Progress has been made in recent years for integrating psychosocial care into routine cancer care, but more work is needed.

Integrating Psychosocial Care Into Routine Cancer Care

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Background: Despite growing recognition that psychosocial care is an essential component of comprehensive cancer care, evidence suggests many patients with cancer do not receive needed psychosocial care.

Methods: Four areas were identified as potentially increasing the number of patients with cancer who receive needed psychosocial care: (1) formulating care standards, (2) issuing clinical practice guidelines, (3) developing and using measurable indicators of quality of care, and (4) demonstrating projects designed to improve the delivery of care.

Results: Standards for psychosocial care are identified, including a standard issued in 2015 by an accrediting organization. Three clinical practice guidelines for provisioning psychosocial care are also identified and reviewed. Methods for monitoring the quality of psychosocial care are characterized and the impact of monitoring changes in quality are evaluated in relation to existing evidence. Examples are provided of 2 large-scale efforts designed to improve the delivery of psychosocial care in community settings.

Conclusions: Although considerable progress has been made in integrating psychosocial care into routine cancer care, work must still be done. Additional progress will be fostered by continued efforts to promote adherence to clinical practice guidelines and care standards for psychosocial care and by the development and dissemination of models that demonstrate how practices can implement these guidelines and standards.

Introduction

Recognition is growing that psychosocial care is an essential component of the comprehensive care of people diagnosed with cancer. In addition to attempting to extend survival rates in people following a cancer diagnosis, the oncology community is recognizing the value of quality of life. Psychosocial care, with its goals of relieving emotional distress and promoting well-being, is central to efforts to improve quality of life. However, evidence suggests that many patients with cancer who might benefit from psychosocial care do not receive it.

Four areas of activity have the potential to increase the number of patients who receive needed psychosocial care:

1. Formulating care standards that address the psychosocial component of care
2. Issuing clinical practice guidelines for the psychosocial care of patients with cancer
3. Developing and using measurable indicators of quality of psychosocial care in oncology settings
4. Demonstrating projects designed to promote the greater implementation of standards for psychosocial care
Definitions
Standards in medical care refer to diagnostic or treatment processes that health care professionals should follow for certain classes of patients, illnesses, or clinical circumstances. Standards may be developed based on evidence, expert consensus, and/or ethical and safety considerations. With regard to the psychosocial domain, standards of care represent recommendations for the organization and delivery of psychosocial care that apply to patients seen in the oncology setting.

Clinical practice guidelines are systematically developed statements designed to assist health care professionals and patients in making decisions about appropriate health care based on specific characteristics of the patient (eg, age, comorbidities), illness (eg, disease severity), or clinical circumstances (eg, symptom presentation). Similar to standards, clinical practice guidelines can be developed based on evidence, expert consensus, and/or ethical and safety considerations.

In general, measuring the quality of care involves assessing the extent to which an organization and delivery of care conforms to standards of care and clinical practice guidelines. A widely used model dating from the 1960s differentiates 3 components important to consider in evaluating quality, namely: (1) the structure of care (eg, resources or personnel), (2) the processes of care (eg, performance of specific diagnostic procedures or treatments), and (3) outcomes of care (eg, survival rates).3 Methods for assessing the quality of psychosocial care have primarily focused on evaluating processes of care.

Standards
Efforts to promote greater awareness of the importance of psychosocial care for patients with cancer received a boost following a 2008 publication from the Institute of Medicine (IOM) summarizing evidence regarding the deleterious effects of unmet psychosocial needs and benefits of providing psychosocial services.2 Despite evidence supporting the effectiveness of psychosocial services, the IOM concluded that many patients do not receive help for problems that might benefit from this type of care.2 To address this problem, the report included a list of recommended actions, including that all entities establishing or using standards for the quality of cancer care adopt a standard that calls for the provision of appropriate psychosocial health services.2 The recommendation further identifies certain processes and goals of care as being components of this standard (Table).2,4,6

Several initiatives predate the IOM report in proposing standards that address psychosocial care. For example, the National Comprehensive Cancer Network (NCCN) included standards of care as part of its clinical practice guidelines for the management of cancer-related distress first published in 1999.7 In addition to identifying policies and procedures related to screening for and managing distress, the NCCN standards call for the formation of interdisciplinary committees

