

## Psychological Care of Patients: Psycho-Oncology's Contribution

By Jimmie C. Holland

The centuries-old stigma attached to cancer precluded patients' being told their diagnoses, and thus, delayed any exploration of how they dealt with their illness. This situation changed in the United States in the 1970s when patients began to be told their cancer diagnosis, permitting the first formal study of the psychological impact of cancer. However, a second and equally long-held stigma attached to mental illness has been another barrier and this has kept patients from being willing to acknowledge their psychological problems and to seek counseling. This "double stigma" has slowed the development of psycho-oncology. However, we began to see rapid changes occurring in the last quarter of the 20<sup>th</sup> century. Valid assessment instruments were developed which were used in well-designed studies. Data from these studies and clinical observations led to increased recognition that psychosocial services are needed by many patients and provide significant assistance in coping with illness.

Psycho-oncology has two dimensions: first, the study of the psychological reaction of patients at all stages of the disease, as well as of the family and oncology staff; second, exploring the psychological, social, and behavioral factors that impact on cancer risk and survival. Psycho-oncology now has a recognized role within the oncologic community through clinical care, research, and training as it relates to prevention of cancer through lifestyle changes, evaluation of quality of life, symptom control, palliative care and survivorship. Presently, there are sufficient research studies from which standards of care have been established. Both evidence and consensus-based clinical practice guidelines have been promulgated. It now possible to monitor the quality of existing psychosocial services by using these benchmarks of quality that have evolved in recent years.

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IT IS an honor to present the American Cancer Society's (ACS) Award Lecture at the American Society of Clinical Oncology Annual Meeting in 2003. It is equally an honor for our field of psycho-oncology to receive this recognition. I am pleased to present a brief history of its development, and also bring attention to the societal attitudes that have slowed its evolution and which continue, even today, to influence people's ideas and beliefs about cancer. At the outset, we recognize the importance of the ACS in educating the public to diminish the myths and fears relative to cancer, and in offering the first psychosocial support to patients through the Society's ostomy groups and Reach to Recovery. Additionally, in the 1970s, the ACS recognized the need to develop an area within oncology that would deal with these crucial psychological and social issues. The field of psycho-oncology owes a large debt of gratitude to the ACS for its early support of conferences focused on improving research methods, developing valid assessment tools, encouraging research training, and providing the first funding for psychosocial and behavioral research, through a peer review committee.

Cancer is a disease that has been feared beyond all others for centuries, in large part because neither its cause nor cure was known and, indeed, "cancer equals death" expressed the general belief.<sup>1</sup> In those earlier centuries, it was the family, the doctor, and perhaps a member of the clergy who were at the patient's bedside to offer emotional support, though neither the cancer diagnosis nor approaching death was acknowledged. This article traces the changes in the understanding and management of the

psychological domain of cancer, and reviews some of the attitudinal barriers that contributed to the delay of psycho-oncology becoming an accepted subspecialty of oncology. Psycho-oncology, a small but emerging field of care, guides the psychological aspects of care, the training of staff in these areas, and provides expertise in psychological, social, and behavioral quality of life research.<sup>2</sup> Collaboration with medical oncologists has been particularly fruitful because it has permitted identification of the most salient problems faced by patients and their doctors, as well as exploration of these questions in studies varying from response to the diagnosis, support through treatment, to palliative care and survivorship. Oncologists carry the heavy psychological burden of being the physician who often follows the patient through the illness trajectory, dealing with the frequent need to give bad news and provide the consistent

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Table 1. Factors That Determine Adjustment

Factors
Disease-related
Site, stage, treatment, rehabilitation
Personal
Personality, coping ability, beliefs, support from others
Social
Cultural attitudes and beliefs about cancer

psychological support. Their understanding of and sensitivity to these human issues in cancer is crucial to patients' well being.

It is helpful to view the three basic factors that contribute to the psychological adaptation of a patient to cancer in context (Table 1). The first factor is the disease itself: the site, type, and stage of the cancer, the available treatment, potential for rehabilitation, and the relationship to a supportive oncology team.<sup>3</sup> Clearly, this is the "given" that cancer brings. The second factor that impacts adaptation is the person, himself or herself: the personality characteristics, coping skills, level of emotional maturity, and social surroundings (family, friends, community). The third contributing factor derives from the society and the culture in which the person lives: the society's prevailing attitudes toward cancer. This societal issue is important because, in addition to affecting the patient, it also impacts the attitudes and beliefs of families, friends, and the medical community as well.<sup>4,5</sup>

