

Frances K. Barg, MEd
Mary Cooley, MSN, RN
Jeannie Pasacreta, RN, PhD
Beth Senay, BA
Ruth McCorkle, PhD

Development of a Self-Administered Psychosocial Cancer Screening Tool

Among patients with cancer, psychosocial issues and problems are common, yet they often go unnoticed and thus untreated until they become severe and significantly interfere with the patient's comfort, quality of life, and potentially survival. Given the increasing complexity of cancer care, psychosocial support must assume a more prominent role in the care of individuals with cancer. Routine use of a screening tool for psychosocial assessment may help facilitate early identification and intervention for individuals who are at risk for psychosocial problems. Based on the prevalence of psychosocial problems described in the literature and the paucity of psychosocial screening instruments that can be applied practically in the clinical setting, the development of a new instrument to identify patients with cancer who have psychosocial problems in multiple domains and who thus are at risk for excessive psychosocial distress throughout the course of treatment is presented. This article provides background information, reviews the literature on the instruments that have been used to screen patients in the oncology setting for psychosocial problems, and presents an instrument based on current deficiencies in this area. The testing of the instrument demonstrates its feasibility for use in the clinical setting.

KEY WORDS: cancer trajectory, psychosocial assessment, psychosocial needs, screening, unmet needs

The diagnosis of cancer and its subsequent treatment often create a major crisis for individuals that results in psychological and social problems. Healthcare professionals can play a key role in facilitating adaptation to this major life stressor. However, to implement appropriate interventions, identification of individuals at risk for psychosocial problems must be made early. Unfortunately, there is evidence that many individuals with cancer experience multiple unmet needs and as a result may experience prolonged distress that may go undetected.^{1,2} Several authors have suggested that the routine use of a screening tool for psychosocial assessment may help facilitate early identifica-

Frances K. Barg, MEd, Project Director, University of Pennsylvania, School of Nursing, Philadelphia, Pennsylvania.

Mary Cooley, MSN, RN, Clinical Nurse Specialist, Veterans Administration Medical Center, Philadelphia, Pennsylvania.

Jeannie Pasacreta, RN, PhD, Psychiatric Consultation-Liaison Nurse, University of Pennsylvania Medical Center, Philadelphia, Pennsylvania.

Beth Senay, BA, Undergraduate Nursing Student, University of Pennsylvania, School of Nursing, Philadelphia, Pennsylvania.

Ruth McCorkle, PhD, American Cancer Society Professor, University of Pennsylvania, School of Nursing, Philadelphia, Pennsylvania.

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Address for reprints: Frances K. Barg, MEd, University of Pennsylvania School of Nursing, 420 Guardian Drive, Philadelphia, PA 19104-6096.

tion and intervention for individuals who are at risk for psychosocial problems.³⁻⁵

Advances in psychosocial care have not paralleled advances in medical care, and psychosocial interventions often are viewed as a dispensable component of treatment. However, given the increasing complexity of cancer care, psychosocial support must assume a more prominent role in the care of individuals with cancer. Jellinek et al⁶ state that the general public has begun to demand that psychological care be a part of cancer treatment. Research is beginning to link psychosocial outcomes with treatment response and long-term survival,⁷ and similarly, untoward psychological states have been linked to diminished functioning and recovery in cancer populations.⁸ Given this information, healthcare providers must find better ways to incorporate routine screening for psychosocial problems into their practice. This article provides background information, reviews the literature regarding psychosocial assessment, and presents a review of instruments that have been used to screen patients with cancer for psychosocial problems. On the basis of current deficiencies in this area, the development of a new tool to screen patients who are at risk for excessive psychosocial problems is presented.

Background

Two surveys were commissioned by the Cancer Control Advisory Board of the Pennsylvania Department of Health. The first described unmet needs of persons with cancer during the first year after diagnosis and the other described unmet needs of persons with cancer during the terminal period. These surveys assessed the degree to which the psychological, social, and economic needs of persons with cancer and their support persons were being met by the existing service delivery system in Pennsylvania.^{1,2} Survey results revealed that 59% of patients with newly diagnosed cancer reported at least one unmet need, whereas 72% of persons who died of cancer in Pennsylvania experienced at least one unmet need during the last month of life. The most frequently cited unmet need in patients with newly diagnosed cancer was finding help in dealing with the emotional impact of cancer. Other unmet needs in this group ranged from unmet financial needs (14%) to unmet transportation needs (4%).

