Expanding the NCCN guidelines for distress management: a model of barriers to the use of coping resources

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Cancer-related distress impacts quality of care, resource use, and patient outcomes. Patients are increasingly screened for distress, yet many do not receive coping resources and psychosocial support services that may help to reduce their distress. Distress screening must be paired with attention to the different phases of the distress and coping process, with emphasis on barriers and facilitators of cancer patients' use of coping resources. This paper offers a conceptual model illustrating key pathways and modifying factors of distress and use of coping resources among cancer patients, and potential roles for cancer care providers and institutions in facilitating effective coping and distress reduction. Building on a review of relevant empirical and theoretical literature, we developed a conceptual model that integrates concepts from Stress and Coping Theory into the National Comprehensive Cancer Network's guidelines for Distress Management. We found that barriers and facilitating factors that may inhibit receipt of coping resources and services to reduce cancer-related distress include health and cancer beliefs, accessibility and acceptability, the role of caregivers in cancer treatment, coordination of care, and the quality of patient-provider relationships. Herein, we highlight largely modifiable factors that can influence the successful uptake of coping resources and services to reduce distress among cancer care providers and systems can better identify and address barriers to the use of distress reduction resources and support services.

istress among cancer patients is increasingly being referred to as a sixth vital sign that requires regular monitoring along with a patient's pulse, respiration, blood pressure, temperature, and pain level.^{1,2}The National Comprehensive Cancer Network (NCCN) has defined cancerrelated distress as "a psychological, social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment."3 Pooled data suggest that about 40% of cancer patients are distressed.⁴ In August 2012, the American College of Surgeons released new cancer hospital accreditation standards requiring that all patients be screened for distress.⁵ The NCCN developed clinical guidelines for distress management³ to help providers and health care systems accurately and routinely identify and treat patients who are experiencing distress. The increased attention to distress management is consistent with a broader trend in oncology toward more comprehensive, patient-centered care.

Now that efforts to implement distress screening are underway in cancer care institutions across the

United States and internationally, it is essential to engage in a parallel process to ensure that patients who have been identified as distressed have access to and receive the coping resources and psychosocial support services they need. Findings from several studies suggest that the process of distress screening alone may play a role in reducing distress, although outcomes have been mixed.⁴ Distress screening can provide a forum for patients and their caregivers to discuss concerns and it offers providers insight into the challenges patients are facing.

Given the diverse array of practical, social, emotional, and physical challenges that can amplify cancer patients' distress, however, many sources of patient distress are outside the purview of patients' primary cancer care providers. One of the most frequently recommended strategies for addressing stressors outside the domain of the primary cancer care team, consistent with the NCCN guidelines for distress management,³ is to connect patients to coping resources and psychosocial support services within their institution or in the community.⁴ These resources and services can include psy-

Accepted for publication January 28, 2014. Correspondence: Arden M Morris, MD, MPH; ammsurg@umich.edu. Disclosures: This research was supported in part by the National Institutes of Health through the University of Michigan's Cancer Center Support Grant (P30 CA046592). JCSO 2014;12:271-277. ©2014 Frontline Medical Communications. DOI 10.12788/jcso.0064

chological counseling, support groups, pain management, complementary and alternative medicine, patient education and support agencies, sexual health therapy, physical therapy, nutrition counseling, spiritual support, transportation assistance, financial counseling, and meditation classes. The strategy of relying heavily on referring patients to coping resources and psychosocial support services to reduce distress is reasonable and practical given the structure and organization of the US health care system. However, a major limitation of this approach is that the rate of patients who are interested in using the recommended resources and who can access the resources is low. Only a third of distressed patients in most studies get the resources and services to which they are referred.⁶⁻¹¹ Little is known of the barriers that inhibit cancer patients' receipt of potentially beneficial coping resources and psychosocial support services and what cancer care providers and institutions can do to remediate these barriers.

