with the provider or satisfaction with care). It is expected that clinicians act on the findings of their assessment in order to optimize the potential for positive outcomes (IOM, 2008; NCCN, 2008).

In summary, these nine controlled studies give a pattern of results that supports the use of psychosocial health care needs assessment in adult patients with cancer. Generalizeability of the findings is limited as the population focus in the reviewed studies was advanced cancer, and particularly lung cancer and the relatively short follow-up times of six months or less.

Recommendation 9:

(a) A comprehensive assessment tool with sound psychometric properties that addresses all domains of psychosocial health care needs is recommended for use in routine clinical practice. A number of valid and reliable tools that can support a systematic approach to identify the broad range of psychosocial and support needs (i.e., Cancer Rehabilitation Evaluation System: CARES and the Supportive Care Needs Survey) are listed in Table 1 on page 17.

b) Focused assessments using a valid and reliable tool should follow a comprehensive assessment and be targeted to identification of the parameters of a specific problem (e.g., pain) and dimensions of a specific problem. For instance, use of the Memorial Symptom Assessment or similar tool to assess all dimensions of symptoms (frequency, severity, distress) amenable to intervention or a specific tool to assess parameters of pain (location, severity, quality, timing, aggravating or alleviating factors).

Evidence-Based Rationale

In addition to the Wen and Gustafson (2004) systematic review, 2 further systematic reviews (Kirkova et al., 2006; Richardson et al., 2007) and 5 primary studies (Hodgkinson, Butow, Hobbs, et al., 2007; Hodgkinson, Butow, Hunt, et al., 2007; Shelby et al., 2006; Wright et al., 2005; Wright et al., 2007) were identified that, taken together, provided information on 40 psychosocial health care needs assessment tools (Appendix E). The papers reviewed provided data on the validity, internal consistency, and reliability and/or responsiveness of 15 of these tools.

Four potential instruments were identified to guide comprehensive, psychosocial person-centered needs assessment. These instruments have been found to be valid and reliable and to reflect a comprehensive consideration of psychosocial needs; they are designed to be self-administered by any person affected by cancer: (A table summarizing the characteristics of these tools is provided in Appendix F.)

1. The Cancer Rehabilitation Evaluation System [CARES] (formerly the Cancer Inventory of Problem Situations [CIPS]) (Ganz et al., 1986; Ganz et al., 1987; Ganz et al., 1992; Meyerowitz, Heinrich, & Schag, 1983; Schag, Heinrich, & Ganz, 1983; Shelby et al., 2006). This system contains 139 items that cover a wide range of physical, psychosocial, vocational, and economic problems. However, because not all items apply to every patient, patients may complete a minimum of 93 items or a maximum of 132 items. Patients rate each problem statement on a 5-point Likert scale, zero representing “not at all” (no problem) and four representing “very much” (severe problem).
2. A shortened version of the CARES, the Cancer Rehabilitation Evaluation System - Short Form [CARES-SF] (Schag, Ganz, & Heinrich, 1991) was developed to facilitate wider use in research and assessment of psychosocial needs. The CARES-SF contains 59 items, and patients complete a minimum of 38 and a maximum of 57. All items in the CARES-SF appear on the original CARES. The multidimensional construction, rating scale, and scoring system is also unchanged from the CARES. The instrument has demonstrated a high relation to the CARES, excellent test-retest reliability, concurrent validity with related measures, and acceptable internal consistency of summary scales (Schag, Ganz, & Heinrich, 1991).
3. The Cancer Care Monitor [CCM] (Fortner et al., 2003) is a symptom-based scale developed for the clinical screening of high frequency cancer-related symptoms and assessment of overall symptom severity and health-related quality of life. The instrument contains 38 items divided into six scales: (1) general physical symptoms, (2) treatment side effects, (3) acute distress, (4) despair, (5) impaired ambulation, and (6) impaired performance. Patients respond to each item via a 10-point Likert scale to indicate the extent to which each symptom is experienced. Initial psychometric testing suggests that CCM items can be scored as a reliable and valid measure of physical, psychological, and functional status, as well as global health-related quality of life (Fortner et al., 2003).
4. The Cancer Patient Need Questionnaire [CPNQ] (Foot & Sanson-Fisher, 1995) assesses cancer patients' perceived need for help across the following five

domains: Psychological, Health Information, Physical and Daily Living, Patient Care and Support and Interpersonal Communication. Items are rated on a 5-point scale (ranging from 1 “no need/not applicable” to 5 “high need”). The Supportive Care Needs Survey [SCNS] (Bonevski et al., 2000; Sanson-Fisher et al., 2000) is a related scale based on the CPNQ.

When choosing an assessment instrument for use in clinical practice, local considerations must be taken into account. Various factors may impact on decision-making, such as available resources, likely or actual burden on patients/families, and the relevance of the instrument to local patient and family populations.

Recommendation 10: Screening for distress tools used as part of routine screening should be brief so as to minimize patient burden and maximize ease of uptake into clinical practice; and should possess adequate sensitivity and specificity and established cut-offs for rapid identification of high risk populations.

Evidence-Based Rationale

An extensive review of screening for distress tools was not within the scope of this guideline but a number of review articles were identified in the search for psychosocial health care needs assessment instruments.

Screening for Distress

Distress has been defined as “a multi-factorial unpleasant emotional experience of a psychological (cognitive, behavioural, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as, depression, anxiety, panic, social isolation, and existential and spiritual crisis.” (NCCN, 2008, p. DIS-2).

Several substantive reviews have provided discussion and psychometric data for various tools that may be used to screen for distress and/or related symptoms of depression and anxiety (IOM, 2008; Mitchell, 2007; Mitchell, 2008; NCCN, 2008; Vodermaier, Linden, & Siu, 2009). Information regarding the most commonly cited instruments across these reviews were summarized and compared on the basis of several characteristics (see Appendix G, Table 1).

Overall, it is emphasized that while instruments with high specificity and sensitivity may be useful to screen for distress and to provide a “red flag indicator” that a need or a problem in a specific domain may exist, they provide limited information in regards to the source of distress, and point to the need for further assessment.

Similarly, although several of the cited tools are designed to measure symptoms of depression and/or anxiety, it is emphasized that these tools are for screening only and are not meant for diagnostic purposes.

Screening for Distress: Physical Symptoms

Symptoms are a causative factor in emotional distress (NCCN, 2008) and a significant source of suffering that impacts the outcomes of quality of life and overall wellbeing. Symptom experience is the perception of the frequency, intensity, distress, and meaning of symptoms as they are produced and expressed, which may have consequences on mood state, psychological status, functional status, quality of life, disease progression, and survival (Armstrong, 2003).

Because of their brevity, two instruments were identified as potentially useful for screening for symptom severity (Edmonton Symptom Reporting Tool [ESAS] (Bruera et al., 1991)) and symptom distress (Symptom Distress Scale [SDS] (Perselli et al., 1993)). Although the ESAS has shown some usefulness in palliative populations (Richardson & Jones, 2009), evidence regarding the overall usefulness of these tools across various cancer populations is not available for review and incorporation into guidelines and recommendations.

It must be recognized that measures of symptom severity are adequate only for the purposes of “red flag” screening for distress and more comprehensive assessment of all parameters of assessment are important, especially to evaluate the clinical value of symptom screening measures, and the effectiveness of subsequent psychosocial and supportive care interventions.

Recommendation 11: Problems and concerns checklists for use as part of “red flag” screening for distress should include all dimensions of psychosocial health care needs using valid and reliable tools where they exist. Problems and concerns checklists should be recognized as “indicators” of a need or concern only and should trigger a therapeutic dialogue between patient and clinician to obtain a more comprehensive and/or focused understanding of the problem or concern.

Evidence-Based Rationale

Health care organizations may develop their own “problem checklists” or use existing problem checklists embedded in best practice guidelines (NCCN, 2008) as part of a program to identify psychosocial concerns. Although such tools may assist in highlighting specific patient and family problems that may require intervention, there is insufficient evidence of psychometric rigour to support their ability to reliably identify needs in a consistent manner such that a comprehensive assessment is still required. The problem list of the NCCN Distress Thermometer (Roth et al. 1998) has

reported internal consistency ranging from $\alpha=0.81$ to 0.90 (Hoffman et al. 2004; Tuinman, Gazendam-Donofrio, & Hoekstra-Weebers, 2008) but few papers report any associations of this particular problem list with distress as measured in the DT zero to ten scale. The Symptoms & Concerns Checklist (Lidstone et al., 2003) was also discussed as potentially useful as a screening for distress instrument, however its use as such was not supported by the reviewed evidence.

Recommendation 12:

(a) Ongoing education of all members of the health care team is critical to ensure competent psychosocial health care needs assessment and appropriate clinician response to findings of “red flag” screening for distress, and comprehensive and focused assessments.

(b) Interdisciplinary collaboration is recommended for routine, standardized psychosocial health care needs assessment and screening for distress and targeting of interventions consistent with practice scope to effectively address multidimensional domains of need and/or facilitate appropriate referral to discipline-specific and/or psychosocial oncology specialists and services.

Evidence-Based Rationale

An inter-professional model that includes for example, the oncologist, psychologist, nurse, social worker, and mental health services and spiritual care has been recommended for the assessment of distress (IOM, 2008). Other guidelines, such as those of the National Comprehensive Cancer Network (NCCN, 2008), did not provide empirical evidence to support a recommendation regarding who should be involved in routine psychosocial health care needs assessment. This decision is usually based on local, contextual health care system environment factors (e.g., care delivery model and type of cancer program) and available resources. However, it is the consensus of the expert panel that members of the front-line inter-professional health care team (primary care team in the community sector) should hold primary responsibility for routine psychosocial health care needs assessment. The expert panel considered it essential to empower clinicians, who are at the “front line” of care, recognizing that this may vary based on the local context for practice. This team may include, but is not limited to, nurses (community- or institution-based), family physicians, oncologists, and social workers appropriately trained in the care of cancer populations and competent in psychosocial assessment, therapeutic communication and psychosocial interventions appropriate to their scope of expertise (see Figure 2). A percentage of the population will have needs that cannot be addressed by front-line clinicians and for whom further referral to psychosocial services is needed.

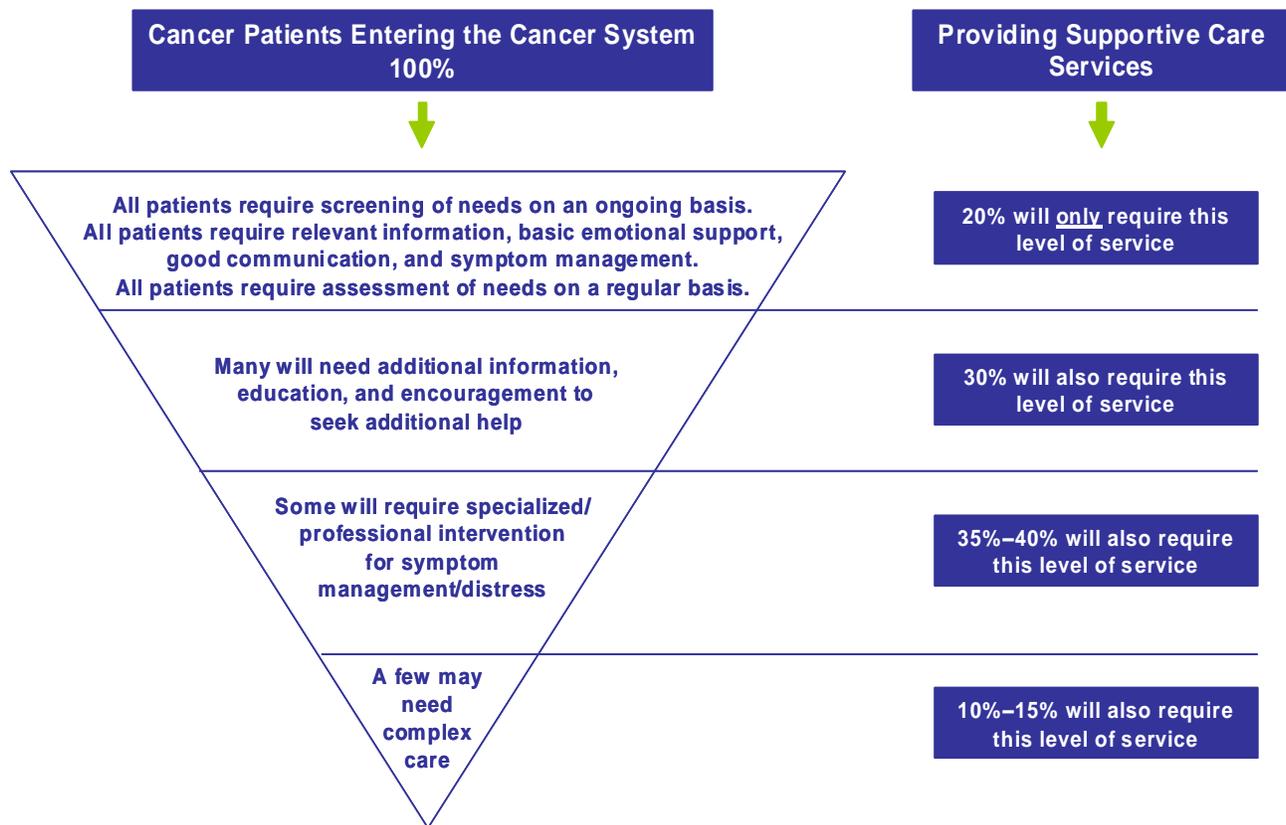


Figure 2: Service Provision Based on Proportion of Patients Requiring Assistance
(Fitch, 2008, Reprinted with permission)

It is assumed that all health care professionals possess some level of competency, training, and a responsibility for ongoing professional development, as outlined in regulatory standards of practice and requirements for professional licensing. However, training to augment basic knowledge of psychosocial issues is needed to ensure specialized psychosocial oncology knowledge and skills in the assessment of psychosocial health care needs and management of distress.