Although persons with terminal illness identified needing help with activities of daily living as the most common unmet need during the last month of life, dealing with the emotional impact of cancer also was identified frequently as an unmet need during this time. In addition, there were significantly more unmet needs during the terminal period than immediately after diagnosis. The unmet needs for the latter group of persons included obtaining health insurance, transportation, and problems with medical staff. Characteristics of persons with cancer who reported unmet needs in Pennsylvania included advanced stage of cancer at diagnosis, young age, low income, history of emotional problems before treatment, and the diagnosis of lung, breast, or uterine cancer. It is important to recognize that although emotional needs were among the most commonly reported

unmet needs, there were other psychosocial problems, such as transportation, insurance, financial, and home care needs, that occurred frequently. Thus, survey results suggest that a screening instrument should address a broad range of psychosocial problems.

The results of these surveys created a stimulus to improve the scope and use of existing support services for persons with cancer and their support persons in Pennsylvania. The University of Pennsylvania School of Nursing, School of Social Work, and Cancer Center participated along with three other contractors across the state in providing a 3-day continuing education program at multiple sites that enhanced the knowledge of healthcare providers in the area of psychosocial support services. The results of this program have been published previously.⁹⁻¹¹ Of particular note was that 44% of course participants ($n = 462$) indicated a need for a screening tool to identify patients who were at risk for psychosocial problems. This motivated project staff at the University of Pennsylvania School of Nursing to review psychosocial instruments that are available and recommend one instrument for general use by staff nurses or health professionals without specialty training (i.e., staff-level professionals) who work with patients with cancer. An additional outcome goal was to link the psychosocial assessment results to an existing computerized community resource data base so that recommended services could be identified by individuals at the community level. This activity was sponsored by the Pennsylvania Cancer Control Program in the Pennsylvania Department of Health under SPC 108550 and SPC 138716.

Review of Literature

Psychosocial screening in an oncology population allows professionals to determine which patients require intervention during and after the course of treatment for cancer. Weisman et al¹² state that psychosocial screening avoids the time-consuming and expensive process of treating all patients for psychosocial problems. Screening also addresses problems before they become severe, alleviating potential or prolonged suffering. Screening for psychological problems is seen as an essential part of comprehensive, multidisciplinary oncology care throughout the disease course. Multiple studies have been done in this area but indicate a wide range of prevalence rates for individuals experiencing clinically significant psychological distress.

In general the most common psychological symptoms reported in patients are anxiety and depression characteristic of a crisis response associated with diagnosis or other transitional points in the cancer trajectory. Holland¹³ points out that the most common times for psychological distress to appear are at pivotal points in the illness trajectory, such as cancer diagnosis, recurrence, loss of function related to disease, medical complications, withdrawal of treatment, death of another patient, and in the face of progressive disease. A pioneer study by Derogatis et al¹⁴ reported an overall prevalence rate for psychiatric disorders of 47% in a sample of 215 inpatients and outpatients with mixed cancer diagnoses across three institutions. This prevalence rate was

based on psychiatric interviews using criteria from the DSM-III system. The most common disturbances were reactive depression, anxiety, or both (32%). Thirteen percent of patients had more severe depressive symptoms constituting major depression; 8% had central nervous system complications characterized by organic mental disorders. Only 11% of patients had a pre-existing psychiatric disorder. The length of time that psychological symptoms last is not well known because a significant number of patients continue to experience prolonged psychological distress, even after the period surrounding diagnosis has passed.^{14,15}

Weisman and Worden have been pioneers in the area of psychosocial assessment and intervention among patients with cancer.^{16,17} The results of their research, known as Project Omega, provide a framework for understanding the plight of patients with newly diagnosed cancer. In their study, 163 patients with newly diagnosed cancer of the breast, lung, and colon; Hodgkin's disease; and malignant melanoma were evaluated by social workers using standardized interviews, psychological testing, and personality inventories. From this study major predictors of excessive psychological distress were identified as high anxiety, pessimistic attitude, marital problems, living alone, low socioeconomic status, alcohol abuse, infrequent church attendance, multiproblem family origin, psychiatric history, advanced stage of disease, more reported physical symptoms, low expectation of and receipt of help, perception of the physician as less helpful than expected, and a tendency to resignation. Seven areas of predominant concerns for patients with cancer emerged from this study, including health, self-appraisal, work and finances, family and significant others, religion, friends, and existential concerns.¹⁸