<table>
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<th>Professional Group</th>
<th>Summary and Comments</th>
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<tr>
<td>American College of Surgeons Commission on Cancer4</td>
<td>Specifies standards for organizing, delivering, and monitoring of oncology services. Presented as requirements evaluated during accreditation review. Key example of standards for psychosocial care: Cancer committee develops and implements a process to integrate and monitor on-site psychosocial distress screening and referral for psychosocial care.</td>
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<tr>
<td>Canadian Association of Psychosocial Oncology5</td>
<td>Specifies standards of care for organizing and delivering psychosocial health services. Presented in sections (key principles, organization and structure, educational standards for providers, standards of care). Key examples of standards for psychosocial care: People at risk for or living with cancer are entitled to psychosocial screening using a standardized approach. People affected by cancer are entitled to access appropriate levels of treatment to address their needs.</td>
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<tr>
<td>Institute of Medicine2</td>
<td>Specifies standards for providing appropriate psychosocial services. Presented as processes and goals of care. Key examples of processes and goals of psychosocial care: Facilitate effective communication between patients and health care professionals. Identify psychosocial health needs of each patient. Design and implement a plan to link patient with needed services. Follow-up on, re-evaluate, and adjust plan.</td>
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<tr>
<td>National Comprehensive Cancer Network6</td>
<td>Specifies standards of care for distress management. Presented as imperatives focused on distress management. Key examples of standards for distress management: Distress should be recognized, monitored, documented, and promptly treated. Screening should identify the level and nature of distress. Distress should be assessed and managed according to clinical practice guidelines. Interdisciplinary institutional committees should be formed to implement standards for distress management. Experienced licensed mental health professionals and certified chaplains should be available as staff members or by referral.</td>
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at each institution to implement guidelines for distress management and for the availability of trained, on-site professionals or by referral to deliver psychosocial care (see Table).4,6

Initiatives promoting standards for the psychosocial care of patients with cancer are not limited to the United States. For example, the Canadian Association of Psychosocial Oncology developed standards in 1999 and updated them again in 2010.4,8 In addition to identifying procedures for psychosocial screening and treatment, these standards cover the organization and structure of psychosocial services and the education and training of psychosocial care providers.4

Most standards for psychosocial care are developed by organizations and committees composed of members of the psychosocial oncology clinical and research communities. Thus, concerns exist about the extent to which the wider oncology community has been cognizant of these standards and has adopted them.9 Efforts to promote the adoption of such standards would benefit patients if major accrediting organizations included psychosocial care among their standards.

One such organization is the American College of Surgeons (ACS) Commission on Cancer (CoC), which is a consortium of 47 professional organizations.10 The ACS CoC establishes cancer care standards and monitors the quality of care at approximately 1,500 hospitals, which are estimated to provide care to 70% of patients with cancer in the United States.10 In 2012, the ACS CoC released several standards for patient-centered care.5 Among them is a standard specifying that a local oversight committee should develop and implement a process for psychosocial distress screening and referral for psychosocial care (see Table).2,4,6 These standards are being evaluated in 2015 as part of the ACS CoC accreditation process.11

Clinical Practice Guidelines
Worldwide, numerous organizations have proposed clinical practice guidelines that include recommendations for the psychosocial care of people with cancer.12 For brevity, only the details of 3 North American–based guidelines for psychosocial care will be covered in this article.

National Comprehensive Cancer Network
Clinical practice guidelines from the NCCN for distress management were first issued in 1999; they are updated every year and include recommendations for psychosocial screening, evaluation, treatment, and follow-up primarily presented in the form of algorithms or decision pathways.6 Most of the recommendations represent uniform consensus among experts from NCCN member institutions based on lower-level evidence (eg, clinical experience of expert providers) rather than higher-level evidence (eg, results of randomized controlled trials).