It is also imperative that cancer care organizations support the integration of psychosocial assessment and collaborative care processes into routine practice; this requires that staff have access to credible education programs and psychosocial resources. Organizations should also monitor the cancer system's performance in addressing psychosocial needs. Importantly, organizations must establish clear processes to determine who is involved in psychosocial health care needs assessment; they must also develop appropriate evidence-based interventions with clear indications for referrals. Researchers and international health care systems have articulated a tiered model for intervention (Hutchison, Steginga, & Dunn, 2006) that suggests how different health care professionals may be involved in the provision of psychosocial and supportive

care based on distress scores. In this model, the assessed level of psychosocial distress determines the necessary level of intervention and professional specialization (Table 2).

| <i>Assessed Level of Distress</i> | <i>Intervention</i> |
|-----------------------------------|--|
| Minimal to Mild | Universal Care: Informational and basic practical support (e.g., health care team, patient education) |
| Mild to Moderate | Supportive Care: Emotional, spiritual and peer support (e.g., nursing, social worker, psycho-education, peer support, chaplain) |
| Moderate | Extended Care: Counselling, time limited therapy, skills training (e.g., psychologist, social worker, advanced practice nurse, chaplain) |
| Moderate to Severe | Specialist Care: Specialised therapy for depression, anxiety, relationship problems (e.g., psychologist, psychiatrist, advanced practice nurse, social worker, couple/family therapist) |
| Severe | Acute Care: Intensive or comprehensive therapy for acute and complex problems (e.g., mental health team, psychiatrist). |

Table 2: Tiered Model of Psychosocial Intervention in Cancer (adapted from Hutchison, Steginga, & Dunn, 2006)

7.0 Implementation Considerations

There remains an insufficient evidence base for the efficacy of strategies, either in general or under specific circumstances. However, there is growing consensus regarding certain principles that may help to inform implementation of this guideline. Effective strategies to implement this guideline may involve the following:

- **The development of a team to lead the implementation initiative.** This team should be comprised of representatives from all key stakeholder groups that would be affected by the proposed change in practice (e.g., inter-professional team, clients, administrators). This group may prioritize recommendations within the guideline to be implemented, can identify the barriers and facilitators to change in the local environment, and should plan the approaches to be used.
- **Organizational support.** The lack of time, resources, and support from directors and managers are often barriers to guideline implementation. A formal commitment by the organization, including resources to support implementation strategies (e.g., education sessions, staff involvement) would further the success and sustainability of the initiative).
- **Multi-faceted targets of intervention.** Guideline implementation focused on facilitating practice change of clinicians, should also address policy and structural supports at the organization and system levels that can act as barriers or enablers to guideline uptake. Some key areas of consideration may

include skill development (i.e., training), involvement of opinion leaders, adoption of change into policies and procedures, audit and feedback, reminder systems such as prescribing prompts, facilitating patient awareness of the change, and providing incentives such as financial or other types of rewards (Carey, Buchan, & Sanson-Fisher, 2009; Francke et al., 2008; NICE, 2007; Registered Nurses' Association of Ontario, 2002b).

- **Emphasis on Continuous Quality Improvement:** Approaches recommended by the Institute for Health Quality Improvement in the USA such as Rapid Cycle Change have shown significant results in achieving change in practice and ensuring continuous quality monitoring as part of the organizational culture.

8.0 Research Implications

The panel emphasized the need for more rigorous research, noting that evidence-based practice requires both sound processes (e.g., screening for distress tools and referral mechanisms), and methods of determining their impact on patient outcomes (e.g., well-being, quality of life).

Moreover, the assumption that screening for distress or assessment alone will improve the quality of care is problematic in current research. Further research is needed that focuses on practice change in order to improve patient outcomes. A number of methodological flaws in existing studies were identified such as limited scope, small sample sizes, few randomized trials, and lack of a clear process-outcome link, and the outcomes measured. The panel identified some key methodological issues to be considered in future research, including:

- **Populations to be studied (e.g., who may benefit from screening for distress and assessment, in particular contexts or at specific points along the clinical trajectory):** The specific time point relevant to screening for distress and assessment require further research across different cancer populations and for different phases of the cancer trajectory.
- **Measurement tools.** More research is needed regarding what tools and measures should be included in psychosocial health care needs assessment and screening for distress. Moreover, the acceptability and feasibility of using the existing valid tools from the perspective of patients, families and health care professionals is needed. In order to accurately measure the targeted outcomes of psychosocial needs screening and assessments, researchers must consider the limitations and scope of the available tools, and select a tool that is psychometrically sound in shorter or ultra short versions consistent with the local health care environment.

- **Interventions.** Existing studies focused on increasing information flow to make physicians aware of patient needs or survey findings and did not clearly specify the processes of care or interventions that did or should follow according to the patient's scores on measures. Trials of standardized comprehensive psychosocial health care needs assessment and screening for distress interventions should be combined with evaluations of the processes of care that are influenced by the implementation of that intervention - and specific interventions that are triggered by assessment. Research should examine the interventions and processes of care that are implemented or need to be changed as a result of assessment - not just assume assessment alone will translate into improved patient outcomes.
- **Analyses.** Many studies looked at multiple outcomes and used multiple statistical tests, which called the use of a conventional alpha of 0.05 (2-tailed) into question as a measure of statistical significance. One-tailed p-values may be used more widely where positive findings are anticipated. Some studies applied numerous statistical tests when they used complex measurement tools, and did not consider the impact on interpreting p-values of marginal significance; and attrition was not addressed in the analyses or limitations.

Research to date has targeted information provision to front-line staff who are, unsurprisingly, considered the locus of psychosocial and supportive care screening for distress and assessment, and initial care delivery. Whether or not front-line work is the best focus of research attention and the primary target for psychosocial and supportive care resources, however, may require further examination. Undoubtedly, front-line staff are a very significant fulcrum to improve psychosocial care, but both the levers (i.e., survey instruments and so forth) and the fulcrum itself (i.e., staff selection and training, opportunity and resources) may need modification to produce a greater impact. Only one study looked at the impact of non-front-line staff (i.e., "second-line" staff) (Bramsen et al., 2008) as they interacted with patients. Further studies should aim to implement routine screening for distress and psychosocial health care needs assessment and the actions to be taken to the front-line process in relatively non-disruptive ways so as to test their impact. In addition a re-engineered front-line process should be developed and tested, since studies have so far demonstrated only a modest impact. For example, direct screening for distress and action by "second-line" staff is of interest, and possible cost-shifting may make this economically feasible (e.g., less time spent by front-line staff dealing with psychosocial issues, fewer phone calls to nurses). These are possible modifications to care models that can be empirically tested.

It is also important to consider further theoretical developments in our understanding of psychosocial and supportive care needs. Many articles in the literature document needs and explore numerous interventions. Many studies examine isolated needs and interventions. As such, our understanding of how the range of psychosocial health care needs sequence, interact, and evolve remains underdeveloped. Studies that look at a broader range of needs would help identify which needs or domains of need require the most urgent attention. Studies in physical symptom or needs clusters, for example, may be broadened to include simultaneous assessments of the roles of emotions, psychological processes, mentation and spirituality in identifying, interpreting, and managing those clusters.

In summary, a substantive research program is required to optimize assessment, interventions, and outcome measures. There are signs of such an emerging field, for example, in systematic reviews of screening for distress measures. Greater clinical focus on psychosocial needs is also emerging due to changes in policy that reinforce their recognition (e.g., screening for distress; ambulatory patient satisfaction surveys) and endorsement in standards (e.g., accreditation). The acceleration and promotion of research requires a combination of patient and clinician participation, organizational attention, a consensus within the research community, and sufficient research funds.

9.0 Conclusion

Despite limitations in the research, there is reasonable evidence that psychosocial and supportive care needs are under-addressed, that assessment improves patient outcomes, and that some screening for distress and psychosocial assessment tools have effective psychometric properties that help to “red flag” patients and support comprehensive assessment. The recommendations in this guideline have been designed to explain, ignite, and support the need for quality psychosocial health care needs assessment and screening for distress in persons living with cancer. Using an evidence base that is grounded in research and clinical practice, they stress the importance of assessment as a first step in the explication of need and the implementation of appropriate interventions. At the same time, this document has suggested a range of important considerations as the field moves forward - from needs assessment, clinical service provision, resource allocation, intervention, follow-up, and outcome evaluation, to related research, and more. We believe the adoption of these recommendations into cancer practice will bring us one step closer to a person-focused cancer system that can improve patient and family experience of living with cancer.

10.0 Acknowledgements

Guideline Development Panel

Doris Howell, RN, PhD

Development Panel Lead Chair, Canadian Partnership Against Cancer

RBC Chair Oncology Nursing Research Scientist

Psychosocial, Oncology and Palliative Care,

University Health Network (Princess Margaret Hospital)

Toronto, Ontario

Shelley Currie, MSW, RSW, CSW

Development Panel Co-Chair, Canadian Association of Psychosocial Oncology

Project Support Team - Provincial Family Physician Initiative

Medical Affairs and Community Oncology

Cancer Corridor, Alberta Health Services

Canmore, Alberta

Samantha Mayo, RN, MN

Research Assistant and Staff Nurse (Hematology-Oncology)

Princess Margaret Hospital

Toronto, Ontario

Glenn Jones, BSc, MD, FRCPC, MSc

Dept. of Medicine, McMaster University

Peel Regional Oncology Program

Credit Valley Hospital

Mississauga, Ontario

Michael Boyle, MSW, RSW

Previously,

BC Cancer Agency

Interlock Employee Assistance

Victoria, British Columbia

Thomas F. Hack, PhD, CPsych

Associate Professor, Faculty of Nursing, University of Manitoba

Clinical Psychologist, CancerCare Manitoba

Winnipeg, Manitoba

Esther Green, RN, MSc(T), BScN

Provincial Head, Nursing and Psychosocial Oncology

Cancer Care Ontario

Toronto, Ontario

Lawrence Hoffman, MDCM, FRCP

Senior Psychiatrist Consultation Liaison Service Department of Psychiatry and
Medicine (Hematology Division)
McGill University Health Centre
Assistant Professor of Psychiatry
Royal Victoria Hospital/McGill University
Montreal, Quebec

Judy Simpson, RN, BN, MEd, CHPCN(C)

Previously,
Palliative and Supportive Care Coordinator
Cancer Care Nova Scotia
Halifax, Nova Scotia

Vivian Collacutt, MSW, RSW

Provincial Manager, Community Cancer Support Networks
Medical Affairs and Community Oncology
Cancer Corridor, Alberta Health Services
Edmonton, Alberta

Deborah McLeod, PhD, MN, RN

Clinician Scientist
Capital Health/QEII Cancer Care Program
Dalhousie University
Halifax, Nova Scotia

Carol Digout

Atlantic Guideline Coordinator
Canadian Partnership Against Cancer
Halifax, Nova Scotia

Technical Consultants

Mary Johnston, BSc

Research Coordinator
Dundas, Ontario

Patricia Oakley

Information Specialist
National Research Council - CISTI
Fredericton, New Brunswick

Adaptation Methodology Experts

Margaret B. Harrison RN, PhD

Professor, School of Nursing

Community Health and Epidemiology

Director Queen's Joanna Briggs Collaboration

Senior Scientist Practice and Research in Nursing (PRN) Group

Queen's University

Kingston, Ontario

Joan van den Hoek

Coordinator, Guideline Adaptation

Cancer Guidelines Action Group

Canadian Partnership Against Cancer

Ottawa, Ontario

Administrative Support

Fay Bennie

Project Manager

Cancer Journey Action Group

Toronto, Ontario

Organizational Support

The following organizations are acknowledged for their support in the completion of this guideline:

- Canadian Association of Psychosocial Oncology - for their partnership and support in the completion of this important work
- BC Cancer Foundation - for their initial review of psychosocial oncology guidelines

Conflict of Interest Disclosures

Each member of the guideline development panel completed a Conflict of Interest Document. No conflicts of interest have been identified by members of the guideline writing team that could have compromised the recommendations of this guideline.

Funding sources

Production of this guideline has been made possible through a financial contribution from Health Canada, through the Canadian Partnership Against Cancer.

This guideline is editorially independent of the funding sources. The views and interests of the funding sources have not influenced the recommendations in this guideline.