The purpose of this paper is to use stress and coping theory¹²⁻¹⁵ to highlight factors that can affect patients' decisions and ability to access coping resources and psychosocial support services to reduce their distress. We offer a conceptual model illustrating key pathways and modifying factors of distress and use of coping resources in cancer patients. Our model also indicates the roles cancer care providers and institutions can play in supporting effective patient coping. We conclude with suggestions for how cancer care institutions and providers can better identify and address barriers to the use of distress reduction resources and support services.

Distress management guidelines

The NCCN guidelines for distress management³ (Figure 1) suggest screening for distress by using the single-item Distress Thermometer. The screening tool requires patients to quantify their distress on an analog scale and has been validated among diverse patient samples.^{4,11,16,17} The NCCN recommends pairing use of the Distress Thermometer with use of the Problem List, which is a brief tool for identifying unmet patient needs. The 38-item, self-report Problem List is structured around the question stem, *Please indicate if any of the following has been a problem for you in the past week including today*, and covers the following domains: practical (5 items), family (4), emotional (6), spiritual (1), and physical (21).

As per the NCCN guidelines, the oncology team should manage modifiable physical symptoms and mild distress. Patients with moderate and severe psychosocial distress should be referred to mental health professionals, social workers, or spiritual advisors. NCCN guidelines delineate recommended referral types and courses of evaluation, treatment, and follow-up. To date, the thrust of cancer distress research has been to document the prevalence of distress and distress screening tools, standardization, and institutionalization. These issues are critical; yet, our understanding of how to help distressed patients, especially regarding the uptake and effectiveness of referrals, is limited.^{4,18,19}

A patient-centered model of distress and use of coping resources

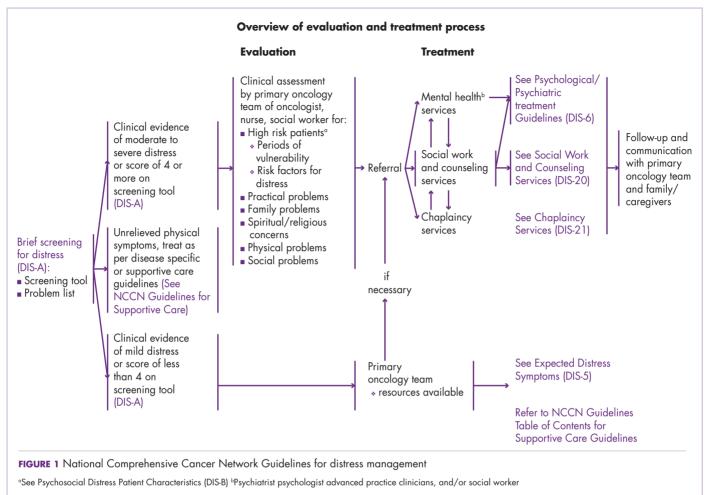
We propose a conceptual model (Figure 2) that illustrates the parallel experiences of patients and health care providers and systems in identifying distress and stressors, engaging in coping processes, and influencing distress outcomes. The model builds on the NCCN's guidelines for distress management to incorporate stress and coping theory. In this way, we emphasize critical factors that may determine whether patients choose to use and are able to access coping resources and psychosocial support services to reduce their distress and the potential roles for health care providers and institutions in reducing barriers and enhancing facilitating factors.

According to stress and coping theory,12-15 when patients are faced with a potential stressor, they engage in a conscious or unconscious two-stage cognitive process of appraisal to decide what coping efforts to use. Distress is generated, maintained, and altered by specific patterns of appraisal and coping efforts based on internal and external factors. Primary appraisal¹⁴ refers to patients' assessment of the likelihood that a problem will cause them distress, including judgment about perceived susceptibility and severity of a potential stressor. Secondary appraisal¹⁴ is the process in which individuals evaluate their capacity to effectively cope with stressors. Patients consider available external coping resources, their own capacity to regulate their emotional response (internal coping resources), and whether coping efforts are likely to be effective. Given the diversity of stressors related to cancer, many patients need psychosocial intervention or other external coping resources to reduce their distress. Some external resources may also bolster patients' internal capacity to cope with stressors.

