

Caring for the Whole Patient: The Science of Psychosocial Care

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This *Journal of Clinical Oncology* Special Series relates to the science of psychosocial care. This series is designed to provide oncology professionals with the most recent information about the psychological, psychiatric, and social aspects of cancer care. The emergence of the field of psychosocial care reflects growing public and professional awareness of the potential for cancer and its treatment to have profound effects on many aspects of life. A principal goal of psychosocial care is to recognize and address the effects that cancer and its treatment have on the mental status and emotional well-being of patients, their family members, and their professional caregivers. In addition to improving emotional well-being and mental health,¹ provision of psychosocial care has been shown to yield better management of common disease-related symptoms and adverse effects of treatment, such as pain² and fatigue.³

Given the centrality of psychosocial issues in cancer, it is surprising that the formal history of this field in the United States dates only to the 1970s.⁴ This relatively late development becomes more understandable when one realizes that only then had the stigma attached to cancer diminished to the extent that most patients were told their diagnosis, thus making it possible to openly study psychosocial issues.⁴ A second factor contributing to the field's late development is the stigma attached to mental illness and psychological problems, even in the context of medical illness.⁴ During the last 40 years, a subspecialty devoted to cancer-related psychosocial care (ie, psycho-oncology) has become firmly established, with its own journals, scientific meetings, and professional societies.

Psychosocial care in oncology received increased attention after the publication in 2008 of an Institute of Medicine (IOM) report entitled, "Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs."⁵ This report reflects the work of a multidisciplinary panel that sought to evaluate how best to translate research findings about psychosocial care into practical applications for the purpose of improving the quality of cancer care. The panel found evidence for the effectiveness of an array of formal psychosocial services including counseling and psychotherapy, pharmacologic management of mental symptoms, illness self-management and self-care programs, family and caregiver education, and health promotion interventions. The panel also found that, despite this evidence, many individuals who could benefit from these services do not receive them.

The editors of this *JCO* Special Series on psychosocial care have chosen a number of topics that illustrate recent advances in this im-

portant area. The remainder of this overview will place these topics into clinical context, and the reader is encouraged to refer to the individual articles contained in this Special Series for additional details.

Jacobsen and Wagner⁶ describe three important developments in recent years that have the potential to greatly increase the numbers of patients who receive needed psychosocial care. One development has been the formulation of standards of cancer care by the IOM panel and a number of professional organizations and accrediting bodies that include the psychosocial component of care.⁷⁻⁹ A second development has been the issuance of clinical practice guidelines by the National Comprehensive Cancer Network (NCCN) and other organizations that include specific recommendations for the psychosocial care of patients with cancer.¹⁰⁻¹² A third development has been the formulation and implementation of measurable indicators of the quality of psychosocial care in oncology settings, including those used as part of the American Society of Clinical Oncology's Quality Oncology Practice Initiative.¹³

NCCN was among the first organizations to propose guidelines related to psychosocial care. These guidelines, first issued in 1999, focus on the recognition and management of distress in patients with cancer.¹² As noted by Carlson et al,¹⁴ the rationale for focusing on distress, even though it is not a precise clinical term, is that it is easily understood by the lay person and does not carry the stigma that is often associated with more formal psychiatric terminology. The authors identify a number of brief self-report measures of distress and unmet needs that can be used in combination to identify distressed patients as well as possible sources of distress in these patients that can be targeted for intervention.¹⁴ Although NCCN guidelines recommend routine screening for distress,¹² there has been limited research that evaluates whether implementation of distress screening programs leads to better outcomes. Evidence to date suggests that screening can improve communication between patients and clinicians and increase psychosocial referrals but is inconclusive with respect to the effects on quality of life and other patient-reported outcomes.¹⁴

Fann et al¹⁵ describe a different approach to the delivery of integrated psychosocial care that is based on the collaborative care model of depression that is found to be effective in primary care settings.¹⁶ Key elements of this approach include implementation of depression screening to identify patients with depression, use of evidence-based protocols for treatment of depression, structured collaborations between primary medical providers and mental health

specialists, and active monitoring of adherence to depression treatment and outcomes.¹⁷ Several randomized trials have now demonstrated that this approach is both feasible and effective for treating depression in patients with cancer.^{18,19} Building on this evidence, the authors identify several ways in which the collaborative care model could be adapted to address other important psychosocial issues in oncology settings, such as health promotion.¹⁵