The views expressed herein represent the views of the National Guideline Expert Panel, a sub-group of the Standards, Guidelines and Indicators Working Group of The Cancer Journey Action Group, Canadian Partnership Against Cancer.

11.0 Glossary

Family: Defined by the patient as the significant person(s) in their lives who are part of their immediate social support system. Family members can include, but are not limited to, spouses/partners, parents, children, siblings, neighbours, or significant members of the community (Registered Nurses' Association of Ontario, 2002a).

Inter-professional care: The provision of comprehensive health services to patients by multiple health care professionals who work collaboratively to deliver the best quality of care in every health care setting (Interprofessional Care Steering Committee, 2007).

Needs Assessment: Psychosocial health care needs assessment was defined as the identification and examination of psychological, behavioural, and social problems (IOM, 2008), and other empirically identified domains of need (physical, information, spiritual) as articulated earlier in this report, and encompasses: (1) a clearly defined process, done with, or by the person with (or suspected as having) cancer; (2) involving some form of consistent framework; (3) involving regular comprehensive assessment at clearly defined intervals; (4) based on patients' accounts of their needs and wishes which they expect professional care to meet; and finally (5) informing the decisions of a range of health care professionals involved in cancer care (Richardson, 2005, p. 1).

Psychosocial Oncology: A specialty in cancer care concerned with understanding and treating the social, psychological, emotional, spiritual, quality-of-life and functional aspects of cancer, from prevention through bereavement. It is a whole-person approach to cancer care that addresses a range of human needs that can improve quality of life for people affected by cancer (Canadian Association of Psychosocial Oncology, n.d.).

Reliability: the degree to which measurement with the assessment tool can be replicated (Streiner & Norman, 1989; Streiner, Norman, & Munroe Blum, 1989).

Sensitivity: the rate of detecting true positive cases (Streiner & Norman, 1989; Streiner, Norman, & Munroe Blum, 1989).

Specificity: the rate of detecting true negative cases (Streiner & Norman, 1989; Streiner, Norman, & Munroe Blum, 1989).

Validity: the degree to which the assessment tool measures psychosocial health care needs (Streiner & Norman, 1989; Streiner, Norman, & Munroe Blum, 1989).

12.0 References

- Accreditation Canada. Qmentum Program 2009 Standards: Cancer Care and Oncology Services (Ver 2). Ottawa, On, Canada (2008) <http://www.accreditation-canada.ca>.
- ADAPTE Collaboration. (2007). ADAPTE Framework. Retrieved July 22, 2008, from <http://www.adapte.org/rubrique/adapte-framework.php>
- AGREE Collaboration. (2001). Appraisal of guidelines for research and evaluation (AGREE) instrument. Retrieved July 22, 2008, from http://www.agreetrust.org/docs/AGREE_Instrument_English.pdf
- Ahern, J., & Philpot, P. (2002). Assessing acutely ill patients on general wards. *Nursing Standard*, 16(47), 47-54.
- Armstrong, T. S. (2003). Symptoms experience: A concept analysis. *Oncology Nursing Forum*, 30(4), 601-606.
- Ashbury, F. D., Findlay, H., Reynolds, B., & McKerracher, K. (1998). A Canadian survey of cancer patients' experiences: Are their needs being met? *Journal of Pain and Symptom Management*, 16(5), 298-306.
- Australian National Breast Cancer Centre and National Cancer Control Initiative. (2003). *Clinical practice guidelines for the psychosocial care of adults with cancer*. Camperdown, NSW: National Breast Cancer Centre.
- Boberg, E. W., Gustafson, D. H., Hawkins, R. P., Offord, K. P., Koch, C., Wen, K., et al. (2003). Assessing the unmet information, support and care delivery needs of men with prostate cancer. *Patient Education and Counselling*, 49, 233-242.
- Bonevski, B., Sanson-Fisher, R. W., Girgis, A., Burton, L., Cook, P., Boyes, A., et al. (the Supportive Care Review Group). (2000). Evaluation of an instrument to assess the needs of patients with cancer. *Cancer*, 88(1), 217-225.
- Boyes, A., Newell, S., Girgis, A., McElduff, P., & Sanson-Fisher, R. (2006). Does routine assessment and real-time feedback improve cancer patients' psychosocial well-being? *European Journal of Cancer Care*, 15(2), 163-171.

- Bramsen, I., van der Linden, M. H., Eskens, F. J., Bijvank, E. M., van Groeningen, C. J., Kaufman, H. J., et al. (2008). Evaluation of a face-to-face psychosocial screening intervention for cancer patients: Acceptance and effects on quality of life. *Patient Education and Counselling*, 70(1), 61-68.
- Bruera, E., Kuehn, N., Miller, M. J., Selmsler, P., & Macmillan, K. (1991). The Edmonton Symptom Assessment System (ESAS): A simple method for the assessment of palliative care patients. *Journal of Palliative Care*, 7, 6-9.
- Canadian Association of Psychosocial Oncology. (n.d.). What is psychosocial oncology? Retrieved October 10, 2008, from http://www.capo.ca/eng/about_psychosocial_oncology.asp.
- Canadian Partnership Against Cancer (the Partnership). (2009). Guide to implementing Screening for Distress the 6th Vital Sign moving toward person-centred care. Toronto: Author
- Carey, M., Buchan, H., & Sanson-Fisher, R. (2009). The cycle of change: Implementing best-evidence clinical practice. *International Journal of Quality in Health Care*, 21(1), 37-43.
- Derogatis, L. R., & Melisaratos, N. (1983). The brief symptom inventory: An introductory report. *Psychological Medicine*, 13(3), 595-605.
- Detmar, S. B., Muller, M. J., Schornagel, J. H., Wever, L. D., & Aaronson, N.K. (2002). Health-related quality-of-life assessments and patient-physician communication: A randomized controlled trial. *Journal of the American Medical Association*, 288(23), 3027-3034.
- Fitch, M. I. (2008). Supportive care framework: Theoretical underpinnings. In M.I. Fitch, H. B. Porter, & B.D. Page (eds.), *Supportive Care Framework: A Foundation for Person-Centered Care*. Pembroke, ON: Pappin Communications.
- Fitch, M. I. (2000). Supportive care for cancer patients. *Hospital Quarterly*, 3(4), 39-46.
- Fitch, M. (1994). *Provincial Cancer Network Supportive Care Work Group: Report and recommendations*. Submission to Cancer Care Ontario: Toronto.
- Foot, G., & Sanson-Fisher, R. (1995). Measuring the unmet needs of people living with cancer. *Cancer Forum*, 19, 131-135.
- Fortner, B., Okon, T., Schwartzberg, L., Tauer, K., & Houts, A. C. (2003). The Cancer Care Monitor: Psychometric content evaluation and pilot testing of a computer administered system for symptom screening and quality of life in adult cancer patients. *Journal of Pain and Symptom Management*, 26(6), 1077-1092.

- Francke, A. L., Smit, M. C., de Veer, A. J. E., & Mistiaen, P. (2008). Factors influencing the implementation of clinical guidelines for health care professionals: A systematic meta-review. *BMC Medical Informatics and Decision Making*, 8(38).
- Ganz, P. A., Rosfessart, J., Polinsky, M. L., Schag, C. C., & Heinrich, R. L. (1986). A comprehensive approach to the assessment of cancer patients' rehabilitation needs: The cancer inventory of problem situations and a companion interview. *Journal of Psychosocial Oncology*, 2, 27-42.
- Ganz, P. A., Schag, C. A. C., Lee, J. J., & Sim, M. S. (1992). The CARES: A generic measure of health-related quality of life for patients with cancer. *Quality of Life Research*, 1, 19-29.
- Ganz, P. A., Schag, C. C., Polinsky, M. L., Heinrich, R. L., & Flack, V. F. (1987). Rehabilitation needs and breast cancer: The first month after primary therapy. *Breast Cancer Research and Treatment*, 10, 243-253.
- Gerteis, M., Edgman-Levitan, S., Daley, J., & Delbanco, T. L. (ed). (1993). *Through the patient's eyes: Understanding and promoting patient-centered care*. San Francisco, CA: Jossey-Bass.
- Gustafson, D. H., Taylor, J. O., Thompson, S., & Chesney, P. (1993). Assessing the needs of breast cancer patients and their families. *Quality Management in Health Care*, 2, 6-17.
- Hack, T. F., Degner, L. F., & Parker, P. A. (2005). The communication goals and needs of cancer patients: A review. *Psycho-Oncology*, 14, 831-45.
- Hodgkinson, K., Butow, P., Hobbs, K. M., Hunt, G. E., Lo, S. K., & Wain, G. (2007). Assessing unmet supportive care needs in partners of cancer survivors: The development and evaluation of the Cancer Survivors' Partners Unmet Needs measure (CaSPUN). *Psycho-Oncology*, 16(9), 805-813.
- Hodgkinson, K., Butow, P., Hunt, G. E., Pendlebury, S., Hobbs, K. M., Lo, S. K., et al. (2007). The development and evaluation of a measure to assess cancer survivors' unmet supportive care needs: The CaSUN (Cancer Survivors' Unmet Needs measure). *Psycho-Oncology*, 16(9), 796-804.
- Hoffman, B. M., Zevon, M. A., D'Arrigo, M. C., & Cecchini, T. B. (2004). Screening for distress in cancer patients: The NCCN rapid screening measure. *Psycho-Oncology*, 13(11), 792-799.
- Holmes, H.N. (ed). (2003). *3 minute assessment*. Philadelphia: Lippincott Williams and Wilkins.

- Howell, D. (2007). Literature review and environmental scan psychosocial, supportive and palliative care standards and guidelines, an initiative of the Guidelines, Standards and Indicators Committee of Rebalance Focus Action Group Canadian Strategy for Cancer Control (CSCC), technical document
- Howell, D. (2009) Literature review and environmental scan psychosocial, supportive and palliative care standards and guidelines. The Cancer Journey Action Group Canadian Partnership against Cancer. Addendum 2009), technical document
- Hutchison, S. D., Steginga, A. K., & Dunn, J. (2006). The tiered model of psychosocial intervention in cancer: A community based approach. *Psycho-Oncology*, 15, 541-546.
- Institute of Medicine (IOM). (2008). *Cancer care for the whole patient: Meeting psychosocial health needs*. Nancy E. Adler and Ann E. K. Page, eds. Washington, DC: The National Academies Press.
- Interprofessional Care Steering Committee, Interprofessional Care Project. (2007). *Interprofessional care: A blueprint for action in Ontario*. Toronto: HealthForce Ontario, Government of Ontario.
- Kirkova, J., Davis, M. P., Walsh, D., Tiernan, E., O'Leary, N., LeGrand, S. B., et al. (2006). Cancer symptom assessment instruments: A systematic review. *Journal of Clinical Oncology*, 24(9), 1459-1473.
- Kristeller, J. L., Rhodes, M., Cripe, L. D., & Sheets, V. (2005). Oncologist Assisted Spiritual Intervention Study (OASIS): Patient acceptability and initial evidence of effects. *The International Journal of Psychiatry in Medicine*, 35(4), 329-347.
- Lidstone, V., Butters, E., Seed, P. T., Sinnot, C., Beynon, T., & Richards M. (2003). Symptoms and concerns amongst cancer outpatients: Identifying the need for specialist palliative care. *Palliative Medicine*, 17, 588-585.
- Linden, W., Yi, D., Barroetavena, M., MacKenzie, R., & Doll, R. (2005). Development and validation of a psychosocial screening instrument for cancer. *Health and Quality of Life Outcomes*, 3(1), 54.
- McLachlan, S. A., Allenby, A., Matthews, J., Wirth, A., Kissane, D., Bishop, M., et al. (2001). Randomized trial of coordinated psychosocial interventions based on patient self-assessments versus standard care to improve the psychosocial functioning of patients with cancer. *Journal of Clinical Oncology*, 19(21), 4117-4125.
- Meyerowitz, B. E., Heinrich, R. L., & Schag, C. C. (1983). A competency-based approach to coping with cancer. In T. G. Burish and L. Bradley (eds.), *Coping with chronic illness: Research and applications*. New York: Academic Press.