Barriers and facilitators to using resources and services

The literature shows that factors affecting cancer care delivery include a patient's beliefs about health and cancer, accessibility to and acceptability of care, the role of caregivers in cancer treatment, coordination of care, and the quality of patient-provider relationships. Although research identifying mediators between coping resources and their use is limited, it is plausible that the same types of barriers and facilitators are at work.

Patients' health and cancer beliefs are known to affect their decision making, treatment adherence, psychological distress, and clinical outcomes.^{20,21} Personal and cultural



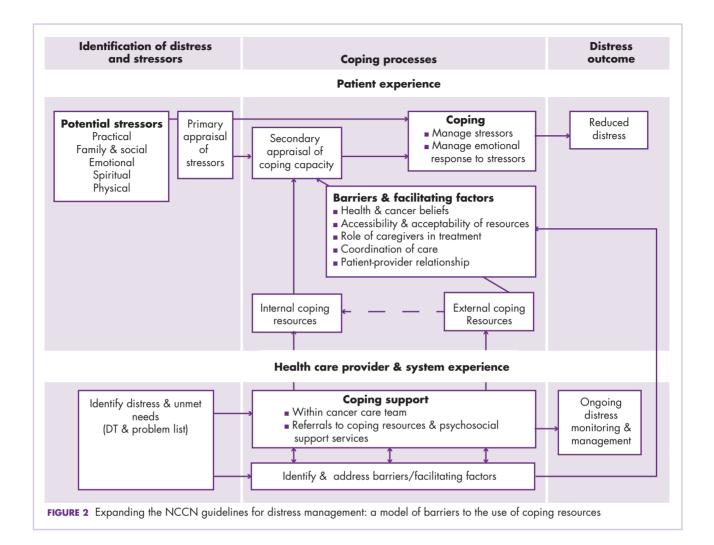
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beliefs can influence whether patients identify a need for help and the types of coping resources and services they desire. For example, coping resources and recommendations driven by medical models of health may not appeal to or engage patients whose culturally derived beliefs about cancer differ from those of the dominant culture. Patients who are exposed to services that are not salient to their concerns and priorities may avoid using coping resources in the future.¹⁰

Accessibility to and acceptability of coping resources are often cited as reasons patients do not take advantage of referrals.^{22,23} Lack of health insurance, underinsurance, and the bureaucracy involved in getting insurance coverage for services, especially mental health services, can be burdensome. Some services and resources may be prohibitively expensive out-of-pocket or may be difficult to access because of inconvenient hours, a patient's lack of child care or transportation, or language barriers.²² Finally, some coping resources and psychosocial services may be considered culturally unacceptable because of discomfort with help seeking, privacy concerns, stigma, conflicting values, or pessimism about the effectiveness of the suggested service.^{10,24}

The role of caregivers as legitimate stakeholders in cancer treatment is increasingly recognized as a critical component of successful recovery.²⁵ Patients often rely heavily on caregivers for emotional support, health care advocacy, adherence to provider recommendations, instrumental support for treatment, and attending to other needs when patients may be incapable of independently meeting those needs. Engaging caregivers in patient care can improve patients' capacity to access coping resources and psychosocial support services. Psychosocial interventions may also be more effective when they involve both patients and caregivers.²⁶

Coordination of care can also influence the likelihood that patients are able to access and use resources and services to cope with stressors and reduce distress. Living



with cancer and cancer treatment often involves a range of health care providers. Coordination of psychosocial distress screening, management, and follow-up between cancer care providers has been poorly developed.²⁷ Even relatively integrated cancer treatment teams often lack clarity about whose responsibility it is to monitor, address, and facilitate access to coping resources and support services.