#### *Attitudinal Barriers and Stigma Associated With Cancer*

In the 1800s, like the preceding centuries, a cancer diagnosis was felt to be a death sentence and revealing the diagnosis to a patient was considered cruel and inhumane because the patient would lose all hope and could cope better not knowing. This led to the "conspiracy of silence," with the doctor and family keeping the secret from the patient. All who were part of the cover-up judged it to be an acceptable white lie. Tolstoy's story of *The Death of Ivan Ilyich* graphically describes the isolation Ivan Ilyich felt in the 19th century when his family and doctor pretended that his intense stomach pain was nothing serious. He struggled alone with his pain and private awareness that he was mortally ill, acknowledged only by his faithful servant.<sup>6</sup>

Attitudes barring openness about a cancer diagnosis continued well into the 20th century. The family would not reveal the diagnosis outside the family because of the attached stigma. Shame, guilt, and fear that it was contagious led to social isolation. After anesthesia was developed in the 19th century and antisepsis reduced infections, surgery became possible (though uncommon) to cure a cancer if it was found early, and it could be removed before it had spread. For the first time, educating the public about early diagnosis became important. Programs encouraging people to seek consultation for symptoms suspicious of cancer began through the ACS in 1913. It represented the first attempt to alter the public's fatalistic attitudes toward cancer. The Society's mandate was to "disseminate knowledge concerning the symptoms, treatment and prevention of cancer".<sup>7</sup> To counter the ignorance, fatalism, and fears, warning signs of cancer were publicized. Such slogans as "Fight cancer with

knowledge" were used to combat the fears. Despite the greater public information, however, many people neglected the danger signals, largely because of fatalistic attitudes, and they sought consultation only after long delay.

Radiation joined surgery as a treatment for cancer early in the first quarter of the 20th century, adding an important, new dimension. Memorial Hospital in New York, NY, founded in 1884, played a major role in the use of radium for cancer. In 1937, the National Cancer Institute (NCI) was created as the first of the National Institutes of Health. In 1948, Farber reported the first temporary remissions of childhood acute leukemia with aminopterin, followed by the early responses of Hodgkin's disease to nitrogen mustard. These efforts began an active search for new chemotherapeutic drugs and chemotherapy was soon added as the third treatment modality for cancer, combined with increasingly more effective surgery and radiation, which could be given in more carefully calibrated doses.<sup>5</sup> The first chemotherapy cure of a cancer, choriocarcinoma, by the single agent methotrexate, was achieved in the early 1950s. The triple approach dramatically altered the prognosis for several previously fatal tumors of children and young adults, notably childhood acute lymphocytic leukemia, testicular cancer, and Hodgkin's disease. These cures in the 1960s, of previously fatal cancers, did much to change attitudes of doctors and the public alike; pessimism about cancer treatment diminished and a new interest evolved in the long-term effects of cancer treatment, especially the development of second tumors and physical and psychological sequelae.

This period of increased optimism about the cure of some cancers coincided with growing concerns about informed consent. Patients' rights became more important as revelations of the post World War II Nuremberg trials disclosed experimentation on humans without consent. The repercussions, plus evidence of some experimentation on patients in the United States without their consent (including patients with cancer), led to the promulgation of federal guidelines for research with human subjects. The era of social upheaval in America (1960s-1970s) received strong contributions from the movements for the rights of women, consumers, and finally patients, who began to demand to know their diagnosis, prognosis, and treatment options. Breast cancer figured most prominently in the battles, in which women pressed for a two-stage biopsy and less aggressive surgery by primary treatment with lumpectomy and radiation.<sup>8</sup> The revealing of the diagnosis became a legal mandate in the United States and is largely respected, except in situations where cultural factors cloud the issues.

During these post World War II years, the only formal psychological support for cancer patients was through the ACS's "visitor" programs. Patients who had had a laryngectomy or colostomy were asked to speak with patients who hesitated to undergo a disabling (yet often curative) procedure. Self-help laryngectomy and ostomy clubs were formed by patients. These were followed by the highly successful Reach-to-Recovery program started in the 1950s by the ACS, in which women who had had a mastectomy (radical or ultraradical in those days) visited women after their operation.

Despite widespread endorsement by patients, as well as receiving gratitude for providing psychological help, these advocacy organizations spawned by the ACS had an uphill battle to gain acceptance in the medical community. Physicians felt patients would discuss treatments with each other, and they would be adversely affected psychologically. This was despite the fact that few adverse effects were ever reported. The strong bias against encouraging patients to talk with one another continued into the last quarter of the 20th century, when experience began to show that the benefits of social support far outweighed any risks. Readers who are interested in the historical details of cancer medicine and the social attitudes associated with it are referred to the articles by Patterson,<sup>4</sup> Shimkin,<sup>5</sup> and Holland et al.<sup>9</sup>