- Mitchell AJ (2008). Are one or two simple questions sufficient to detect depression in cancer and palliative care? A Bayesian meta-analysis. *British Journal of Cancer*, 98(12), 1934-43.
- Mitchell, A. J. (2007). Pooled results from 38 analyses of the accuracy of distress thermometer and other ultra-short methods of detecting cancer-related mood disorders. *Journal of Clinical Oncology*, 25, 4670-4681.
- National Comprehensive Cancer Network (NCCN). (2008). *Distress management*. Retrieved July 22, 2008, from http://www.nccn.org/professionals/physician_gls/f_guidelines.asp.
- National Institute for Health and Clinical Excellence (NICE). (2007). *How to change practice: Understand, identify and overcome barriers to change*. London: Author.
- National Institute for Clinical Evidence (NICE). (2004). *Improving supportive and palliative care for adults with cancer: Executive summary*. London: Author.
- Ontario Cancer Treatment and Research Foundation (The), Supportive Care Program Committee (1994). *Providing supportive care for individuals living with cancer*. Toronto: Author.
- Perselli, C., Camporesi, E., Colombo, A. M., Cucci, M., Mazzoni, G., & Paci, E. (1993). Quality of life assessment in a home care program for advanced cancer patients: A study using the Symptom Distress Scale. *Journal of Pain and Symptom Management*, 8, 306-311.
- Radloff, L. S. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement*, 1(3), 385-401.
- Registered Nurses' Association of Ontario (RNAO). (2002a). *Supporting and strengthening families through expected and unexpected life events*. Toronto: Author.
- Registered Nurses' Association of Ontario (RNAO). (2002b). *Toolkit: Implementation of clinical practice guidelines*. Toronto: Author.
- Richardson, A., Medina, J., Brown, V., & Sitzia, J. (2007). Patients' needs assessment in cancer care: A review of assessment tools. *Supportive Care in Cancer*, 15(10), 1125-1144.
- Richardson, A., Sitzia, J., Brown, V., Medina, J., & Richardson, A. (2005). *Patients' needs assessment tools in cancer care: Principles and practice*. London: King's College London.
- Richardson, L. A., & Jones, G. W. (2009). A review of the reliability and validity of the Edmonton Symptom Assessment System. *Current Oncology*, 16(1), 53-64.

- Rodin, G., Mackay, J. A., Zimmerman, C., Mayer, C., Howell, D., Katz, M., et al. (2008). Evidence-based series #19-2: Section 1, provider-patient communication: A report of evidence-based recommendations to guide practice in cancer. Retrieved August 30, 2008, from <http://www.cancercare.on.ca/pdf/pebc19-2s.pdf>.
- Rosenbloom, S. K., Victorson, D. E., Hahn, E. A., Peterman, A. H., & Cella, D. (2007). Assessment is not enough: A randomized controlled trial of the effects of HRQL assessment on quality of life and satisfaction in oncology clinical practice. *Psycho-Oncology*, 16(12), 1069-1079.
- Roth, A. J., Kornblith, A. B., Batel-Copel, L., Peabody, E., Scher, H. I., & Holland, J. C. (1998). Rapid screening for psychological distress in men with prostate carcinoma: A pilot study. *Cancer*, 82, 1904-1908.
- Sanson-Fisher, R. W., Girgis, A., Boyes, A., Bonevski, B., Burton, L., Cook, P., et al. (the Supportive Care Review Group). (2000). The unmet supportive care needs of patients with cancer. *Cancer*, 88(1), 226-237
- Sarna, L. (1998). Effectiveness of structured nursing assessment of symptom distress in advanced lung cancer. *Oncology Nursing Forum*, 25(6), 1041-1048.
- Schag, C. C., Ganz, P. A., & Heinrich, R. L. (1991). Cancer Rehabilitation Evaluation System-Short Form (CARES-SF): A cancer specific rehabilitation and quality of life instrument. *Cancer*, 15, 1406-1413.
- Schag, C. C., Heinrich, R. L., & Ganz, P. A. (1983). Cancer inventory of problem situations: An instrument for assessing cancer patients' rehabilitation needs. *Journal of Psychosocial Oncology*, 1, 11-24.
- Shelby, R. A., Lamdan, R. M., Siegel, J. E., Hrywna, M., & Taylor, K. L. (2006). Standardized versus open-ended assessment of psychosocial and medical concerns among African American breast cancer patients. *Psycho-Oncology*, 15(5), 382-397.
- Stephen, J., & Boyle, M. (2005). CPGs for psychosocial oncology: Towards standardized Canadian evidence-based practices. *Oncology Exchange*, 4(5), 19-21.
- Streiner, D. L., & Norman, G. R. (1989). *Health measurement scales: A practical guide to their development and use*. Oxford: Oxford University Press.
- Streiner, D. L., Norman, G. R., & Munroe Blum, H. (1989). *PDQ epidemiology*. Toronto: B. C. Decker.

- Taenzer, P., Bultz, B. D., Carlson, L. E., Specia, M., DeGagne, T., Olson, K., et al. (2000). Impact of computerized quality of life screening on physician behaviour and patient satisfaction in lung cancer outpatients. *Psycho-Oncology*, 9(3), 203-213.
- Tuinman, M. A., Gazendam-Donofrio, S. M., & Hoekstra-Weebers, J. E. (2008). Screening and referral for psychological distress in oncologic practice. *Cancer*, 113(4), 870-878.
- Vachon, M. (2006). Psychosocial distress and coping after cancer treatment. *Cancer Nursing*, 29(2 Suppl), 26-31.
- Vachon, M. L. (1998). Psychosocial needs of patients and families. *Journal of Palliative Care*, 14(3), 49-53.
- Veach, T. A., Nicholas, D. R., & Barton, M. A. (2002). *Cancer and the family life cycle: A practitioner's guide*. New York: Brunner-Routledge.
- Velikova, G., Booth, L., Smith, A. B., Brown, P. M., Lynch, P., Brown, J. M., et al. (2004). Measuring quality of life in routine oncology practice improves communication and patient well-being: A randomized controlled trial. *Journal of Clinical Oncology*, 22(4), 714-724.
- Vodermaier, A., Linden, W., & Siu, C. Screening for emotional distress in cancer patients: A systematic review of assessment instruments. Journal of the National Cancer Institute. Accessible at <http://jnci.oxfordjournals.org/cgi/content/short/djp336v1?rss=1> as of Oct. 14, 2009.
- Wen, K-Y., & Gustafson, D. H. (2004). Needs assessment for cancer patients and their families. *Health and Quality of Life Outcomes*, 2, 11.
- White, L. (2003). *Documentation in the nursing process*. Thomson Delmar Learning Canada.
- Wright, E. P., Kiely, M., Johnston, C., Smith, A. B., Cull, A., & Selby, P. J. (2005). Development and evaluation of an instrument to assess social difficulties in routine oncology practice. *Quality of Life Research*, 14(2), 373-386.
- Wright, P., Smith, A., Roberts, K., Selby, P., & Velikova, G. (2007). Screening for social difficulties in cancer patients: Clinical utility of the Social Difficulties Inventory. *British Journal of Cancer*, 97(8), 1063-1070.
- Zigmond, A. S., & Snaith, R. P. (1983). The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica*, 67, 361-370.

Appendix A: ADAPTE Methodology

The initial stages of this project were informed by the guideline adaptation methodology developed by the ADAPTE Collaboration. The ADAPTE process is a systematic approach to considering the use and/or modification of existing guidelines developed in one context for application in a different context, so as to enhance the efficient production and use of high-quality adapted guidelines (ADAPTE Collaboration, 2007). The ADAPTE process is currently under evaluation for usability, acceptability, relevance and benefits to different user groups. Its use in this project was in the context of this evaluation. More detailed information on the ADAPTE process is available on www.adapte.org.

Appendix B: Guideline Search and AGREE Review

Search Strategy

Guidelines were identified primarily from the Literature Review and Environmental Scan conducted for the Re-Balance Focus Action Group. In March 2007, the Standards, Guidelines and Indicators Sub-group of the Re-Balance Focus Action Group established under the Canadian Cancer Control Strategy conducted a comprehensive literature review and environmental scan to identify Guidelines and Standards specific to psychosocial, supportive and palliative care in cancer (D. Howell, personal communication, July 22, 2008). To ensure the currency of this list, an Information Specialist (PO) and Research Assistant (MJ) Research Consultant and Research Assistant used the same search strategy to conduct an update search in order to identify guidelines and standards published between 2007 and 2008. The following processes were used to search for guidelines and standards:

1. Review of scientific literature sources using empirical databases - HealthStar, Medline, CINHAL, Embase and PsycINFO databases were systematically searched by a Research Consultant using the following search terms:

HealthStar Search terms: psychology and social support, palliative care, combined with terms of neoplasms, guideline or practice guideline.

Medline Search Terms: psychology and social support, palliative care combined with terms of neoplasms, guideline or practice guideline.

CINHAL Search Terms: psychosocial, psychosocial aspects of illness, hospice and palliative nursing, combined with terms of neoplasms or cancer and practice guidelines or standards.

EMBASE Search Terms: psychosocial care, palliative nursing or palliative therapy or cancer palliative therapy, cancer patient or cancer combined with terms of practice guideline

PsycINFO Search Terms: psychosocial factors or psychosocial readjustment or psychosocial rehabilitation, palliative care, combined with terms of neoplasms, treatment guidelines or professional standards.

2. Review of grey literature sources such as annual reports or publications of organizations as identified on the world-wide web - The internet search engine utilized was Google Scholar. Search terms included: cancer support, cancer symptoms, psychosocial oncology, cancer aftercare, cancer survivorship, cancer paired with terms of guidelines and separately with standards term.

3. Review of local, provincial, national and international databases -

- a) All oncology professional associations and organizations for Psychosocial Oncology and Palliative Care inclusive of Oncology Social Workers, Clinical Oncology.
- b) All Canadian Provincial Cancer Care Organizations within provinces' websites were searched (except Quebec: no provincial source found) including the "site map" to reveal any guideline or standard embedded under another topic inclusive of provincial cancer organizations, regional and local cancer organizations within provinces and specific guideline development organizations in cancer care at the provincial level such as the Program in Evidence-Based Medicine, which is under the auspices of Cancer Care Ontario.
- c) International organizations, agencies, or associations whose mandate is focused on systematic reviews or guideline development.

The organizations and agency's sites that were searched are included in Table 1 on page 51.

Inclusion/exclusion criteria

Inclusion:

1. Guidelines focused on clinical practice relevant to **adult psychosocial and spiritual health care needs assessment** (inclusive of physical symptoms, distress/emotional response, social, spiritual factors) for cancer patients and their families. **Guidelines may or may not be related to specific cancer populations.**
 - a. Clinical practice guidelines: those specific to situations in which clinicians are making decisions about direct patient care.
 - b. Best practice guidelines: those that identify the best choice from a range of appropriate health care options, as defined by a consensus of experts.
2. Published between 2003-2008

Exclusion*:

1. Guidelines that did not include reference to the evidence to inform recommendations.
2. Guidelines focused strictly on assessment and management of individual physical symptoms (e.g., pain, oral mucositis, nausea/vomiting, dyspnea, etc.).
3. Guidelines focused solely on interpersonal processes (e.g., therapeutic relationships, communication, etc.).

*Excluded guidelines may have still been considered by the panel during the guideline development process, but were not considered for guideline adaptation.

Included guidelines

Preference was given to guidelines and guides to practice that based the development of substantive statements/recommendations on a review of evidence from the literature and/or were based on a source that used evidence to support the guideline development process.

1. Fraser Health Hospice Palliative Care Program. (2006). *Depression in the terminally ill*. Retrieved July 22, 2008, from <http://www.fraserhealth.ca/Services/HomeandCommunityCare/HospicePalliativeCare/Pages/SymptomGuidelines.aspx>
2. National Breast Cancer Centre and National Cancer Control Initiative. (2003). *Clinical practice guidelines for the psychosocial care of adults with cancer*. Camperdown, NSW: National Breast Cancer Centre.
3. National Comprehensive Cancer Network (NCCN). (2008). *Distress management*. Retrieved July 22, 2008, from http://www.nccn.org/professionals/physician_gls/f_guidelines.asp.
4. National Consensus Project for Quality Palliative Care. (2004). *Clinical practice guidelines for quality palliative care*. Pittsburgh: Author.
5. Qaseem, A., Snow, V., Shekelle, P., Casey, D. E., Cross, J. T., and Owens, D. K. For the Clinical Efficacy Assessment Subcommittee of the American College of Physicians. (2008). Evidence-based interventions to improve the palliative care of pain, dyspnea, and depression at the end of life: A clinical practice guideline from the American College of Physicians. *Annals of Internal Medicine*, 148, 141-146.
6. Registered Nurses' Association of Ontario (RNAO). (2002). *Crisis intervention*. Toronto: Author.
7. Rodin, G., Katz, M., Lloyd, N., Green, E., Mackay, J. A., Wong, R., and members of the Supportive Care Guidelines Group. (2006). *Evidence-based series #13-6: Section 1: The management of depression in cancer patients: A clinical practice guideline*. Online: <http://www.cancercare.on.ca/>
8. Scottish Intercollegiate Guidelines Network (SIGN). (2005). *Management of breast cancer in women: A national clinical guideline*. Edinburgh: Author.

9. Scottish Intercollegiate Guidelines Network (SIGN). (2008). *Management of cervical cancer: A national clinical guideline*. Edinburgh: Author.

Guideline assessments

Each guideline was independently reviewed and scored by 4 panel members, using the Appraisal of Guidelines for Research and Evaluation (AGREE) instrument (AGREE Collaboration, 2001). The AGREE instrument provides a framework for the evaluation of guideline quality on the basis of 6 domains: scope and purpose; stakeholder involvement; rigour of development; clarity and presentation; applicability; and editorial independence. Domain scores and overall assessments from each reviewer were compiled for each guideline, and results were presented for discussion at an in-person panel meeting. Panel members were provided copies of all guidelines to facilitate discussion of the results and asked to reach consensus on the suitability of each guideline for guideline adaptation via the ADAPTE process. Each guideline was discussed as to why it was or was not recommended. Particular attention was paid to rigour scores and guideline scope.