The patient–provider relationship can facilitate or inhibit patient access to and use of coping resources and psychosocial support services. Chaitchik and colleagues²⁸ showed that physicians tended to underestimate how much information their patients wanted and overestimate their own informativeness, while often not providing the type of information most relevant to their patients' concerns. Good communication ensures that cancer treatment providers are better informed about and able to be responsive to their patients' needs and preferences.

Discussion

Distress is a harmful dimension of stress that can lead to

negative physical and emotional health outcomes.²⁹ In cancer patients, distress results when patients possess insufficient internal and external coping resources to mediate the accumulation of stressors derived from the disease, treatment side effects, lifestyle changes, and other factors that are directly and indirectly related to living with cancer. Increased distress has been associated with poorer treatment adherence,^{30,31} rates of surveillance screening,³² adoption of cancer recurrence prevention behaviors,³³ patient–provider communication,³⁴ and satisfaction with medical care.^{35,36} Distressed cancer patients have longer inpatient stays³⁷ and higher overall health care costs.³⁸ Distress may also contribute to poorer quality of life^{36,39} and reduced survival.⁴⁰⁻⁴²

The identification and management of distress have become priorities in cancer care because of an increased awareness of the prevalence and deleterious impact of distress on health outcomes, a report by the Institute of Medicine that detailed shortcomings in the provision of psychosocial services,¹⁹ new accreditation requirements, and a move toward patient-centered models of care. Although there may be some benefit of distress screening alone in reducing cancer patient distress,⁴ many patients could benefit from the wealth of coping resources and psychosocial support services available, many of which are currently underused.⁷⁻⁹ This is especially true for the most distressed patients and those whose sources of distress are outside of the expertise of the primary cancer care team. Some patients may prefer no intervention, but it is critical that cancer care providers understand what factors influence whether patients become linked to these services if patients desire intervention.

Recommendations

We propose that distress screening efforts must be paired with attention to the phases of the distress and coping process, with emphasis on the barriers and facilitators of cancer patients' use of coping resources and psychosocial support services. Our conceptual model uses concepts from stress and coping theory¹²⁻¹⁵ to highlight how largely modifiable factors can influence the cognitive processes of appraisal, through which cancer patients determine how they will cope with distress including resources they may be able to use to enhance their efforts. We illustrate the parallel experiences of patients and health care providers and systems to suggest where providers can intervene to provide coping support. Evidence-based recommendations must be developed to direct and support cancer care providers and health systems in reducing barriers to patient receipt of coping resources and identifying the resources patients are most likely to accept. By attending to these factors, distress reduction interventions can increase the likelihood that patients actually receive the help they need.

Although research is limited on the barriers cancer patients face in using coping resources and psychosocial support services and associated interventions, several strategies could improve the identification and mediation of the barriers to using coping resources. Many of these are consistent with or slight variations on existing trends in the field of distress management, health care reform, and efforts to move toward a patient-centered medical model.

The parallel process of institutionalizing distress screening is a key to improving linkages between distressed patients and resources and services to help them cope with distress. Of particular importance is the repeated screening of patients to help health care providers and systems monitor changes in the magnitude of distress and unmet needs reported by cancer patients over time and over phases of disease and treatment. When practices and policies are put in place to facilitate the reduction of distress, including interventions to address the barriers and facilitators discussed above, repeated screening data can be used for evaluative purposes. One particular system that could facilitate the institutionalization of distress screening is electronic medical records. Requiring providers to enter distress data (eg, as part of vitals), easily accessible and prominent places for distress data in the record, and ways of tracking distress over time can reinforce the importance of distress among providers, facilitate coordination of distress management, and bring attention to patients whose distress is not being reduced and who require further attention.

Institutional feedback mechanisms can also play a role in efforts to more effectively reduce cancer patient distress by increasing linkages between distressed patients and coping resources and psychosocial support services. Feedback mechanisms can give providers and institutions insight about how consistently distress screening is being implemented, aspects of distress management efforts are that successful and those warranting additional attention, referral patterns, and whether patients receive the resources and services they are referred to. They can also identify units whose efforts may be particularly effective at connecting their patients to needed services, and whose strategies could be studied and replicated elsewhere.