Recommendations for the management of mood disorders (eg, major depression) help illustrate how the clinical practice guidelines are organized. For example, the NCCN guidelines recommend that all patients undergo brief psychosocial screening for distress using a valid and reliable self-report tool.6 The importance of systematic screening is underscored by research indicating that oncologists typically underestimate the level of distress in their patients.13–15 For patients who have moderate to severe distress, referral to psychosocial care professionals is recommended.6 If patients are displaying signs and symptoms of a mood disorder, the initial recommendation is further evaluation, diagnostic studies, and modification of the factors potentially contributing to the symptoms (eg, concurrent medications, pain).6 Based on these findings, subsequent recommendations may include initiating psychotherapy and antidepressant medication, possibly in combination with anxiolytic medication. Consideration of referral to social work or chaplaincy services is also recommended before follow-up and re-evaluation.6

Pan-Canadian
In 2010, the Canadian Partnership Against Cancer and the Canadian Association of Psychosocial Oncology jointly issued the Pan-Canadian guidelines based on methodology developed by the ADAPTE Collaboration.16 Development of the guidelines began with a systematic search to identify other relevant guidelines, systematic reviews, and guidance documents—a process that led to the formulation of a guideline presented in the form of recommendations (accompanied by information on the level of supporting evidence) and an algorithm describing the process for screening, assessing, and managing depression and anxiety.16 Unlike the NCCN guidelines that address a wide range of psychiatric disorders and psychosocial problems, the Pan-Canadian guidelines focus on depression and anxiety.6,16

Using depression as an example, the guidelines include specific recommendations for screening, assessing, and treating depression.16 These recommendations are similar in many respects to those in the NCCN guidelines, in part because the NCCN guidelines were part of the systematic search during the creation of the Pan-Canadian guidelines.16 However, the algorithm does differs from the NCCN algorithm; for example, the Pan-Canadian algorithm recommends screening for depression rather than distress, and it identifies separate care pathways based on the severity of depression rather than on the type of mood disorder.16

American Society of Clinical Oncology
The American Society of Clinical Oncology (ASCO)
issued clinical practice guidelines in 2014 for the screening, assessment, and care of anxiety and depressive symptoms in adults with cancer. The ASCO guidelines were adapted from the Pan-Canadian guidelines, so they also used ADAPTE methodology and many of the ASCO recommendations and algorithms mirror those in the Pan-Canadian guidelines. However, the ASCO panel modified the Pan-Canadian guidelines in several instances and developed new recommendations based on additional evidence and expert opinion.

Using the recommendations on depression as an example, the ASCO guidelines specify distinct care pathways based on the severity of depression. By contrast to the Pan-Canadian guidelines, which recommend use of the Edmonton Symptom Assessment System to screen for depression, the ASCO guidelines recommend the Patient Health Questionnaire. In addition, the ASCO guidelines include detailed recommendations for follow-up of patients identified as having depression.

Guideline Harmonization
Having 3 or more clinical practice guidelines from Canada and the United States, along with numerous other guidelines from other countries, may cause confusion among health care professionals and patients with cancer seeking guidance about when and how psychosocial care should be delivered. A possible solution to this problem is a process known as guideline harmonization. One such example of guideline harmonization is the ongoing, worldwide collaboration designed to standardize various clinical practice guidelines for the long-term follow-up of children and young adults with cancer; this collaboration has resulted in harmonized guidelines for breast cancer surveillance in women with cancer who have received chest irradiation. Similar to this approach, relevant stakeholders should seek to develop a set of harmonized guidelines that address the screening, assessment, and management of more common psychosocial problems encountered by people with cancer, beginning with depression and anxiety.

Measuring Quality
A paucity of data exists about the extent to which standards and clinical practice guidelines for psychosocial care of patients with cancer are being implemented. One source of evidence is a survey of 20 NCCN member institutions completed by a representative of each institution. Although psychosocial services were available at 19 of these institutions, only 12 institutions (60%) were conducting routine outpatient screening for distress, as stipulated in the NCCN standards of care and clinical practice guidelines for distress management. Among these 12 institutions, 6 reported routinely screening all outpatients as recommended and 6 reported routinely screening select patients (eg, candidates for transplant). Of the 14 institutions conducting any routine inpatient or outpatient screening, 13 (93%) reported that, consistent with NCCN guidelines, patients identified as being in distress were referred to a mental health professional.

The IOM report and the findings of an NCCN survey suggest the need to foster greater implementation of recommendations for the psychosocial care of patients with cancer. One way to foster greater implementation might be to measure and provide feedback to health care professionals about the quality of the psychosocial care their patients with cancer receive. Research has shown that medical oncology practices provided with feedback demonstrating their poor performance on quality indicators will improve over time on those same indicators. Could psychosocial care for patients with cancer likewise be improved by measuring and reporting to oncology practices their performance on indicators of the quality of psychosocial care? To help answer this question, the IOM recommended that organizations setting standards for cancer care use performance measures for psychosocial care as part of quality-oversight activities.