Decision process followed by panel

Decisions were established through panel discussions, whereby any differences of opinion were resolved with consensus. If consensus was unable to be reached, a vote was cast.

Results

Frasier Health Hospice Palliative Care Program (2006) - Focus on terminally ill patients and depression was judged to be too narrow for the scope of the present guideline. Limited details were reported to support rigour of development.

National Breast Cancer Centre and National Cancer Control Initiative (2003) - Scored highly on AGREE domains and was recommended for use in clinical practice. This guideline received the highest domain score on rigour. It was found to be largely consistent with scope of the present guideline and very comprehensive.

National Comprehensive Cancer Network (NCCN) (2008) - Focus on assessment specific to distress was discussed as too narrow for the scope of the present guideline. However, the guideline was discussed as valuable to the present guideline because it is reflective of interprofessional practice and is easily implemented in practice due to its algorithm format. Links from evidence to recommendations were unclear and limited details were reported to support rigour of development.

National Consensus Project for Quality Palliative Care (2004) - Focus on a broad palliative care context was not limited to adult cancer patients and thus, was not

congruent with the scope of the present guideline. Recommendations were vague and limited details were reported to support rigour of development.

Qaseem, A., Snow, V., Shekelle, P., Casey, D. E., Cross, J. T., and Owens, D. K. For the Clinical Efficacy Assessment Subcommittee of the American College of Physicians (2008). - Focus on pain, dyspnea and depression at the end of life was discussed as too narrow for the scope of the present guideline. Limited details were reported to support rigour of development. The section on supporting caregivers was discussed as potentially informative for the present guideline.

Registered Nurses' Association of Ontario (RNAO) (2002) - Focus on nursing practice related to crisis intervention was discussed as too narrow for the scope of the present guideline. Links from evidence to recommendations were unclear and limited details were reported to support rigour of development.

Rodin, G., Katz, M., Lloyd, N., Green, E., Mackay, J. A., Wong, R., and members of the Supportive Care Guidelines Group (2006) - Focus on the treatment of major depression was outside the scope of the present guideline. Limited details were reported to support rigour of development.

Scottish Intercollegiate Guidelines Network (SIGN) (2005) - Focus on patients with breast cancer, with limited consideration of psychosocial care, was discussed as too narrow for the scope of the present guideline. Rigour of development was evident with satisfactory reporting of details.

Scottish Intercollegiate Guidelines Network (SIGN) (2008) - Focus on treatment of cervical cancer was discussed as too narrow for the scope of the present guideline. However, the guideline included a more expanded and integrated consideration of psychosocial care as compared to the 2005 SIGN guideline (above). Specific strengths were identified, such as the description of resource implications of the recommendations, which the panel identified as important to consider in the present guideline. Rigour of development was evident with satisfactory reporting of details.

Overall impressions

Based on the overall assessment of the guidelines, it was a unanimous group decision to use the **Australian National Breast Cancer Centre and National Cancer Control Initiative 2003 guideline** as a foundational document to guide the development of the present guideline. However, despite the number of guidelines reviewed, there was a lack of evidence-based guidelines that were specifically within the scope of psychosocial assessment. Although the National Breast Cancer Centre and National Cancer Control Initiative guideline and NCCN guidelines address specific aspects of the assessment process, it was found that the recommendations provided in these guidelines offered limited generalizability within the context of a routine psychosocial assessment in a broad cancer population. As a result, it was acknowledged that a separate literature search for systematic reviews and empirical studies would be

necessary to facilitate the development of recommendations that address the health questions of interest in the present guideline.

Table 1: Websites Searched for Guidelines and Standards

| Canadian Cancer Academic Centers |
|--|
| <p>Alberta Cancer Board: www.cancerboard.ab.ca British Columbia Cancer Agency: www.bc.cancer.ca Cancer Care Manitoba: www.cancercare.mb.ca Cancer Care Nova Scotia: www.cancercare.ns.ca Cancer Care Ontario: www.cancercare.on.ca Newfoundland Cancer Treatment and Research Foundation: www.nctrf.nf.ca Toronto Sunnybrook Regional Cancer Center: www.tsccc.on.ca Saskatchewan Cancer Agency: www.scf.sk.ca PEI Cancer Care: www.pei.cancer.ca Fraser Health Hospice Palliative care Program: www.fraserhealth.ca <u>University Sites affiliated with Comprehensive Cancer Centres:</u> Kingston General Hospital Regional Cancer Centre: www.krcc.on.ca Jurvanski Cancer Centre-Hamilton, Ontario: www.hhs.ca Alberta University Web Library: www.ualweb.library.ualberta.ca Queens University: www.ctg.queensu.ca McGill University: www.mcgill.ca University Health Network: www.uhn.on.ca <i>Note: Search cancer and Quebec- no findings</i> <i>Searched specific hospital websites in Quebec (Montreal General, Sinai and no cancer specific sources found)</i></p> |
| International Cancer Academic Centers |
| <p>www.library.nhs.uk/palliative University of Michigan: www.153.cancer.med.umichigan.edu/map.htm M.D. Anderson: www.mdanderson.org St. Jude's Children's: www.stjude.org Roswell Park: www.roswellpark.org; www.rpci.med.buffalo.edu Royal Marsden: www.royalmarsden.nhs.uk Cancer Care Alliance (UK): www.cancercarealliance.nhs.uk Commission on Cancer: www.facs.org</p> |
| Professional Associations and Agencies |
| <p>Association of Pediatric Oncology Nurses: www.apon.org American Society of Clinical Oncology : www.asco.org Association of Oncology Social Work: www.aosw.org Nova Scotia Association of Social Workers: www.nsasw.org National Association of Social Workers: www.socialworkers.org POGO: www.pogo.on.ca Canadian Nurses Association: www.can.org Alberta College of Social Workers: www.acsw.ab.ca Canadian Association of Psychosocial Oncology: www.capo.ca Children's Oncology Group: www.childrensoncologygroup.org Canadian Association for Psychosocial Oncology: www.capo.org Oncology Social Work Australia: www.oncologysocialworkaustralia.com Oncology Nursing Society: www.ons.org American Society of Clinical Oncology: www.asco.org American Society for Therapeutic Radiology and Oncology: www.astro.org RNO: www.rno.org European Psychosocial Oncology: www.pycho-oncology.net Canadian Association of Provincial Cancer Agencies: www.capa.ca National Association of Social Workers: www.na.swdc.org Centre to Advance Palliative Care: www.capc.org International Society of Cancer Nurses: www.sncc.org Royal College of Anesthetists: www.rcoa.ac.uk Canadian Anesthetists' Society: www.cas.ca Dieticians of Canada Oncology Network: www.dieticians.ca International Psycho-oncology Society: www.psycho-oncology.net Canadian Hospice Palliative Care Association: www.chpca.ca Canadian Association of Radiation Oncologists: www.caro.ca European Oncology Nursing Society: www.cancerworld.org American Academy of Hospice and Palliative Care Medicine: www.aahpm.org</p> |

| |
|--|
| <p>Associations of Community Cancer Centres: www.accc-cancer.org International Society of Pediatric Oncology: www.siop.nl Center to Advance Palliative Care: www.ca.pc.org Hospice Foundation of America: www.hospicefoundation.org</p> |
| Academic and Government Associated Websites |
| <p>NCCN: www.nccn.org NCI: www.nci.nih.gov/cancertopics www.qualityhealth.org.nz National Breast Cancer Centre (Australia): www.nbcc.org.au SIGN: www.sign.ac.uk National Institute for Health and Clinical Excellence: www.nice.org.uk (guidance.nice.org.uk) National Health and Medical Research Council: www.nhmrs.gov.au Public Health Agency of Canada: www.phac-aspc.gc.ca New Zealand-MOH: www.nzgg.org</p> |
| Cancer Resource Websites |
| <p>The International Confederation of Childhood Cancer Parent Organizations: www.icccpo.org National Family Caregivers Association: www.nfcares.org www.cancerpath.ca www.cancercure.no The Healing Journey program-PMH: www.healingjourney.ca International Confederation of Childhood Cancer Parent Organizations: www.icccpo.org Cancer Care Society: www.cancer.ca American Cancer Society: www.acs.org People Living With Cancer (ASCO): www.plwc.org Grief Recovery- Action Program for moving beyond loss www.grief.net www.hopecope.com Canadian Virtual Hospice: www.hospice.ca The Cancer Council of Australia: www.cancer.org.au Cancer Advocacy Coalition Canada: www.canceradvocacycoalition.com Cancer Strategy for Cancer Control: www.cancercontrol.org The Cancer Council-New South Wales: www.cancercouncil.com.au Bereavement Ontario Network: www.bereavementontarionetwork.ca Child Life Council: www.childlife.org Crisis, Grief and Healing: www.webhealing.com Lance Armstrong Foundation: www.laf.org The National Coalition for cancer survivorship: www.canceradvocacy.org Vanderbilt Children's: www.vanderbeltchildrens.org</p> |
| Guideline Specific Websites |
| <p>www.guideline.gov www.cancerindex.org Directory of Clinical Practice Guidelines National Guideline Clearing House National Quality Measures Clearinghouse National Library for Health Care (NICE) The Medical Outcomes and Guidelines Sourcebook Quality of Care for Oncologic Conditions and HIV Sourcebook National Comprehensive Cancer Network Scottish Intercollegiate Guideline Network (SIGN) Cochrane Collaboration</p> |

Appendix C: Summary of External Review

Methods

Feedback was obtained through a survey of 25 individuals - 21 from across Canada and four from other countries. The survey consisted of ten items evaluating the methods used to assemble the evidence and agreement with the draft recommendations. Written comments were invited. The survey was sent by courier on February 20th, 2009. Follow-up reminders were made on March 6th by e-mail and on March 13th by telephone.

Nine members of the National Advisory Steering Committee of the Cancer Journey Action Group, Standards, Practice Guidelines, and Indicators Subgroup were also asked to review the guideline report, which was sent to them by e-mail.

Results

Responses were received from 20 of the original survey sample (80% response rate). Questionnaires were completed by four psychologists, five social workers, two nurses, a psychiatrist, an administrator, a vocational rehabilitation counsellor, a family physician, a researcher and two chaplains; one respondent described their role as an oncologist and administrator; one respondent described their role as “pediatric”. Three respondents indicated that they currently follow a practice guideline on assessment of psychosocial health care needs; one uses the NCCN guideline on distress management, one uses the Australian guideline and one uses both.

Responses from the original survey sample (N=20) to specific questionnaire items about the Canadian guideline on assessment of psychosocial health care needs are summarized in the table below.

TABLE 1: RESPONSES TO FEEDBACK SURVEY

| Item | Number (% of 20) | | |
|--|-------------------------|----------------------------|-------------------------------|
| | Strongly agree or agree | Neither agree nor disagree | Strongly disagree or disagree |
| The rationale for developing recommendations, as stated in the “Introduction” and “Scope and Purpose” sections of this draft report, is clear. | 18 (90.0%) | 0 | 2 |
| There is a need for a Canadian practice guideline on the assessment of psychosocial health care needs of the adult cancer patient. | 19 (95.0%) | 1 | 0 |
| The literature search described in the draft report is complete. | 11 (55.0%) | 8 | 0 |
| The literature search described in the draft report is relevant. | 16 (80.0%) | 2 | 0 |

| | | | |
|---|-----------------------|--------|-------------------------------|
| I agree with the methods used to summarize the evidence included in the draft report. | 18 (90.0%) | 1 | 0 |
| The results of the studies described in the draft report are interpreted according to my understanding of the data. | 14 (70.0%) | 4 | 0 |
| The draft recommendations are clear. | 16 (80.0%) | 2 | 0 |
| I agree with the draft recommendations as stated. | 18 (90.0%) | 0 | 1 |
| I would feel comfortable having these recommendations applied in my hospital. | 19 (95.0%) | 0 | 0 |
| How likely would you be to make use of the recommendations in your own practice? | Very likely or likely | Unsure | Not at all likely or unlikely |
| | 16 (80.0%) | 1 | 0 |

N.B. Not all respondents completed all questionnaire items.

Reviewers' Comments

Thirteen respondents (65%) from the original survey sample and seven members of the advisory committee provided written comments. Respondents from the advisory committee included two guideline-development experts, an administrator, a psychologist, a nurse, a pharmacist and a dietician.

Feedback suggesting substantive changes to the draft guideline report was synthesized and distributed to the guideline development panel members. The feedback was discussed and an action plan was developed for addressing the concerns and suggestions arising from the review, as appropriate. Revisions based on this discussion were integrated into the final iteration of the guideline.

Acknowledgements

All reviewers are acknowledged for their participation and valuable contribution to the development of this guideline.

