



Jimmie C. Holland, MD

Jimmie C. Holland, MD, recognized internationally as the founder of the subspecialty of psycho-oncology, is Attending Psychiatrist and holds the first endowed chair in Psychiatric Oncology, the Wayne E. Chapman Chair at Memorial Sloan Kettering Cancer Center. She is Professor of Psychiatry at Weill Medical College of Cornell University. She began the first full-time Psychiatric Service in a cancer hospital in 1977 at Memorial Sloan Kettering Cancer Center, and in 1996 she became the first woman Chair of a clinical department at Memorial. Dr. Holland was PI of the first research training grant in psycho-oncology which has continued uninterrupted for 34 years.

Dr. Holland established the first committee studying psychological and quality of life issues in a cooperative group, the Cancer Leukemia Group B. In the 1980s she became the Founding President of the International Psycho-oncology Society (1984) and of the American Psychosocial Oncology Society (1986). She has been senior editor of multiple textbooks, and in 1992, she started the first international journal in the field, *Psycho-Oncology*, and continues as co-editor. Dr. Holland has chaired the NCCN Panel on Management of Distress since its beginning in 1997. She was elected to the Institute of Medicine in 1995 and served on the panel that established a new standard of quality cancer care which demands that the psychosocial domain be integrated into routine cancer care. Dr. Holland has received numerous awards from the ACS, ASCO, AACR, and other national and international associations.

Was There a Patient in Your Clinic Today Who Was Distressed?

Jimmie C. Holland, MD; Mark Lazenby, PhD, APRN; and Matthew J. Loscalzo, LCSW

Most who work in an outpatient clinic or office would likely answer yes to the question asked in the title of this commentary. Data from as long ago as the 1970s confirm that, indeed, approximately one-third of patients with cancer experience significant distress, primarily anxiety or depression.¹ A landmark study in 1976 noted the value of identifying distress early in patients, during the first 100 days after a cancer diagnosis, when patients are very vulnerable.¹ In this study, researchers screened patients for distress and provided psychosocial counseling, which significantly reduced distress levels. Patients were then better able to cope with the subsequent hassles associated with their illness and treatment.

However, we clinicians can be slow learners. NCCN led the way in addressing this issue, 20 years ago, by suggesting that routine screening for distress in newly diagnosed patients would improve overall care. Then, in 1997, the first NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) for the management of distress in patients with cancer were formulated by a multidisciplinary panel.^{2,3} The panel noted that oncologists were reluctant to ask patients about psychological and psychiatric problems—and patients were equally reluctant to answer—because of the stigma associated with psychological issues. The panel said, “Find a better word that, one is not stigmatized, to use with patients when asking about psychological problems.”

The word “distress” was chosen and, using a principle successful in pain management, the panel recommended asking patients, “How is your distress level on a scale of 0 to 10?” Distress is normal among people with cancer, and patients have come to accept the term. This simple question has provided a way to “red flag” patients who are distressed beyond the expected. Someone on the cancer care team can then further query patients with distress as to the nature of the problem and, when necessary, formulate an appropriate psychosocial treatment plan, which may include a referral for mental health services, either in the hospital or in the community.

The Institute of Medicine (IOM) built on these first distress management guidelines, finding a strong evidence base for a wide range of psychosocial interventions (psychotherapeutic, behavioral, and psychopharmacologic).⁴ Based on the strength of the evidence, the IOM concluded that quality cancer care today must integrate the psychosocial domain into routine cancer treatment. After this decision by the IOM, the American College of Surgeons Commission on Cancer (CoC) added a standard for accreditation for 2015 that requires clinics to develop an onsite psychosocial program to identify patients with distress and triage them to appropriate psychosocial health care resources.⁵