The first step in this process is to develop measurable indicators of the quality of psychosocial care. Toward this end, the American Psychosocial Oncology Society formed a workgroup in 2007 charged with developing quality indicators. Members of the workgroup included 5 mental health professionals (psychologists, psychiatrists, and social workers) with extensive experience in the delivery of psychosocial care to patients with cancer. The committee focused on developing process measures of the quality of psychosocial care that could be evaluated by medical record abstraction. Following a review of the relevant literature, including the IOM report and the NCCN guidelines, committee members identified several potential indicators that were then reduced in number using a modified Delphi method. This process resulted in selection of measures assessing 2 components considered to be necessary (although not sufficient) for providing quality psychosocial care.

The first quality indicator specifies evidence should exist in the patient's medical record that his or her current emotional well-being was assessed within 1 month of the patient's first visit with a medical oncologist. The second quality indicator stipulates that, if a problem with emotional well-being was identified, then evidence should exist in the patient's medical record supporting that action was taken to address the problem or an explanation provided for why no action was taken. Measuring these indicators is operationalized by formulating questions that can be answered “yes” or “no” based on the review of an individual pa-
Two sources offer preliminary evidence that suggests providing feedback on the quality of psychosocial care might lead to improvements in care. One source is ASCO's Quality Oncology Practice Initiative, a voluntary, practice-based quality improvement program. In 2008, 2 quality indicators for psychosocial care were added to its core set of measures completed by all participating practices. Practices participating in the practice initiative have the opportunity to submit chart audit information at 6-month intervals. Following submission of their data, practices are given performance feedback on each indicator as well as the average performance score of all other participating practices. Using data provided by participating practices, an analysis was conducted to determine whether performance on these indicators improved between fall 2008 (when they became part of the core set) and fall 2009. The analysis was based on participating practices and data from approximately 15,000 patients at each time point. The average rate per practice for performing an assessment of emotional well-being improved over time, from 64% to 73% (P < .001). By contrast, the average rate per practice for taking action if a problem with emotional well-being was identified increased from 74% to 76% (P = .41). Additional evidence comes from the Florida Initiative for Quality Cancer Care. As part of a larger project examining quality of cancer care, performance rates for the 2 psychosocial indicators were available for 10 practice sites in Florida that completed chart audits of patients with colorectal, breast, or non–small-cell lung first seen by a medical oncologist in 2006 (n = 1,609) and 2009 (n = 1,720). Following the 2006 chart audit, all 10 practices received feedback on their performance and were encouraged to develop their own quality improvement efforts if performance rates were below 85%. The mean percentages of patients whose emotional well-being was assessed were 53.1% in 2006 and 51.3% in 2009, reflecting a nonsignificant decrease (P = .661). However, significant increases were seen in the prevalence of documented problems in emotional well-being among all patients (from 13.0% to 16.0%) and among patients whose emotional well-being was assessed (from 24.5% to 31.3%; P ≤ .021). The percentages of patients for whom action was taken to address a problem in emotional well-being were 57.4% in 2006 and 45.3% in 2009, thus reflecting a nonsignificant decrease (P = .998).

Taken together, these findings suggest that providing feedback alone may be more effective in promoting psychosocial screening, identifying distressed patients, or both, than improving the delivery of psychosocial care to patients in need. Efforts to improve the delivery of psychosocial care to patients in distress are likely to face a number of additional barriers, including competing clinical priorities, poor reimbursement for mental health services, and lack of psychosocial staff to accept referrals. This situation points to the need to conduct demonstration projects that seek to identify and test different approaches to improving the quality of psychosocial care in oncology settings. Consistent with this view, the IOM included a recommendation that federal funding agencies support a large-scale demonstration and evaluation of how standards for psychosocial care could be implemented across diverse treatment settings.

Demonstrating Approaches to Improving Care
Several examples have been published of efforts to implement routine distress screening programs in oncology settings. These efforts vary widely in the tools used to screen, the methods used to collect information from patients and deliver it to clinicians, and whether the information obtained from patients is present to clinicians with referral recommendations — all of which are features that limit the ability to draw conclusions from this literature. However, reason exists to question the value of solely implementing distress screening without also implementing referral recommendations for distressed patients. Evidence for this concern can be found in a study that compared a usual practice condition in which oncologists rated their patients' distress and decided whether referrals were indicated vs a screening condition in which oncologists received information about whether a patient's level of distress exceeded a cut-off, thus suggesting referral to psychosocial care. Findings showed that 5.5% of patients in distress receiving standard care and 69.1% of patients in distress in the screening condition received referrals; in addition, 3.7% of patients in distress receiving standard care compared with 27.6% of patients in distress in the screening condition accepted the referral.