Other research has suggested the need for a routine screening tool to identify high-risk individuals. Bergman et al¹⁸ advocate developing an efficient, objective, and specific method of screening that can be applied by healthcare staff during the intake interview. Waligora-Serafin et al¹⁹ conducted a study that examined the relationship between the number and kinds of concerns of patients with newly diagnosed cancer and their level of mood disturbance. In addition, they compared the number and kinds of concerns that were identified by a standardized tool (inventory of current concerns) versus the number and kinds of concerns that patients report to healthcare providers. Forty-four outpatients with newly diagnosed cancer completed self-report forms that assessed their mood state and the types of psychosocial concerns that they experienced during their treatments. Measurements were conducted at the beginning of treatment and at 3 months and 6 months. The psychosocial concerns also were assessed by performing a chart audit. Results of the study indicated that in patients with newly diagnosed cancer, the level of mood disturbance was strongly associated with the overall level and number of concerns as identified by the standardized tool. However, the chart audit results focused almost exclusively on health concerns and did not reflect the other issues of concern that the outpatients with newly diagnosed cancer had experienced.

Similarly, Derogatis et al²⁰ conducted a study that evaluated the nature and degree of differences between individuals with cancer and their primary treatment physi-

cians in the perceptions of psychological symptoms. Twenty-three inpatients with cancer and their primary treatment physicians participated in this study. Results indicated a discrepancy in perception of psychological symptoms between patients and their physicians. The physicians tended to rate patients significantly higher on dimensions of anxiety and significantly lower on depression than the patients rated themselves. The results of both studies lend strong support for the need to identify a routine screening tool that could help identify, in an objective, systematic fashion, individuals with cancer who are at risk for psychosocial distress.

Various models have been used to address the meaning of psychosocial assessment. In an early discussion of the elements of a psychological assessment, Snyder and Wilson²¹ examined 10 dimensions that were recommended to be included in the assessment process. These were the patient's response to stress; interpersonal relationships; motivation and life style; thought processes and verbal behavior; nonverbal behavior; awareness and handling of feelings; support systems; talents and strengths; physical health; and an awareness of the interviewer's feelings about the interview. Christ²² also looked at potential sources of stress in her approach to psychosocial assessment of people with cancer. She recommended that social workers organize the assessment from an ecological framework, including five areas: the cancer treatment system, the presence or absence of psychopathology, the reactivation of underlying conflict during the diagnostic and treatment process, a reaction to a specific stress, and "dis-synchrony," which refers to "an unevenness at different points in time in specific cognitive appraisals or affective states of family members . . . patients and . . . the health care system."

In a discussion of the psychosocial evaluation of the hospice patient, Lusk²³ described the importance of basic demographic information, social history, physical resources, and psychosocial functioning. Adams-Greenly²⁴ stressed the importance of a link between assessment and appropriate, flexible, yet specific, interventions. She urged a multidimensional perspective in the assessment of pediatric patients with cancer and their families. This approach requires an evaluation of the stage of disease, socioeconomic vulnerability, degree of psychopathology and coping capacity, family cohesion and communication, and personal/family history. In a later article, Adams-Greenly²⁵ linked each of these areas of assessment to a range of interventions with children and their families.

Stam et al²⁶ defined five psychosocial problem categories: healthcare system concerns; personal concerns (denial, body image, adjustment reactions or mood disturbances); instrumental concerns (finances, transportation, equipment, housing); physical-somatic complaints; and family/significant other concerns (relationship issues, role difficulties, sexual dysfunction, bereavement issues, anticipatory grief).

Used here, the term "psychosocial problem" is defined as the self-report of distress or need in one or more areas of six psychosocial dimensions by the patient with cancer: demographic characteristics, psychological status, social situation, information needs, physical status, and patient concerns.

Review of Standardized Scales

Because there were a number of content areas recommended to be included in the screening process, a multidisciplinary panel of experts in psychosocial oncology met to review a variety of instruments and assessment procedures that were being used by health professionals in cancer care. A panel of experts in psychosocial oncology identified criteria that were deemed desirable in an oncology psychosocial assessment screening tool. Criteria include the following:

1. a cancer-specific instrument: that is, the instrument should be able to diagnose psychosocial risk factors that are inherent in the cancer experience;
2. an instrument that could be self-administered and subsequently interpreted by a staff nurse or health professional without specialty training (i.e., staff-level professionals);
3. an instrument that could identify people who are at risk for psychosocial problems and distress;
4. an instrument that is short and does not contribute to response burden;
5. an instrument that would be used to triage patients into an established referral system; and
6. an instrument that can identify problems in multiple dimensions.

