Asking “How Are You?”

Stewart B. Fleishman, MD

We have all been there. Your child comes home from school and you ask, “What did you learn today?” and the reply is predictably, “nothing.” Flash forward to your examination room, seeing Mr. Jones for a follow-up in the middle of his treatment for lung cancer. Open door, enter room. “How are you today, Mr. Jones?” Reflexive answer, “Fine.” Mr. Jones’ wife and son seem to be having generalized tonic-clonic activity just beyond Mr. Jones’ visual field in pantomime. They are trying to unobtrusively tell you, “Let’s talk, outside.” Adjourn to hallway. “He can’t walk to the corner and he’s hardly eating. He won’t tell you himself. We need to do something!” Sound familiar?

NCCN has evolved into the preeminent organization defining optimal care through guidelines for the diagnosis and treatment of virtually all types of cancer. It is impossible to envision any medical encounter, anywhere, that does not begin with, “Hello. My name is Dr. SoandSo/Nurse SoandSo. How are you coming along?” Most of our patients and their families want providers to inquire, be genuinely interested in the response, and be ready and able to help. That is especially important for those who give the socially automatic response that stymies further evaluation. Surprisingly, though, a minority of patients with cancer resent being asked, “How are you?” The more vocal say, “How do you expect me to feel? I have cancer.” Things are not so simple in our world.

Back in 1996, from conversations in airport departure areas after clinical trials meetings, to meeting rooms at various agencies in many time zones and on conference calls, a multidisciplinary group, under the direction of Dr. Jimmie Holland started to brainstorm. At the request of Dr. Rodger Winn, Chair of the NCCN Guidelines Steering Committee, NCCN offered to initiate an innovative solution to this rather formidable obstacle in quality cancer care. This task provided an extraordinary opportunity to define the patient experience and codify extant methods to mediate suffering, spanning cancer type, stage, and treatment. The multidisciplinary group included oncology specialist physicians, nurses, social workers, psychologists, chaplains, and patient advocates. The American Psychosocial Oncology Society (then called the American Society of Psychosocial and Behavioral Oncology/AIDS) supplemented NCCN travel funds when necessary to carry the project to completion, and the Distress Management Panel continues to meet and revise the guidelines to this day.

The meetings were electric with creativity. It took some time to agree that the usual words like *depression* or *anxiety*, used both in everyday language and clinical entities, would prove unacceptable to patients with usual and expectable reactions. Therefore, through consensus, the term *distress* was adopted as an overall concept, because it is owned by every cancer provider and virtually universal to every patient. Assessing overall distress and each component spanning the physical, emotional, social, spiritual, and practical realms required a quick and recognizable tool paralleling current practice. A 0 to 10 scale with a thermometer, much like that used for the measurement of temperature and pain, met the need to have both quantitative and qualitative dimensions in a familiar model. With distress as a multidimensional construct, efforts to subgroup its elements with an eye toward intervention led to a “problem list” to codify the individual components of distress and organize them for ease in management or referral. The difficult task of prioritizing those needs ensued, with keeping the assessment to a 1-page unit as the group’s goal. Additionally, whatever tool was developed needed to have utility in every setting in which cancer was diagnosed and treated, including single-provider office practices, multispecialty

Stewart B. Fleishman, MD

Stewart B. Fleishman, MD, currently surveys cancer centers around the country for accreditation by the American College of Surgeons Commission on Cancer. He is the Founding Director of Cancer Supportive Services at Continuum Cancer Centers of New York: Beth Israel and St. Luke’s-Roosevelt, now part of the Mt. Sinai Health System.

Dr. Fleishman is the author of *LEARN to Live Through Cancer: What You Need to Know and Do* and the accompanying provider’s textbook *Manual of Cancer Treatment Recovery: What the Practitioner Needs to Know and Do*. After fellowship in psycho-oncology at Memorial Sloan Kettering Cancer Center, he was among the first group of physicians Board Certified in Hospice and Palliative Medicine. He was the Associate Chief Medical Officer of Continuum Hospice Care and its Ethics Committee Chair.

Dr. Fleishman was also the Vice Chair of the Quality of Life Subcommittee at CALGB (now the Alliance for Clinical Trials in Oncology), and serves as member of the NCCN Distress Management Panel.

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

Fleishman

provider groups, community-based programs, and patient care programs in large research institutions.

It was the group's idea that the effort to screen for distress would open up the dialogue between patients, families, and staff that would otherwise normally be lost in busy office or inpatient visits, especially for, but not limited to, the patients who give the socially acceptable answer though experiencing subthreshold concerns. It was never intended to become a symptom-burden or quality-of-life assessment tool.