Appendix D: Psychosocial Health Care Needs Assessment for Adults with Cancer - Randomized/Quasi-Randomized Trials and Prospective Comparative Cohort Studies

TABLE 1: STUDY DESIGN, POPULATION, ALLOCATION GROUPS

| Study | Main Question | Allocation | Population | Assessment Intervention | Control |
|----------------------------------|---|--|---|---|---|
| Velikova et al., 2004 UK | Does provision to oncologists of survey findings have an impact? | Patients at random | 286 adult patients attending an oncology clinic and starting treatment | Self-administered computerized questionnaires with feedback to physician at every clinic visit | 1.same questionnaires without feedback to physician (attention control) 2.no questionnaire (control) |
| McLachlan et al., 2001 Australia | Does provision of survey findings to oncologists and nurses have an impact? | Patients at random | 450 adult patients attending oncology clinics, with low levels of needs | Self-administered computerized questionnaires with feedback to physician; after discussion with physician and patient, nurse-coordinator formulated an individualized management plan including identification of services | Questionnaire data not made available to oncologist (one-third of all patients) |
| Taenzer et al., 2000 Canada | Does provision of survey findings to clinic staff have an impact? | Sequential cohorts of patients | 53 adult patients with lung cancer attending a clinic | Self-administered computerized questionnaires with feedback to nurse and physician | Usual care |
| Detmar et al., 2002 Netherlands | Does provision to trained oncologists of a QOL survey have an impact? | Physicians allocated at random (crossover) | 214 adult patients receiving palliative chemotherapy as outpatients | Summary of responses to quality-of-life questionnaire given to physician and patient at 2 nd , 3 rd and 4 th visit | Physician not receiving a report (i.e., usual care) |
| Rosenbloom et al., 2007 USA | Does provision to a treating nurse of survey results and verbal interpretation have an impact? | Patients at random | 213 adult patients receiving chemotherapy for advanced breast, lung or colorectal cancer | Structured interview by research nurse exploring areas of physical, psychological, social, functional and spiritual concern identified on quality-of-life assessment at baseline, 1-month and 2-month visits - results shared with treating nurse | 1. quality of life assessment not shared with treating nurse 2. no quality of life assessment |
| Boyes et al., 2006 Australia | Does provision to oncologists of scored answers along with suggested actions have an impact? | Alternate patients | 80 adult patients attending an oncology clinic for 1st consultation | 15-20 minute computerized questionnaire at four clinic visits - results fed back to oncologist with suggested strategies | Same questionnaire but results not made available to oncologist |
| Bramsen et al., 2008 Netherlands | Does one-on-one interview with a patient increase the chance of referral and have an impact? | Patients to sequential cohorts | 129 newly admitted adult inpatients with cancer, not all newly diagnosed patients | Semi-structured interview with a psychologist or social worker (+ follow-up contact if requested by patient) | Usual care |
| Sarna, 1998 USA | Does a structured nursing assessment (including a survey) have an impact? | Patients at random | 48 adult patients with a diagnosis of stage III/IV lung cancer within last 2-3 months | Structured nursing assessment protocol administered by research nurse at every clinic visit; summary of responses to questionnaires were shared with the treating nurse | Usual nursing assessment; i.e., responses to questionnaires were not shared with the nurse |
| Kristeller et al., 2005 USA | Is a semi-structured spiritual inquiry by physicians acceptable to patients and have an impact? | Alternate patients | 118 adult patients attending oncologists' offices at any point after one month from diagnosis | A short semi-structured interview using open-ended questions dealing with spiritual concerns, administered by oncologist | Usual care |

TABLE 2: ASSESSMENT TOOLS, OUTCOME MEASURES, FOLLOW-UP

| Study | Assessment Instruments | Outcome Measures | Follow-up |
|-------------------------|--|--|--|
| Velikova et al., 2004 | <ul style="list-style-type: none"> - European Organization for Research and Treatment of Cancer, Quality of Life Questionnaire (EORTC QLQ-C30) - Hospital Anxiety and Depression Scale (HADS) | <ul style="list-style-type: none"> - Functional Assessment of Cancer Therapy - General (FACT-G) - content analysis of taped medical consultation | 6 months |
| McLachlan et al., 2001 | <ul style="list-style-type: none"> - Cancer needs Questionnaire (CNQ) + 2 items for sexual and spiritual needs - European Organization for Research and Treatment of Cancer, Quality of Life Questionnaire (EORTC QLQ-C30) - Beck Depression Inventory (BDI) Short Form | <ul style="list-style-type: none"> - CNQ (primary outcomes: psychologic needs, information needs) - EORTC QLQ-C30 - BDI Short Form - patient satisfaction | 6 months |
| Taenzer et al., 2000 | European Organization for Research and Treatment of Cancer, Quality of Life Questionnaire (EORTC QLQ-C30) | <ul style="list-style-type: none"> - Patient Satisfaction Questionnaire (PDIS), adapted to the oncology setting - structured exit interview - medical record audit | Single visit |
| Detmar et al., 2002 | European Organization for Research and Treatment of Cancer, Quality of Life Questionnaire (EORTC QLQ-C30) | <ul style="list-style-type: none"> - content analysis of taped medical consultation - Dartmouth Primary Care Cooperative Information Functional Health Assessment (COOP) - World Organization Project of National Colleges and Academics (WONCA) charts - Patient Satisfaction Questionnaire C - Medical Outcome Study 36-Item Short-Form Health Survey (SF-36) | At 4 th visit |
| Rosenbloom et al., 2007 | Functional Assessment of Cancer Therapy - General (FACT-G) | <ul style="list-style-type: none"> - Functional Living Index - Cancer (FLIC) - Brief Profile of Mood States (POMS-17) - Medical Outcomes Study Patient Satisfaction Questionnaire III (PSQ-III) - five treatment outcomes recorded by research nurse | 6 months |
| Boyes et al., 2006 | <ul style="list-style-type: none"> - List of 12 physical symptoms (rating of symptom interference) - Hospital Anxiety and Depression Scale (HADS) - truncated version of Supportive Care Needs -- Survey (psychological, health systems/information, patient care and support, physical and daily living) | <ul style="list-style-type: none"> - list of 12 physical symptoms - HADS - truncated version of Supportive Care Needs Survey - acceptability survey of patients and clinicians | 3 follow-up visits |
| Bramsen et al., 2008 | Semi-structured interview covering physical, emotional, social, spiritual and coping issues, based on methods developed by Weisman et al. | <ul style="list-style-type: none"> - EORTC quality-of-life questionnaire (QLQ-30) - General Health Questionnaire (GHQ-12) - Impact of Event Scale (IES) | Mailing, 4 weeks after discharge |
| Sarna, 1998 | Symptom Distress Scale (SDS) | <ul style="list-style-type: none"> - Symptom Distress Scale (SDS) - Hospital Anxiety and Depression Scale (HADS) - Karnofsky Performance Status (KPS) - Physical Functioning Scale (PFS) | 5 assessments over 5 months |
| Kristeller et al., 2005 | Oncologist Assisted Spirituality Intervention Study (OASIS) inquiry developed for the study, using a format shown to be effective for interventions dealing with smoking and high-risk alcohol use | <ul style="list-style-type: none"> - Functional Assessment of Cancer Therapy - General (FACT-G QOL) - Brief Symptom Inventory - Depression subscale (BSI-D) - Duke University Index of Religiosity (DUREL) - Functional Assessment of Chronic Illness - Spiritual Well-Being subscale (FACIT-Sp) - Satisfaction | Immediately after and 3 weeks after assessment |

TABLE 3: OUTCOME DATA RELEVANT TO PSYCHOSOCIAL HEALTH CARE NEEDS ASSESSMENT

| Study | Physical well-being | Emotional, Psychological and Psychiatric well-being | Social and Family well-being | Spiritual and Religious well-being | Functional well-being | Other |
|-------------------------|--|--|------------------------------|--|--|---|
| Velikova et al., 2004 | Better at 1 to 3 months but not at 6 months | Better emotional well-being in intervention group compared to unscreened control group (p=0.008) but not compared to 'attention control' (screening questionnaires administered but not shared with clinician) | No significant differences | Not measured | Better at 2 to 3 months but not at 6 months | Better overall quality of life (FACT-G score) in intervention group compared to unscreened control group (p=0.006) but not compared to 'attention control' (screening questionnaires administered but not shared with clinician); Number of EORTC QLQ-30 symptoms mentioned during clinical encounter higher in intervention group than control groups (p=0.03); No change in clinical management (e.g., prescriptions) |
| McLachlan et al., 2001 | No significant difference | No significant difference overall (however, at 6 m symptoms were less in those with moderate-to-severe symptoms at baseline, p=0.001) | No significant difference | Worse in intervention group at 6 months compared to control (p=0.02) but not at 2 months | No significant difference | No significant difference at 2 months in health information needs; sex/intimacy; visit times |
| Taenzer et al., 2000 | Not measured | Not measured | Not measured | Not measured | Not measured | No significant differences in patient satisfaction with clinic visit; more quality of life items (overall and specific to patient) were discussed during visit in the intervention group than control; more charting of quality of life items in charts for intervention group than control but no significant difference in action taken |
| Detmar et al., 2002 | Dyspnea and fatigue scores better in intervention group (p=0.02) but no differences in other symptoms | No significant difference (however, a greater improvement over time was observed in mental health in the intervention group, p=0.04) | No significant difference | Not measured | No significant difference in role or cognitive functioning | Communication score higher in intervention group (p=0.01); No significant difference between groups in: physician awareness of patient's health-related quality of life; patient management; patient or physician satisfaction; health-related quality of life measured by the SF-36; duration of visits |
| Rosenbloom et al., 2007 | No sig differences among groups in physical well-being or nausea | No significant differences among groups in psychological well-being or negative affect | No significant differences | Not measured | No significant differences among groups in hardship-due-to-cancer subscale | No significant differences among groups in overall quality of life; satisfaction with medical treatment; overall health-related quality of life |
| Boyes et al., 2006 | Fewer debilitating symptoms in intervention group at 3 rd visit | No significant differences between groups in change in HADS scores since baseline | Not measured | Not measured | Not measured | Supportive care needs: No significant difference between groups in change since baseline |
| Bramsen et al., 2008 | Pain (p<0.01) and physical functioning (p<0.05) better in screened group compared to control but no differences for other symptoms | Screened group better on positive mental health scale (p<0.01) but not on total score for GHQ-12 or on emotional functioning scale on QLQ-C30 | No significant differences | Not measured | Screened group better on role functioning scale of QLQ-C30 (p<0.05) but not on cognitive functioning or financial difficulties | 51% of those approached agreed to the screening interview; Referral to psychosocial care - 24% of intervention patients and 8% of controls (p<0.01) |

| Study | Physical well-being | Emotional, Psychological and Psychiatric well-being | Social and Family well-being | Spiritual and Religious well-being | Functional well-being | Other |
|-------------------------|--|---|------------------------------|--|---|---|
| Sarna, 1998 | Less symptom distress over time in the intervention group compared to control (p=0.0004) | Not reported | Not measured | Not measured | Not reported | None |
| Kristeller et al., 2005 | No significant difference on physical subscale of FACT-G QOL | Change in depression score better with intervention than control (p<0.01); no significant difference on emotional sub-scale of FACT-G QOL | No significant difference | No difference between groups on FACIT-Sp score or index of religiosity | No significant difference on functional sub-scale of FACT-G QOL (however, overall change from baseline significantly greater with the intervention) | Intervention group significantly better than control in satisfaction with relationship with physician and total quality of life score |

Appendix E: Tools for Psychosocial Health Care Needs Assessment in Adults with Cancer

- Table 1: All Eligible Instruments (N=40)
- Table 2: Instruments with Data Available on Validity, Internal Consistency, and Reliability and/or Responsiveness (N=15)
- Table 3: Domains Covered by Instruments with Data Available on Validity, Internal Consistency, and Reliability and/or Responsiveness