Coordination and centralization of the response to patients with identified distress can also pool the resources and expertise within a cancer treatment institution or collection of community cancer care providers. It is challenging for any one provider or unit to be aware of the diversity of coping resources and psychosocial support services available within a community, especially given the proliferation of resources available online. Coordination of care by a centralized entity whose mission it is to learn about and identify coping resources for distressed cancer patients could contribute to development of a systematic process for referring patients to support services, following up to see if patients get access these services, troubling-shooting barriers, and evaluating the impact of different services and revising their referral procedures accordingly. In addition, specific people or positions must be held accountable for following up with patients who have been identified as distressed. In many cases, physicians within the primary cancer treatment team lack the time, communication and interpersonal skills, and familiarity with coping resources to be ideally situated to fulfill this role. Given the training in both psychological and logistical support, social workers may be particularly suited and institutionally situated to address complex barriers with patients, to develop individualized distress management plans, and to facilitate communication among key players - cancer care providers, psychosocial support services, patients, and caregivers - so that they can collectively work to alleviate patient distress.⁴³

Appraisal and coping cognitions and processes have been shown to be predictive of distress and related mental health constructs in cancer patients.⁴⁴⁻⁴⁷ More research is needed on how to apply research and assessment tools on these topics into distress management in cancer patients. For example, additional screening measures could be adopted to assess patients' appraisal processes (eg, Cognitive Appraisal of Health scale,⁴⁸ Stress Appraisal Measure⁴⁹) and coping dispositional style (eg, Coping Inventory for Stressful Situations,⁵⁰ Brief COPE⁵¹). The insight provided by these measures can be paired with worksheets and activities to help patients, caregivers, and providers develop distress management plans that identify and build on individual patients' appraisal and coping styles and resources, while acknowledging and addressing barriers. Appraisal and coping styles must be measured and explicitly incorporated into interventions for these concepts to be effective at reducing barriers to the use of coping resources and, ultimately, at reducing distress.⁵²

In addition, protocols and assessment instruments to further understand other aspects of distress and its sources in cancer patients who report high levels of distress could more effectively match patients with the coping resources and services they need. The Distress Thermometer and Problem List are brief screening tools intended to be paired with more comprehensive assessments after distressed patients have been identified. Given the contributory role of depression and anxiety in distress, it may be helpful to screen all patients who have been identified as distressed for depressive and anxious symptomology. Other tools exist for assessing other Problem List items in greater depth and may provide additional insight into the types of resources or services that may be best suited for the needs of individual patients.

Providers can help reduce cancer patients' distress by cultivating trusting patient-provider relationships characterized by effective, two-way communication. Ongoing distress screenings are opportunities for providers to nurture patient relationships, improve communication, and demonstrate their interest in patients' quality of life.53-56 This focus is particularly warranted, as a good patient-provider relationship can facilitate successful linkages between patients and coping resources and psychosocial support services. Health care providers should engage their patients in open and transparent discussions about patients' interest and capacity to use recommended coping resources and services. Cancer care providers can further help patients to negotiate institutional and structural barriers to accessing coping resources by collaborating with units and providers that focus distress management (eg, social workers) and wielding their influence, connections, and knowledge in the health care arena.

In conclusion, distress is a common and serious comorbidity among cancer patients and warrants the attention it has drawn from accrediting bodies. Given the diversity of stressors and patient characteristics, referring patients to resources for coping and psychosocial support is a logical strategy, yet low rates of patient receipt of these resources inhibit this approach from being more efficacious. We recommend building on the NCCN guidelines to emphasize barriers and facilitating factors that influence whether patients are interested and able to access recommended coping resources. Though eliminating the barriers identified in our model requires social and structural changes, first steps include cultivation of good patient-provider relationships and implementing systems for monitoring the fidelity and supporting the effectiveness of distress screening and management protocols.

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