This standard has put pressure on clinics to comply. Implementation of a new procedure is always difficult, but implementation in the psychosocial realm is even harder because it requires the cooperation of all disciplines working in cancer care. The good news is that cooperative efforts are being formulated. For example, the Association of Community Cancer Centers and the American Psychosocial Oncology Society (APOS) are working to provide consultation to cancer centers. Also, there are 2 NCI-funded educational grants to train cancer center staff in all disciplines and from across the country in the “how to” of developing a program to identify and triage patients with distress. One program is in its third year and has trained 132 individuals to provide strategic support using Web-based, onsite, and telephone-based

methods (www.supportivecaretraining.com). The other is beginning its second year and will, by 2016, have trained 54 cancer centers around the country using in-person workshops and follow-up calls of support (www.apos-society.org/screening). These efforts are paying off, but implementation is slow and requires persistence and staff commitment.⁶

Although change is slow, it is clearly happening, and the oncologist, through attitude and participation, plays a major role in the success or failure of any effort to put distress screening and triage to psychosocial health care resources in place for the first time in a clinic or center.

Oncologists Can Help in Multiple Ways

Advocate with staff on the value of screening. As the senior medical professional in the clinic or office, the oncologist is key in providing leadership and enthusiastic support for the development of a screening program that must engage the administrator, nurse, social worker, mental health professional, and chaplain in the planning. This planning phase is critical because it involves changing attitudes and procedures about psychosocial care. The more cohesion that can be attained in this phase, the more likely the success.

Participate in the planning. Most centers are in the planning phase, which must be conducted methodically and by ensuring that all disciplines “buy in,” since the program does not belong to one discipline. Adequate care must be taken to assure that each discipline has a role that is defined and clear. Assignment of the new procedures must take into account that there is fair distribution and that the outcome is worth the effort. It is wise to pilot procedures in a small area in order to smooth out the kinks and revise as needed. Leadership from the oncologist is important to ensure the full cooperation of all disciplines.

Create a culture in which innovation is exciting and acceptable. Research on implementation of new policies shows how difficult effecting change is when that change requires altering or adding a new procedure, and particularly when it adds to the workload of team members. This requires the understanding that the goal is worth the time and effort. In addition, many places are developing a program that has dual use as a clinical and research tool, which gives it even greater impetus for implementation.

Recognize that there are no gold standards. Each center has different patient populations and its own mix of disciplines. A new program is free to develop a model that works for its own center; however, using the experiences of other centers is helpful, as more centers are now experimenting with innovative approaches. Contacting the 2 educational programs described previously can be helpful.

Note that patient-centered care is now central to reimbursement, and reimbursement is beginning to depend more on value-driven aspects of care. Adding a routine practice to identify and triage patients with distress early in treatment addresses patient-centered care. It also saves time later when patients' distress levels lead them to make frantic calls and emergency department visits. The prevention of severe distress is an outcome that benefits the patient, saves time and stress for the oncologist and other care providers, improves patient satisfaction, and reduces the costs of visits.

Understand that the oncologist is the center of hope and trust for patients who are frightened and feel vulnerable and uncertain. The more patients sense that the clinician is caring for them as a whole person, the more secure they feel.⁷ In a CALGB study conducted in the 1980s patients were asked why they chose to take chemotherapy.⁷ Their reply was often simple: “I trusted the doctor” was a key reason.



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The ideas and viewpoints expressed in this editorial are those of the author and do not necessarily represent any policy, position, or program of NCCN.

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Mr. Loscalzo has held leadership positions at several major academic cancer centers. In October 2014, he was recognized for a lifetime achievement award in clinical care by the International Psycho-Oncology Society. In August 2015, he received the Jimmie Holland Life Time Leadership Award from the American Psychosocial Oncology Society.

Mr. Loscalzo has more than 35 years' experience caring for cancer patients and families and is recognized internationally as a pioneer in the psychosocial aspects of cancer. Professor Loscalzo was the President of the American Psychosocial Oncology Society and the Association of Oncology Social Workers.

He is the PI on two 5 year NIH R25E training grants and a site PI for a new third R25E. He is also on the editorial boards or a reviewer for a number of professional journals and has over 100 publications. His clinical interests are gender medicine; strengths based approaches to psychotherapies, problem-based distress screening, and the creation of supportive care programs.

Communication that bolsters this sense of caring develops during repeated clinic visits. Patients then begin to feel that the doctors and other care providers “care about me as a person.” Early identification of distress helps assure patients that the care provided by their oncologist, as the leader of the oncology team, includes attention to the whole person.

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