Because the committee members each had day jobs, and funding for such a nascent program was limited from within NCCN and extramurally, it took many meetings and lots of compromise and forethought to agree on a prototype assessment. Field testing for validity and reliability took place over the next few years, with comparison to accepted scales. As word got out, various domestic and international groups proceeded with guidelines development and testing, drilling down to specific cancers or treatments or taking a more global view. The treatment guidelines continue to be refined annually and updated by NCCN.

It was also suggested that each institution develop a multidisciplinary committee to monitor the effort and assure that follow-up for moderate or high levels of distress would be addressed responsibly. The more challenging task then became to move forward beyond assessment and define treatment guidelines in parallel to the disease-based NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines), considering the levels of evidence justifying the recommendations to the same standard as treatment guidelines. To our knowledge, this became the first opportunity to do so. Over the subsequent years, the NCCN Guidelines for Distress Management were developed and used as guideposts at the NCCN Member Institutions.

Out of concern that these efforts receive only minimal priority in busy office practices or abbreviated inpatient admissions, as do quality-of-life assessments in clinical trials, some administrative "teeth" were sought to assure their inclusion in regular daily practice. Pain was becoming the fifth vital sign, and influential groups such as the Institute of Medicine were beginning to focus on "care of the total patient" to highlight the critical roles of the psychosocial and spiritual domains. Reimbursement considering patient satisfaction was yet to be born. In 2000, The Joint Commission and the American College of Surgeons Commission on Cancer (CoC) were approached to consider adoption of distress screening measures as part of the standards for accreditation. Once validation studies were complete, the CoC included distress screening as 1 of 3 CoC standards introduced in 2012, with a 3-year planning period, at the more than 1500 approved programs to be accountable for its promulgation by 2015.

Yet this basic "How are you?" component of a medical encounter has been met with fear and misinterpretation throughout the country. As both a member of the NCCN Distress Management Panel and an accreditations surveyor for the CoC, I have had the unique position of helping to define the guideline and reinforcing the standard at site visits for accreditation. Each cancer program chooses which set of national guidelines they will consider for benchmarking, with the overwhelming majority choosing NCCN Guidelines for mandatory chart review and regular reference during tumor boards or cancer conferences.

Misinterpretation of the distress screening standard has caused much concern, particularly among program administrators who see it as requiring a new and costly position necessary for compliance. Colleagues are afraid that patients and families with high distress levels will slow down patient flow on a rushed office schedule when the proverbial "Pandora's box" is opened. Smaller facilities fear they do not have the array of services on hand to make referrals successful, although the guidelines specify that community referrals are encouraged. Yet can anyone, patient or provider,

Asking “How Are You?”

envision a time when someone at an initial consult or follow-up visit would *not* ask, “How are you?”

Adoption of a formal accountable standard by accrediting agencies may be at least a bit heavy-handed, but it has moved the philosophy of care for the total patient into daily operations. In several approved programs, the multidisciplinary nature of this patient care approach has been slow in taking shape. A wide breadth of response to the challenge can be seen across the country. Each program is grappling with basic philosophy: Do we really expect an honest reply to the question, “How are you?” or are we asking the question as reflexively as it is sometimes answered? Exactly whose job is it to ask? How can we respond in a kind, responsible, and efficient way? When do we ask: only once to fulfill minimal requirements, or at pivotal visits when it is the most meaningful? Has the electronic medical record made it easier or more challenging to track this inquiry? How do we accommodate this initiative; the problem often heard is, “we cannot afford to add new positions.”

Not all of our colleagues have endorsed the concept of distress screening where cancer is treated. Concerns include an unintended outcome of service rationing to those who screen “low,” or even a denial of services; the prescription of anxiolytics or antidepressants without a formal workup; or the misguided application of a distress score that increases disparities in cancer treatment rather than modifies them. That would be like prescribing an antihypertensive based on the blood pressure reading of the triage nurse in an Emergency Department, without proper subsequent evaluation; bad medicine in either case.

What have we learned with these efforts? Overall, the intention to incorporate a meaningful, “How are you?” has spurred national debate and widespread acceptance, although without complete buy-in; but it remains a worthwhile effort. Some things we have learned along the way include the notion that the inquiry need not and should not be limited to one provider, but rather should be asked by each provider. Knowing who and when to call is critical, and if the staff knows, this will benefit patients. Meeting minimal standards is a good start, but not the sum total of the effort. Defining what is a pivotal visit and being sensitive to the issue of timing is part of the nuance of any clinical encounter. For instance, 3 days after cis-platinum, no patient is at his or her best. The idea of a single global rating scale still makes sense for a triage tool, because it continues to open the dialogue.

With the development of new patient-centered standards to include distress screening, a patient navigation process, and a survivorship care plan, the complex world of today’s cancer treatment is being redesigned to be more human and streamlined. As advances are made in genomic and personalized oncology, these now-mandatory patient-centered components of care again place the patient truly in the center of personalized treatment.