TABLE 1: ALL ELIGIBLE INSTRUMENTS (N=40)

| Instrument | Information Available on: | | | | | Source |
|--|--|----------------------|-------------------------|-------------------------|----------------|--|
| | Validity | Internal Consistency | Test-retest Reliability | Inter-rater Reliability | Other | |
| <i>Patient-completed instruments</i> | | | | | | |
| A Computerized Symptom Assessment Instrument | Correlation** | | | | | Kirkova et al. (2006) |
| CAMPAS-R Cambridge Palliative Assessment Schedule | | Cronbach alpha | | | | Kirkova et al. (2006) |
| CARES Cancer Rehabilitation Evaluation System | Correlation | Cronbach alpha | √ | | responsiveness | Wen & Gustafson (2004) Richardson et al. (2007) Shelby et al. (2006) |
| CARES -Short Form Cancer Rehabilitation Evaluation System | Correlation | Cronbach alpha | √ | | responsiveness | Wen and Gustafson (2004) Shelby et al. (2006) |
| CaSPUN Cancer Survivors' Partners Unmet Supportive Care Needs | Correlation | Cronbach's alpha | √ | | | Hodgkinson, Butow, Hobbs, et al. (2007) |
| CaSUN Cancer Survivors' Unmet Supportive Care Needs | Correlation | Cronbach alpha | √ | | | Hodgkinson, Butow, Hunt, et al. (2007) |
| CCM Cancer Care Monitor (also know as the Patient Care Monitor) | Convergent Divergent*** Factor analysis | Cronbach alpha | √ | | | Richardson et al. (2007) |
| Concerns checklist | Factor analysis | | | | | Richardson et al. (2007) |
| CPNS Cancer Patient Need Survey | | Cronbach alpha | | | | Wen & Gustafson (2004) |
| CPNQ Cancer Patient Need Questionnaire | Discriminant [†] | Cronbach alpha | √ | | | Wen & Gustafson (2004) |
| ESAS Edmonton Symptom Assessment System | Discriminant Correlation | Cronbach alpha | √ | | | Kirkova et al. (2006) |
| INM Information Needs Measure | | Kendall zeta | | | | Wen & Gustafson (2004) |
| MDASI M. D. Anderson Symptom Inventory | | Cronbach alpha | | | | Kirkova et al. (2006) |
| MSAS Memorial Symptom Assessment Scale | | Cronbach alpha | | | | Kirkova et al. (2006) |
| OCPC Oncology Clinic Patient Checklist | | | | | | Richardson et al. (2007) |

| | | | | | | |
|---|---|--------------------------|---|--|----------------|--|
| OTTAT Oncology <u>Treatment</u> Toxicity Assessment Tool | | Cronbach alpha | | | | Kirkova et al. (2006) |
| PCNA Prostate Cancer Needs Assessment | Correlation | Agreement among 3 raters | v | | | Wen & Gustafson (2004) |
| PINQ Patient Information Need Questionnaire | Correlation | Cronbach alpha | | | responsiveness | Wen & Gustafson (2004) |
| POMS Profile of Mood States | Correlation | | | | | Kirkova et al. (2006) Shelby et al. (2006) |
| Problem Checklist | Factor analysis | Cronbach alpha | | | | Richardson et al. (2007) |
| RSCL Rotterdam Symptom Checklist | Factor analysis | Cronbach alpha | | | | Kirkova et al. (2006) |
| SCNS Supportive Care Needs Survey | Discriminant Factor analysis | Cronbach alpha | | | | Wen & Gustafson (2004) Richardson et al. (2007) |
| SDI Social Difficulties Inventory | Convergent Discriminant Sensitivity Specificity PPV | Cronbach alpha | v | | | Wright et al. (2005) Wright et al. (2007) |
| SDS Symptom Distress Scale | Discriminant | Cronbach alpha | v | | | Kirkova et al. (2006) |
| Symptoms and concerns checklist | Convergent | Cronbach alpha | v | | | Richardson et al. (2007) |
| TINQ-BC Toronto Informational Needs Questionnaire- Breast Cancer | Correlation | Cronbach alpha | | | | Wen & Gustafson (2004) |
| Worthington <u>Chemotherapy</u> Questionnaire | Discriminant Factor analysis | | v | | | Kirkova et al. (2006) |
| <i>Patient and caregiver- completed instruments</i> | | | | | | |
| PNI Psychosocial Needs Inventory | Discriminant | Cronbach alpha | | | | Wen & Gustafson (2004) |
| <i>Caregiver- completed instruments</i> | | | | | | |
| HCNS Home Caregiver Need Survey | Correlation | Cronbach alpha | | | responsiveness | Wen & Gustafson (2004) |
| <i>Family- completed instruments</i> | | | | | | |
| FAMCARE [Measures family satisfaction with advanced cancer care] | Correlation | Cronbach alpha | v | | | Wen & Gustafson (2004) |
| FIN Family Inventory of Needs | Correlation | Cronbach alpha | | | | Wen & Gustafson (2004) |
| FIN-H Family Inventory of Needs - Husbands [of women with breast cancer] | | Cronbach alpha | v | | | Wen & Gustafson (2004) |
| NSS Need Satisfaction Scale [bereaved families] | Correlation | Cronbach alpha | | | | Wen & Gustafson (2004) |
| <i>Interview/observer-rated instruments</i> | | | | | | |
| DINA Derdiarian Informational Needs Assessment | | Cronbach alpha | v | | responsiveness | Wen & Gustafson (2004) |

| | | | | | | |
|---|--------------|----------------|---|---|--|--|
| Reduced E-STAS | | | | | | Kirkova et al. (2006) |
| HCS-PF Home Care Study-Patient Form [attitudes toward medical care] | Discriminant | Cronbach alpha | | | | Wen and Gustafson (2004) |
| IHA form Initial Health Assessment [Canadian] | | | | | | Richardson et al. (2007) |
| NEST The Needs Near the <u>End-of-Life</u> Care Screening Tool | | Cronbach alpha | | | | Wen & Gustafson (2004) Richardson et al. (2007) |
| PNAT Patient Needs Assessment Tool | Correlation | Cronbach alpha | v | v | | Wen & Gustafson (2004) Richardson et al. (2007) |
| SPARC Sheffield Profile for Assessment and Referral to Care | | Correlations | | | | Richardson et al. (2007) |

* Applicable only to instruments administered by a clinician (Interview/Observer-rated)

** Correlation with another measure of the same construct; convergent validity

*** Low correlation with a test that measures a different construct

† Instrument is able to distinguish patients with different stages of disease or at different points on cancer continuum

PPV, positive predictive value

TABLE 2: INSTRUMENTS WITH DATA AVAILABLE ON VALIDITY, INTERNAL CONSISTENCY, AND RELIABILITY AND/OR RESPONSIVENESS (N=15)

| Instrument | Number of items | Time to complete (minutes) | Validity | Internal consistency * | Test-retest reliability | Inter-rater reliability | Responsiveness |
|--|-----------------|----------------------------|---|------------------------|------------------------------|-------------------------|------------------|
| <i>Patient completes</i> | | | | | | | |
| CARES Cancer Rehabilitation Evaluation System | 93-139 | 20 | Correlated with SCL-90, KPS, DAS, VAS for QoL; Correlated with open-ended assessment | 0.87 - 0.94 | Agreement 87% - 91% | | Change over time |
| CARES -Short Form Cancer Rehabilitation Evaluation System | 38-57 | NR | Correlated with CARES, FLIC, KPS, DAS Correlated with open-ended assessment | 0.60 - 0.84 | Agreement 81% - 86% | | Change over time |
| CaSPUN Cancer Survivors' Partners Unmet Supportive Care Needs | 42 | 10 | Correlated with mental QoL, anxiety and depression | 0.94 | Kappa = 0.28 | | |
| CaSUN Cancer Survivors' Unmet Supportive Care Needs | 42 | 10 | Correlated with physical and mental QoL, anxiety and depression | 0.96 | Kappa = 0.13 | | |
| CCM Cancer Care Monitor | 38 | 12 - 20 | Convergent and divergent validity with BSI, SF-36, MSAS, LSI, SWLS | 0.80 - 0.89 | r = 0.87 - 0.74 over 1-2 wks | | |
| CPNQ Cancer Patient Need Questionnaire | 71 | 20 | Distinguishes different stages of disease | 0.78 - 0.90 | Kappa > 0.4 | | |

| | | | | | | | |
|--|-----|--------|---|---|--------------------------------|-------------------------------------|--|
| ESAS Edmonton Symptom Assessment System | 9 | | 'moderate to good' | Reliability rated 'moderate' | | | |
| PCNA Prostate Cancer Needs Assessment | 135 | 43 | Correlated with overall satisfaction with care | Agreement among 3 raters | R = 0.97 after 2 weeks | | |
| PINQ Patient Information Need Questionnaire | 17 | NR | Correlated with RSC, State-Anxiety Inventory and MMPI D-scale | 0.88 - 0.92 | | | Change over time, before and after treatment |
| SDI Social Difficulties Inventory | 22 | NR | interview by social worker as standard: ICC = 0.61 Sensitivity = 80% Specificity = 75% PPV = 29% 'Moderate to good' correlation with LEDS and CARES-SF | >0.7 | Kappa 0.5 - 0.8 for items | | |
| SDS Symptom Distress Scale | 10 | 'Good' | 'moderate' | Reliability rated 'moderate to good' | | | |
| Symptoms and concerns checklist | 32 | 5 | Convergent validity with SDS, POS. Discriminates between outpatients and inpatients | 0.85 | Kappa 0.35 to 0.77 over 2 days | | |
| Caregiver-completed instruments | | | | | | | |
| HCNS Home Caregiver Need Survey | 90 | 30 | Correlated with KPS | 0.93 | | | Detected change over time |
| Family-completed instruments | | | | | | | |
| FAMCARE [Measure family satisfaction with advanced cancer care] | 20 | 22 | Correlated with McCusker and overall satisfaction with care | 0.93 | R = 0.92 < 23 hours | | |
| Interview/observer-rated instruments | | | | | | | |
| PNAT Patient Needs Assessment Tool | 16 | 20-30 | Correlated with KPS, GAIS, BSI, MPAC, BDI, ISEL | 0.85 - 0.94 | | Friedman: 0.73 - 0.87 for subscales | |

* Cronbach alpha unless stated otherwise

BDI, Beck Depression Inventory; BSI, Brief Symptom Inventory; CARES-SF, Cancer Rehabilitation Evaluation System - Short Form; DAS, Dyadic Adjustment Scale; FLIC, Functional Living Index Cancer; GAIS, Global Adjustment to Illness Scale; ISEL, Interpersonal Support Evaluation List; KPS, Karnofsky Performance Status; LEDS, Life Events and Difficulties Schedule; LSI, Life Satisfaction Index; MMPI D-scale, Minnesota Multiphasic Inventory Depression Scale; MPAC, Memorial Pain Assessment Scale; MSAS, Memorial Symptom Assessment Scale; NR, not reported; POS, Palliative care Outcome Scale; QoL, quality of life; RSC, Rotterdam Symptom Checklist?; SCL-90, Symptom Checklist-90; SDS, Symptom Distress Scale; SF-36, medical outcomes study SF-36 Health survey; SWLS, Satisfaction With Life Scale; VAS, visual analogue scale

Note: Data taken from sources listed in Appendix D, Table 1.

TABLE 3: DOMAINS* COVERED BY INSTRUMENTS WITH DATA AVAILABLE ON VALIDITY, INTERNAL CONSISTENCY, AND RELIABILITY AND/OR RESPONSIVENESS

| Instrument | Physical | Emotional | Psychological | Social* | Spiritual | Practical | Information | Other |
|---|----------|-----------|---------------|---------|-----------|-----------|-------------|--|
| Patient completes | | | | | | | | |
| CARES Cancer Rehabilitation Evaluation System | √ | | √ | √ | | | | Medical interaction |
| CARES -Short Form Cancer Rehabilitation Evaluation System | √ | | √ | √ | | | | Medical interaction |
| CaSPUN Cancer <u>Survivors'</u> Partners Unmet Supportive Care Needs | √ | √ | | √ | | | √ | |
| CaSUN Cancer <u>Survivors'</u> Unmet Supportive Care Needs | √ | √ | | √ | | √ | √ | Socio-economic, survivorship |
| CCM Cancer Care Monitor | √ | | √ | | | √ | | |
| CPNQ Cancer Patient Need Questionnaire | | | √ | √ | | √ | √ | |
| ESAS Edmonton Symptom Assessment System | √ | | √ | | | | | |
| PCNA Prostate Cancer Needs Assessment | | | | √ | | | √ | Care delivery |
| PINQ Patient Information Need Questionnaire | | | | | | | √ | |
| SDI Social Difficulties Inventory | | | | √ | | √ | | Financial, Communication |
| SDS Symptom Distress Scale | √ | | √ | | | | | |
| Symptoms and concerns checklist | √ | | √ | | | | | Patient defined concerns |
| Caregiver completes | | | | | | | | |
| HCNS Home Caregiver Need Survey | √ | | √ | √ | √ | √ | √ | MD care/ availability; Other prof. |
| Family completes | | | | | | | | |
| FAMCARE [family satisfaction with cancer care] | √ | | | | | √ | √ | |
| Interview/Observer-rated | | | | | | | | |
| PNAT Patient Needs Assessment Tool | √ | | √ | √ | | | | |
| * Domains of Psychosocial Health Care Needs as defined by the Conceptual Framework (Table 1, p. 15) | | | | | | | | |