Two projects illustrate larger multicenter efforts aimed at improving the psychosocial care of people with cancer. In 2007, the National Cancer Institute Community Cancer Centers Program (NCCCP) was initiated to enhance cancer research and the quality of cancer care in community hospitals. Influenced by IOM recommendations, the NCCCP working group developed a tool, the Cancer Psychosocial Care Matrix (CPCM), that defined 10 components of care comprising a comprehensive psychosocial care program. Within each component, the CPCM delineated measurable milestones designed to guide program development toward a site's full potential for delivering psychosocial care. Specifically, the site is asked to identify which performance level (≤ 5 levels) they are demonstrating to deliver quality psychosocial care. For example, the CPCM includes an item that allows sites to conduct a self-assessment of the extent to which processes are put in place for meeting the IOM report.
A critical milestone occurred in 2012 when the ACS CoC issued standards requiring the development and implementation of processes for psychosocial distress screening and referrals for psychosocial care. Adherence to these standards is being evaluated in 2015 as part of the ACS CoC accreditation, so considerable motivation exists for many oncology care sites to evaluate and, if needed, improve their processes in this area. In anticipation of this new standard taking effect, several major professional societies involved in psychosocial care have collaborated to issue recommendations that address the 6 components of the standard:

1. Overall plan for screening
2. Timing of screening
3. Method and mode of screening
4. Tools for screening
5. Assessment and referral
6. Documentation of screening and related actions in the medical record

These recommendations build on published clinical practice guidelines. Another important recommendation that came out of the IOM report stipulated that the organizations setting standards for cancer care should implement performance measures for psychosocial care as part of quality oversight activities. The Quality Oncology Practice Initiative of ASCO is one of the largest cancer-related quality monitoring systems in the United States.
with more than 900 registered practices. Spurred in part by the IOM report, the initiative adopted indicators of the quality of psychosocial care for its core module that are required of all participating practices.

Findings based on audits of the Quality Oncology Practice Initiative and the Florida Initiative for Quality Cancer Care suggest that providing feedback about the quality of psychosocial care can have a positive impact on rates of psychosocial screening. However, change is lacking for taking action in cases where problems in emotional well-being were identified; thus, this finding suggests feedback alone is insufficient for improving the delivery of psychosocial services. Possible explanations for such findings include lack of referral procedures for psychosocial care, lack of identified resources for providing psychosocial care, or both.

Oncology practices seeking to address these issues would benefit from knowing how other practices have responded to similar challenges. One source of information might be case studies describing how practices improved their provision of psychosocial care. An example of this type can be found in a publication that provided a description of how a regional cancer center developed counseling services to address the unmet psychosocial needs of its patients.

The IOM report also recommended that funding agencies support a large-scale demonstration and evaluation of how standards for psychosocial care can be implemented across diverse treatment settings. This recommendation was addressed as part of the federally funded NCCCP. Based on guidance provided by the IOM, participating sites implemented planning efforts that resulted in substantial improvements in psychosocial care delivery. Additional reports have provided more in-depth descriptions of efforts to implement distress screening and psychosocial referral and the acceptability and impact on processes of care in those efforts. Work in this area would also benefit from published findings from rigorously designed, quality improvement projects designed to document the processes used to improve psychosocial care and the outcomes achieved, including the impact on patient quality of life. Such studies should also consider relevant conceptual frameworks such as the PRECEDE-PROCEED model, which focuses on identifying and influencing predisposing, enabling, and reinforcing factors for implementing changes. Reports of this type have yet to appear in the literature and should be considered a high priority for future efforts to promote psychosocial care for patients with cancer.

Conclusions

Although considerable progress has been made in recent years in integrating psychosocial care into routine cancer care, much work remains to be done. Additional progress will be fostered by continued efforts to promote adherence to clinical practices guidelines and care standards for psychosocial services and through the development and dissemination of models demonstrating how practices can effectively implement these guidelines and standards.

References