The availability of a sound evidence base is central to efforts to develop integrated models of psychosocial care delivery. As reviewed by Li et al,²⁰ research on the pharmacologic management of depression in patients with cancer is limited; consequently, treatment guidelines must be derived in part from research in psychiatric and nononcology medical populations. Investigators have conducted considerably more research on the use of psychosocial interventions in the management of depression in patients with cancer. Taken together, findings in this area suggest that a multicomponent approach is likely to be most effective, with psychosocial interventions being tailored to the severity of depression and the stage of disease, and combined with pharmacotherapy for more severe forms of depression.²⁰ The review by Traeger et al²¹ yields similar conclusions with respect to the management of anxiety in patients with cancer. Delirium is another example of a psychosocial issue for which an integrated care delivery model requires a sound research base. As reviewed by Breitbart and Alici,²² there have been an increasing number of delirium treatment studies as well as prevention studies published in recent years. The evidence most clearly supports the short-term, low-dose use of antipsychotic medications for control of delirium symptoms.²² There is also evidence for the benefits of assessing and modifying key clinical factors that can precipitate delirium (eg, pain, sleep disturbance, and poor nutrition).²²

Stimulated in part by a 2006 IOM report that identified important gaps in the care of cancer survivors,²³ the period after the completion of cancer treatment is now a major focus of psychosocial care. This development is consistent with the IOM report's view that the essential components of survivorship care include intervention for the consequences of cancer treatment.²³ Among the longer-term consequences of cancer diagnosis and treatment that were identified in the IOM report are several that can be addressed through psychosocial care (eg, emotional distress, sexual dysfunction, and employment and insurance concerns).²³ Stanton²⁴ highlights the importance of providing psychosocial care during the re-entry phase of cancer survivorship—that is, in the several months immediately after treatment completion. Patients' psychosocial concerns are likely to be heightened during this period because of perceptions that they have lost the safety net of active treatment and because of challenges faced in resuming or altering former occupational and social roles.²⁴

Adolescents and young adults experience a separate set of challenges as a result of the disruptive impact that cancer and its treatment can have on normal developmental transitions in this age group. Zebrack and Isaacson²⁵ identify several ways in which psychosocial care during and after cancer treatment needs to be tailored to the unique needs of the adolescent and young adult population.

As noted previously, the scope of psychosocial care extends beyond the patient to encompass family members and professional caregivers. Among family members, addressing the psychosocial needs of those who participate in the patient's care is particularly important. With cancer treatment moving increasingly into the out-

patient setting, family members are being asked to take on greater responsibilities for patient care. Northouse et al²⁶ review evidence that indicates that the stress of caregiving can have a strong negative impact on the health and well-being of the family caregiver. These reactions, in turn, can have a negative impact on the caregiver's ability to provide needed care and on the ill family member's health and well-being. Conversely, psychosocial intervention research indicates that when the caregiver/patient dyad is treated as the unit of care, important synergies are achieved that contribute to the well-being of both.²⁶ The current challenge, as outlined by the authors, is to incorporate this intervention approach into routine clinical practice. Among the barriers that need to be addressed are the lack of professional awareness of caregivers' needs, the lack of professional training in how to intervene with caregivers, and concerns that caregiver interventions are too costly to implement.²⁶

Caring for patients with cancer can also exact a psychological toll on oncologists. One of the most common manifestations of distress in professional caregivers is burnout, a syndrome that is characterized by a loss of enthusiasm for work, cynicism, and a low sense of personal accomplishment.²⁷ Shanafelt and Dyrbye²⁸ cite evidence that suggests that 25% to 38% of oncologists are experiencing burnout at any given point in time. Among the many possible causes of burnout, high workload, inefficiency, loss of autonomy, and lack of meaning in work are central factors.²⁸ Additional factors that are relevant to the practice of oncology include being faced with making life and death decisions on a frequent basis, administering highly toxic therapies with narrow therapeutic windows, having limited ability to prolong life in many patients, and needing to keep up with the rapid pace of scientific and treatment advances.^{29,30} Systematic research into ways to prevent burnout among physicians is still in an early stage of development. Preliminary evidence suggests that a mix of organizational strategies that address workplace issues and personal strategies that promote wellness and enhance the meaning derived from professional activities merit additional evaluation.

Receiving training in communication skills may be another means for oncologists to improve their professional lives. Beyond its potential role in reducing work-related stress, communicating well with patients has been linked to greater satisfaction and reduced anxiety among patients, better patient health outcomes, and fewer malpractice claims.³¹ Kissane et al³² review evidence that demonstrates that providing oncology clinicians with formal training in skills for communicating with patients has a strong positive impact on their communication behaviors. On the basis of the evidence, they argue that communication skills training should be a standard part of oncology training programs, and they outline a core curriculum that cover topics such as how to discuss prognosis at each illness phase and how to promote shared decision making in the selection of anticancer treatments.

The 11 articles in this Special Series demonstrate the depth and breadth of the science that underlies the psychosocial care of people who are affected by cancer. Although important gaps in research still exist, work in this area has evolved to the extent that evidence-based recommendations can be formulated for many frequently encountered psychosocial issues. A common theme in many of the articles, however, is the continuing need to translate research findings into clinical practice, given that psychosocial care still does not reach many who could benefit from it. The growing trend for psychosocial care to

be included in standards for quality cancer care represents an important step toward its greater availability and routine use. Our hope is that this Special Series will also contribute to this goal by promoting greater knowledge and understanding of psychosocial care among oncology professionals.

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