In general, the primary purpose of the instrument will be to identify adults with cancer who are experiencing psychosocial problems and thus are at risk for excessive psychosocial distress during the course of the cancer trajectory. In addition, potential referral sources in the Commonwealth of Pennsylvania that may address patient problems can be identified by the tool.

Seven psychosocial assessment procedures or instruments used in oncology settings were identified: the Omega Screening Instrument (SI),²⁷ the Brief Symptom Inventory (BSI),²⁸ DSM-III R Classification System,²⁹ Parkes Bereavement Assessment,³⁰ Self Reporting Oncology Nursing Assessment,³¹ Cancer Rehabilitation Evaluation System (CARES),³²⁻³⁴ and the Medical Outcome Studies 36-Item Short Form Health Survey (MOS-SF-36).³⁵ (See Table 1 for summary of instruments). Although these instruments or clinical interview schedules are based on different measurement systems, and thus come from diverse conceptual orientations, they are used in clinical and research settings to ascertain who may need psychosocial services. Review of the instruments outlined in Table 1 reveals that most take a long time to complete, are not broad enough to screen patients for psychosocial problems in multiple dimensions, cannot be interpreted by staff-level professionals, and cannot be used for triage into an established referral system. Table 2 describes the presence or absence of these criteria in each of the tools identified. Because none of the instruments reviewed adequately met the established criteria for a cancer psychosocial screening tool, the panel of experts decided that a new screening tool was needed.

Procedure and Framework

A clinical screening tool involves deliberate collection of data to determine whether an individual requires additional assessment or intervention.²⁹ There are two major frameworks within measurement theory to guide the development of a screening tool. These frameworks are norm-referenced and criterion-referenced procedures. Norm-referenced measures are used to determine how an individual compares with other members of a particular group. A criterion-referenced framework is useful in measuring individual status in relation to a fixed standard.³⁶ This latter framework was selected for the development of our tool. Waltz et al³⁷ have identified a procedure for structuring the development of a criterion-referenced tool. This procedure includes:

1. specifying a conceptual model;
2. explicating objectives or domain definitions;
3. preparing test specifications;
4. constructing the measures;
5. setting standards for interpreting results;
6. administering the tool; and
7. assessing the reliability and validity of the tool.

The fulfillment of each of these phases is described here.

Specifying a Conceptual Model

The tool was designed to assess for the presence of multidimensional aspects of psychosocial problems to avert or identify psychosocial distress.

Explicating Domain Definitions

Psychosocial domains and content of individual items were established by a panel of clinical experts, including oncology clinical nurse specialists, psychiatric consultation liaison nurses, a medical oncologist, a psychiatrist, an oncology social worker, a psychometrician, and five postdoctoral research fellows in psychosocial oncology. Content was established by criterion-referenced clinical expertise. Each expert was asked to identify content areas essential to assessment when screening for psychosocial distress. Each expert's list was reviewed for common domains, and items were merged to develop the tool. Once final agreement was obtained among the experts, each professional was asked to review the final draft to determine its fit with problems associated with their discipline and to determine its overall ease of administration.

Preparing Test Specifications

Because our initial needs assessment indicated that the tool should be able to be administered and scored by a staff-level clinician before the development of psychosocial

Table 1. *Psychosocial Assessment Tools*

	<i>SI</i>	<i>BSI</i>	<i>DSM-III R</i>
Measured Characteristics	Predicts level of emotional distress that patients with newly diagnosed cancer may experience 2-6 mos after diagnosis	Measures 9 primary psychiatric (symptoms) dimensions; 3 scales measure overall distress, number of symptoms, and intensity of symptoms	Provides clear descriptions of diagnostic categories of mental disorders
Method of Administration	18-question structured interview	53-item self-report inventory	Clinical interview
Length of Time	1 hr	5-10 mins	N/A
Population	Adults with newly diagnosed breast, lung, colon, melanoma, Hodgkin's, gynecologic cancer	Adult psychiatric patients and adult patients with cancer	Psychiatric
Scoring Technique	Patient responses to 20 variables in the screening instrument are given a possible score of either 0 or 1; the sum of the scores is used to assess risk of emotional distress; possible score, 0-20; >7 is considered risk for distress	Each item is rated on a 5-point scale of distress (0-4): 0 = not at all; 4 = extremely	Clinician must determine presence or absence of specific clinical features and then use the criteria provided as guidelines to make the diagnosis.
Reliable	Yes	Yes	Purpose is to improve reliability of clinical judgments; criteria reflect consensus of current knowledge of mental disorders but do not encompass all conditions that may be legitimate objects of treatment
Valid	Yes	Yes	
Special Considerations	Must be used by a trained clinical interviewer	—	Must be used by individuals with special training