Appendix F: Example Instruments for Psychosocial Health Care Needs Assessment

| | Cancer Rehabilitation Evaluation System (CARES) [formerly the Cancer Inventory of Problem Situations (CIPS)] | Cancer Rehabilitation Evaluation System - Short Form (CARES-SF) | Cancer Care Monitor (CCM) | Cancer Patient Needs Questionnaire (CPNQ) |
|---|--|---|--|---|
| Purpose | To assesses day-to-day problems and rehabilitation needs of patients with cancer, and to measure of health-related quality of life. Developed for clinical and research use. | To document rehabilitation problems and quality of life. Developed for use in clinical trials and as a screening instrument. | To screen for high-frequency cancer-related symptoms. To assess overall symptom severity and quality of life. Developed for use in community oncology. | To assess the unmet global needs of people living with cancer. |
| Populations studied | United States: <ul style="list-style-type: none"> - 779 patients with prostate, lung or colorectal cancer at any stage of disease - 109 patients after primary surgery for early-stage breast cancer - 227 disease-free survivors of lung, colon or prostate cancer - 120 patients with various cancers (reliability and validity evaluation of CIPS) | Holland (instrument translated into Dutch and 'cancer' changed to 'illness'): <ul style="list-style-type: none"> - 485 patients with breast, colorectal, lung or other cancers at any stage of disease United States: <ul style="list-style-type: none"> - re-analysis of data from CARES studies - 89 African-American women with breast cancer | United States: <ul style="list-style-type: none"> - 449 outpatients with various cancers (30% had breast cancer) at any stage of disease - 60 outpatients with various cancers (37% had breast cancer) at any stage of disease | Australia: 358 outpatients attending medical or radiation oncology clinics |
| Method of Administration | <ul style="list-style-type: none"> - Self-administered using paper form - Computerized scoring and report writing | <ul style="list-style-type: none"> - Self-administered using paper form, or completed by telephone interview | <ul style="list-style-type: none"> - Self-administered using paper form or tablet computer | <ul style="list-style-type: none"> - Self-administered using paper form |
| Time to Complete | 20 minutes | 11 minutes (average; range = 2-45 minutes) | 11 minutes (paper); 7 minutes (electronic) | 20 minutes |
| Summary Scales and Number of Items | <i>Patient completes 93-132 of 139 available items, depending on circumstances (e.g., chemotherapy):</i> Physical (26) Psychosocial (44) Medical interaction (11) Marital (18) Sexual (8) There are also 32 miscellaneous items and 31 subscales. | <i>Patient completes 38-57 of 59 available items, depending on circumstances, plus 10 screening questions:</i> Physical (10) Psychosocial (17) Medical interaction (# unknown) Marital (6) Sexual (# unknown) There are also an unreported number of miscellaneous items. | <i>38 items:</i> Physical symptoms (11) Treatment side effects (8) Acute distress (4) Despair (7) Impaired ambition (4) Impaired performance (4) | <i>71 items across 5 domains:</i> Psychosocial Health information Physical and daily living Patient care and support Interpersonal communication + 2 items about patient's desired access to support services and people. |
| Scoring | <ul style="list-style-type: none"> - Problem statements rated on 5-point scale (0= "does not apply" to 4="applies very much") - Global score, 5 scales, 31 subscales. - Includes option "Do you want help?" (yes/no) for clinical use | <ul style="list-style-type: none"> - Problem statements rated on 5-point scale (0= "does not apply" to 4="applies very much") - Global score, 5 scales, 31 subscales. - Includes option "Do you want help?" (yes/no) for clinical use | <ul style="list-style-type: none"> - Each item rated on a 10-point scale - For physical symptoms and side effects: (0="not a problem" to 10= "as bad as possible") - For distress, despair, ambition, performance: (0="not at all true" to 10= "completely true") - Scale scores reported as normalized T scores with a mean of 50 and standard deviation of 10 (a given T score would have an equivalent percentile rank across all scales) | <ul style="list-style-type: none"> - Each item rated on 5-point scale (1= "no need/not applicable" to 5 = "high need for help") |

| | | | | |
|--|---|---|--|--|
| <p>Validity (other than face validity)</p> | <p>Correlation with QOL measures in early-stage breast cancer: FLIC = 0.74, KPS = 0.60</p> <p>Highest correlations on physical summary score.</p> <p>Relationship with extent of disease in colorectal, lung and prostate cancer.</p> <p>No differences between breast cancer patients treated by modified radical vs. segmental mastectomy.</p> <p>Correlation of global CIPS score with: QOL-Before cancer = 0.13 QOL-After cancer = 0.54 (p<0.0010) SCL-90 = 0.76 (p<0.0010) KPS = -0.46 (p<0.0010) DAS = 0.19</p> | <p>Significant differences in global scores by:</p> <ul style="list-style-type: none"> - stage of disease - KPS score - treatment modality - tumour response. <p>Significant correlation between scores on CARES-SF physical and psychosocial scales and physical concerns reported using an open-ended format.</p> <p>Agreement with CARES: 86% for global score and 81-86% for scales.</p> <p>Correlation with: Visual analogue rating of QOL = 0.55 SCL-90 = 0.74 KPS = 0.50 DAS = 0.16</p> | <p>Correlations with other measures:</p> <ul style="list-style-type: none"> - CCM physical symptom scale and BSI scales: somatisation scale = 0.73; global severity index = 0.69; positive symptom distress = 0.62; positive symptom total = 0.63 - CCM despair scale and BSI_depression scale = 0.67 - CCM performance scale and SF-36 scales: Positive physical functioning = 0.77; Physical role fulfillment = 0.68; Vitality = 0.66 - CCM physical symptom scale and MSAS scales: Physical symptom scale = 0.67; Global distress scale = 0.68 - CCM treatment side effects scale and MSAS scales: Physical symptom scale = 0.71; Global distress scale = 0.64 - CCM QOL score: significantly different across EOTRC performance ratings, ranging from 57.5 for group with EORTC score 0 to 37.7 for EORTC score 3; correlated with SF-36 physical health summary (0.68); MSAS total score (0.75); MSAS global distress index (0.73) <p>Agreement between CCM and nurse interview on 19 CCM items on physical symptoms and treatment side effects: Kappa for presence of symptom ranged from 0.43 to 0.96 for individual items; 4 items had kappa >0.75. No significant difference on severity of symptoms (max. differences 0.68 points on 10-point scale). Using nurse's rating as gold standard: Sensitivity >0.8 for all 19 items; specificity >0.8 for 13 items</p> | <p>Factor analysis reported as evidence of validity.</p> <p>Patients with more advanced stages of disease reported more unmet needs and those with cancer in remission reported fewer needs than others (no statistics reported)</p> |
| <p>Internal Consistency</p> | <p>$\alpha = 0.82 - 0.94$ (across scales)</p> | <p>$\alpha = 0.90$ (global) $\alpha = 0.49 - 0.87$ (across scales)</p> | <p>$\alpha = 0.80 - 0.89$ (across scales) $\alpha = 0.84$ (QOL)</p> | <p>$\alpha = 0.78 - 0.90$ (across factors)</p> |
| <p>Reproducibility (Test-Retest Reliability)</p> | <p>For CIPS, "second time soon after the first": % agreement = 86% (overall) % agreement = 84% - 88% (individual scales)</p> | <p>Over 1 wk: ICC= 0.91 (global score) ICC = 0.72 - 0.91 (individual scales)</p> | <p>In patients not undergoing treatment (6 scales and overall): 1-7 days: 0.74 to 0.90 8-14 days: 0.38 to 0.87</p> | <p>Over 10-14 days: Kappa >0.4 for all items (no other statistics reported)</p> |
| <p>Responsiveness</p> | <ul style="list-style-type: none"> - Improved scores over time after surgery for breast cancer - No significant changes with length of survivorship for colon and lung cancer - Worsening scores related to time in survivors of prostate cancer. | <ul style="list-style-type: none"> - Changes in scores over time tracked changes over time in KPS score, FLIC score, tumour progression, treatment | <p>Not reported</p> | <p>Not reported</p> |

| | | | | |
|----------------------|--|---|--|---|
| Patient Satisfaction | Not reported | Completed without assistance by 90% of patients. 30% reported having difficulties with 1 or 2 items, 30% with 3-6 items and 22% with ≥ 7 items. | Patients preferred computer-administered version to paper form. | Not reported |
| Availability | For purchase from CARES Consultants, California. | Copyrighted by CARES Consultants, California. | Item wording and scales published by Fortner et al., 2003. | Not found |
| Primary References | <p>Ganz, P. A., Schag, C. A., & Cheng, H. L. (1990). Assessing the quality of life--a study in newly-diagnosed breast cancer patients. <i>Journal of Clinical Epidemiology</i>, 43(1), 75-86.</p> <p>Schag, C. A., Heinrich, R. L., Aadland, R. L., & Ganz, P. A. (1990). Assessing problems of cancer patients: Psychometric properties of the cancer inventory of problem situations. <i>Health Psychology</i>, 9(1), 83-102.</p> <p>Ganz, P. A., Schag, C. A. C., Lee, J. J., & Sim, M. S. (1992). The CARES: A generic measure of health-related quality of life for patients with cancer. <i>Quality of Life Research</i>, 1, 19-29.</p> <p>Schag, C. A., Ganz, P. A., Wing, D. S., Sim, M. S., & Lee, J. J. (1994). Quality of life in adult survivors of lung, colon and prostate cancer. <i>Quality of Life Research</i>, 3(2), 127-141.</p> | <p>Schag, C. C., Ganz, P. A., & Heinrich, R. L. (1991). Cancer Rehabilitation Evaluation System-Short Form (CARES-SF): A cancer specific rehabilitation and quality of life instrument. <i>Cancer</i>, 15, 1406-1413.</p> <p>te Velde, A., Sprangers, M. A., & Aaronson, N. K. (1996). Feasibility, psychometric performance, and stability across modes of administration of the CARES-SF. <i>Annals of Oncology</i>, 7(4), 381-390.</p> <p>Shelby, R. A., Lamdan, R. M., Siegel, J. E., Hrywna, M., & Taylor, K. L. (2006). Standardized versus open-ended assessment of psychosocial and medical concerns among African American breast cancer patients. <i>Psycho-Oncology</i>, 15(5), 382-397.</p> | <p>Fortner, B., Baldwin, S., Schwartzberg, L., & Houts, A. C. (2006). Validation of the Cancer Care Monitor items for physical symptoms and treatment side effects using expert oncology nurse evaluation. <i>Journal of Pain and Symptom Management</i>, 31(3), 207-14.</p> <p>Fortner, B., Okon, T., Schwartzberg, L., Tauer, K., & Houts, A. C. (2003). The Cancer Care Monitor: Psychometric content evaluation and pilot testing of a computer administered system for symptom screening and quality of life in adult cancer patients. <i>Journal of Pain and Symptom Management</i>, 26(6), 1077-1092.</p> | <p>Foot, G., & Sanson-Fisher, R. (1995). Measuring the unmet needs of people living with cancer. <i>Cancer Forum</i>, 19(2), 131-5.</p> |

BSI, Brief Symptom Inventory; DAS, Dyadic Adjustment Scale; EORTC, European Organization for Research and Treatment of Cancer; FLIC, Functional Living Index - Cancer; ICC, Intra-class correlation coefficient; KPS, Karnofsky Performance Status; MSAS, Memorial Symptom Assessment Scale; QOL, quality of life; SCL, Symptom Checklist

Appendix G: Screening for Distress: Symptoms, Problems and Concerns

TABLE 1: SCREENING FOR PSYCHOLOGICAL DISTRESS TOOLS

| Instrument | Purpose and Population | Number of Items | Method of Administration and Question Format | Comments | Primary Reference (s) |
|--|---|--|--|---|-----------------------------------|
| Brief Symptom Inventory - 18 [BSI-18] | To assess clinically relevant psychological problems | 18 | Self-administered. Individuals are instructed to respond to each item in terms of “how they have been feeling during the past 7 days.” Response is via a five point likert scale ranging from 0 (“not at all”) to 4 (“always”). | Reliability, validity, sensitivity, and specificity have been widely documented across various cancer populations (IOM, 2008). | (Derogatis and Melisaratos, 1983) |
| Center for Epidemiological Studies Depression Scale [CES-D] | To measure depressive symptoms | 20 | Self-administered. Individuals are instructed to respond according to how often (via likert scale) they have felt or behaved in a certain way in the past week (e.g., “I was bothered by things that usually don’t bother me”): rarely or none of the time, some or a little of the time, occasionally or a moderate amount of time, most or all of the time) | Demonstrates good psychometric properties as a screening tool, including sensitivity, specificity, and internal consistency. (Vodermaier, Linden , & Siu, 2009). | (Radloff, 1977) |
| Distress Thermometer [DT] | To measure the level of distress, coming from any source (even if unrelated to cancer) | 1 (+ 35-item Problem Checklist) | Self-administered. Individuals are instructed to circle the number (from zero [no distress] to 10 [extreme distress]) that best describes how much distress they have experienced over the past week. | Well-known and validated in many studies (NCCN, 2008) Brief and easy to administer (NCCN, 2008) Demonstrates an uneven pattern of sensitivity and specificity findings (Mitchell, 2007; Vodermaier, Linden , & Siu, 2009). | (Roth et al., 1998) |
| Hospital Anxiety and Depression Scale [HADS] | To assess mood in non-psychiatric hospital settings | 14 items (7 items in anxiety subscale, 7 items in depression subscale) | Self-administered. Individuals are instructed to underline the reply (via likert scale) that best reflects how they have been feeling in the last week (e.g., “I feel tense or ‘wound’ up”): most of the time, a lot of the time, from time to time, not at all) | Demonstrates extensive validation across disease types and stages, and across languages/culture (Vodermaier, Linden , & Siu, 2009). | (Zigmond & Snaith, 1983) |
| Psychosocial Screen for Cancer [PSSCAN] | To screen for psychosocial issues in cancer patients, specifically anxiety, distress, social support and quality of life. | 21 items | Self-administered. Involves “yes/no” responses, visual analogue scale responses, likert sale responses, recall of the number of days in the last month during which physical or emotional health was “not good”, and recall of number of days impaired. | Anxiety and depression subscales highly sensitive and specific when compared to HADS. Has performed well on psychometric tests and tests of reliability and validity in three samples totalling almost 2,000 patients (IOM, 2008). Software enables use electronically (IOM, 2008; Vodermaier, Linden , & Siu, 2009). | (Linden et al., 2005) |