(Table continues)

crises, we determined that the instrument optimally should be given to patients at their first encounter. The cancer psychosocial assessment, intervention, and referral tool has been developed as a self-report scale. Individuals are instructed to read the directions and complete it. In each of the six dimensions, specific combinations of items are summarized to establish the patient's level of risk for psychosocial problems or potential for ongoing problems. A summary sheet is attached at the end of the form to help healthcare providers identify patients who may be at risk for psychosocial problems in relationship to their cancer diag-

nosis and treatment plan. Visually impaired patients or individuals who cannot read can have the items read to them.

Constructing the Items

Items were formulated and revised numerous times during a 10-month period. The experts judged six dimensions essential for the cancer psychosocial assessment, intervention, and referral tool. The dimensions and areas

Table 1. *Psychosocial Assessment Tools (continued)*

<i>Bereavement Risk Assessment</i>	<i>Self-Reporting Oncology Nursing Assessment</i>	<i>CARES</i>	<i>MOS-SF-36</i>
Identifies people at risk for distress and in need of help after the person's death	Uses Gordon's system of functional health problems: health maintenance, health perception, nutrition-metabolic, sleep-rest, cognitive-perceptual, self-concept, role-relationship, sexuality, coping-beliefs and values	Measures rehabilitation needs of patients; 1 overall score reflects impact of cancer on patient; 5 subscales measure physical, psychosocial, medical intervention, marital, and sexual needs	Health concepts, physical, social and role function, mental health, general health perception, bodily pain, and vitality
Healthcare provider fills out 8 questions assessing key factors predicting bereavement outcome	Patient completes form before clinical interview with nurse	Self-report questionnaire	Self-administration, telephone administration, or personal interview
—	30-45 mins	20-45 mins	5-10 mins
Hospice	Adults with cancer	Adults with cancer	>14 yrs of age
Each factor is given a numeric rank from 1-5; possible scores range from 8-40; anyone with a score of 18 or more is considered high risk	Nurse develops a list of nursing diagnoses after completion of interview	Computerized scoring; healthcare professional enters data into computer for printout	Likert method of summated ratings
Yes	N/A	Yes	In process of obtaining data
Yes	N/A	Yes	
—	Must be familiar with NANDA list of nursing diagnoses	Assist in identification of individuals who benefit from pain management, information, reassurance	Use in clinical practice, research, health policy evaluations, and general population survey

SI, screening instrument; BSI, Brief Symptom Inventory; CARES, Cancer Rehabilitation Evaluation System; MOS-SF-36; Medical Outcome Studies 36-Item Short Form Health Survey; N/A, not applicable; NANDA, North American Nursing Diagnosis Association.

reflecting their content are listed in Table 3. Sample questions include:

- In the last month, how often did you have problems with (appetite, nausea, sleep, pain, fatigue)?
- In the last month, how much distress did the following (appetite, nausea, sleep, pain, fatigue) cause you?
- Do you take any of the following (pain, nerve or anxiety medicine, sleep medication, depression medication)?

Would you like to talk to someone about your emotional concerns?

Setting Standards for Interpreting Results

Content experts indicated domains or combinations of domains within their clinical area of expertise that would

Table 2. Summary of Criteria to Evaluate Psychosocial Assessment Tools^a

Criteria	SI	BSI	DSM-III R	Bereavement	Nursing	CARES	MOS-SF-16
Identifies factors inherent in cancer	+	-	-	-	+	+	-
Administered and scored by staff level professional	-	+	-	+	+	+	+
Identify people at risk for distress	+	+	+	+	-	+	+
Short	-	+	N/A	+	+	-	+
Triage into referral system	-	-	N/A	-	-	-	-
Multidimensional	-	-	N/A	-	+	+	+

SI, screening instrument; BSI, Brief Symptom Inventory; CARES, Cancer Rehabilitation Evaluation System; MOS-SF-16, Medical Outcome Studies 36-Item Short Form Health Survey; N/A, not applicable.

^a +, present; -, absent.

indicate that an individual was at risk for psychosocial problems. Their clinical judgment was validated by a second group of experts and an extensive review of the literature. This decision-making and standard-setting process, as well as a description of the actual administration of the tool and an assessment of the reliability and validity of the measure, will be reported in a another article. In addition to summarizing the information obtained on the form, healthcare providers are given instructions regarding how to identify

the need for referrals and document the referral. Potential referrals include:

1. monitoring by a primary health provider (medical doctor or registered nurse);
2. education and teaching about diagnosis and treatment;
3. psychological or psychiatric evaluation;
4. individual or family counseling;
5. support group;
6. social services, insurance, financial, and substance abuse counseling;
7. physical or occupational counseling;
8. public health, home care and information about community agencies that can provide needed home assistance.

Table 3. Six Dimensions and Examples of Content for the Psychosocial Assessment Tool^a**Demographic Information**

Age
Employment status
Medical insurance
Marital status

Psychologic Status

History of emotional problems
History of hospitalization for emotional problems
The effect of cancer diagnosis on relationships
Presence of distress related to functional impairment
Outlook regarding successful treatment

Social Situation

Living alone
No one to discuss concerns with
Lack of immediate adult support
Help needed with functional problems

Informational Needs

Need for further information about support services

Physical Status

Presence of other medical conditions
Presence of symptoms related to cancer
Presence of symptom distress related to cancer
Problems with functional areas

Patient Concerns

Emotional concerns
Alcohol, drug concerns
Financial matters
Family concerns

Methods

Permission for the use of human subjects was obtained, and initial pilot testing on 20 subjects from the outpatient clinic at the University of Pennsylvania Comprehensive Cancer Center was conducted to determine readability, ease of administration, ease of scoring, and relationship to clinical observation. Individual items were reviewed and changes were made: several items were reworded, the sequencing of items was changed, and items were eliminated because of redundancy. The next draft was distributed by an oncology clinical nurse specialist to 200 consecutive outpatients during the first week of December 1992. All 200 forms were completed as part of the clinic visit. Returned forms were scored daily and reviewed by project staff; appropriate referrals were made.

The final form, currently in use, contains 47 items. After the patient completes the form, data are summarized and categorized into several relevant dimensions, including demographic information; psychological status; social situation; informational needs; physical status; and concerns (Table 3). Based on the patient's association with high-risk items in each dimension, problem-specific referrals are offered.

Preliminary use of the tool reveals that it is able to detect current psychosocial problems and excessive psycho-

^a Copies of the tool are available upon request.

logical distress in outpatients with cancer and screen for potential problems. Although analysis of data from initial testing of the instrument is beyond the scope of this article, a few words regarding feasibility for use in the clinical setting are in order. Patient reactions to completing the form have been uniformly positive. No patient indicated that the assessment form was too long, too difficult to read, or too intrusive. The average length of time that patients took to complete the questionnaire was 15 minutes. The reading level of the tool was assessed to be at the 8th grade, according to the Gunning Fox Index, which is used to evaluate readability. Although the high literacy of the pilot group served to avoid problems with readability, the questionnaire can be read aloud to low-literacy groups without changing the nature of the information. No patient has reported any increase in distress as a result of completing this tool, and most reacted quite positively to someone being interested in asking about their psychosocial well-being.

Summary and Future Directions

The increasing complexity of cancer care has created an urgent need to incorporate adequate psychosocial support into clinical practice. Studies have indicated that individuals with cancer experience multiple unmet needs and as a result undergo undetected psychosocial problems and distress. As consumers of healthcare demand that psychosocial support be a routine part of their treatment, healthcare providers must meet this challenge. This article has suggested the routine use of a screening tool to detect psychosocial distress. Current instruments used for psychosocial screening were reviewed and found to be incomplete for routine screening in clinical practice. The development of a new tool that can be used for this purpose has been presented. The major strengths of the proposed screening tool for psychosocial problems are: it is time efficient and can be completed by patients while they are waiting for appointments; it contains psychosocial aspects inherent in the cancer experience; it is multidimensional in focus in that it screens for the psychological, social, physical, and financial impact of cancer; it can be interpreted by a staff-level professional; and it is designed to offer problem-specific referrals.

Continued testing and refinement of the psychosocial screening instrument is under way, and psychometric properties will be reported in another article. A standardized scoring procedure will foster additional testing and refinement of the instrument, including comparisons with healthy control subject and patient groups, reliability testing, and association with and, ultimately, prediction of selected treatment outcomes.

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