#### *Attitudinal Barriers Toward Psychological Care of the Medically Ill*

The centuries-old stigma attached to mental illness had a profound impact on developing psychological services for medically ill patients. Like cancer, mental illness had no known cause or cure and therefore, the two were equally feared. Demonic possession was a common attribution; the person was blamed, ostracized, and often shackled and imprisoned in most societies.<sup>10,11</sup>

In the United States, the nineteenth and early twentieth centuries saw mental patients and their physicians (called alienists) isolated in mental hospitals and pastoral settings, away from general hospitals. By the latter 1800s, however, an effort was made to bring the psychiatrists and the mentally ill into general hospitals by placing psychiatric units in general hospitals, training a cadre of psychiatrists who could consult on psychiatric problems in medical patients, and by teaching physicians and students to recognize and treat psychiatric comorbidity in medical patients.<sup>12</sup> Adolph Meyer did much to bring the unifying concept of "psychobiology" to the awareness of physicians. From his position at Johns Hopkins, he and his students had an impact on academic medicine, encouraging the crucial need to treat the whole person. In 1902, the first psychiatric ward was opened in a general hospital in Albany, New York. Psychiatric consultations to medical patients began to develop in the 1930s, encouraged in part by the Rockefeller Foundation, did much to foster the integration of psychological aspects into the overall care of the medically ill.

However, the attitudes toward inviting a psychiatrist to consult on medical wards of the general hospital varied from hostile to indifferent. In 1929, a psychiatrist named George Henry documented his experience with over 2,000 cases seen in a general hospital<sup>13</sup>: "Very few exceptions can be taken to the statement that when psychiatry is first introduced into a general hospital there is likely to be indifference or even resistance on the part of the hospital staff. In one hospital, the superintendent received the proposal of psychiatric aid with the remark that in his experience, 'insanity' was a hopeless disease and furthermore there were no 'insane' patients in the hospital. A chief surgeon's response was, 'I don't know what it's all about, but I guess it won't do any harm.' "

Henry proposed that every general hospital should have a psychiatrist available. In this article, Henry reported on the psychiatric diagnoses of 300 cases he had seen. Despite changes in diagnostic terminology, the percentages are remarkably similar to those encountered in medically ill patients today. The principles enunciated by Henry in 1929, and still applicable, suggest the importance of a mental health professional being a member of an oncology team to deal with the comorbid psychiatric problems and common psychologic factors contributing to medical illness or symptoms.

Such were the beginnings of what became known as consultation-liaison psychiatry. And psycho-oncology came from these beginnings. These initial endeavors came out of the experiences in the psychiatric units that cared for patients with medical illness and psychiatric comorbidity, and also from the psychiatric consultations done on patients on the floors of the general hospitals.<sup>12</sup> Patients with cancer were treated in the general wards of the hospital by general physicians. On the medical side, cancer did not attract much academic interest since, for many years, it was viewed as having little "science" attached to it. Patients sensed that they were regarded as largely untreatable. Doctors spent less time at their bedside, following the custom of not discussing the diagnosis and prognosis and avoiding questions that would lead to such a discussion. The 1930s saw the arrival of many psychoanalysts from Europe. The impact of psychoanalysis on both American psychiatry and society was immense. Flanders Dunbar and Franz Alexander were well known figures whose research focused on psychoanalytic formulation as the genesis of several chronic medical diseases. Depression, grief, stress, and childhood conflicts were seen as strong contributing causes of hypertension, peptic ulcers, asthma, rheumatic arthritis, and cancer. In cancer, patients with a specific malignancy were studied by a retrospective life review to find a pattern of emotional problems that were proposed as the cause of cancer.

Studies published primarily in *Psychosomatic Medicine* and psychoanalytic journals were of theoretical interest to mental health professionals, but they were not of interest to physicians searching for cures in the developing field of oncology and who were concerned with the emotional impact of the disease on patients. The "disconnect" between these early investigators and cancer physicians and surgeons led to a delay in the development of collaborative, prospective studies of patients that explored both medical and psychological perspectives, and ensured an integrated approach to their care.

Hackett, psychiatrist at Massachusetts General Hospital, offered a critique of this period: "... the message [from psychosomatic studies] came across quite distinctly that the paydirt was embedded in psychology. Placing such weight on the importance of emotional issues in the etiology of an illness disengaged the attention of internist and surgeon alike. The psychosomatic movement, with some exceptions, loosened even more the moorings of psychiatry to medical pragmatism."<sup>14</sup>

By the 1960s and 1970s, clinical and experimental psychologists began to study patients with more quantitative measures and finally with methods that permitted exploration of interac-

tions between the physiologic and the psychologic, as exemplified by the work of Mason et al,<sup>15</sup> and by the contributions of behavioral medicine beginning in the 1980s.

The idea that “you wanted to have cancer,” coming out of this period, persisted in public attitudes and was picked up and carried further by some self-help movements based on the concepts of mind-body unity. “You can cure your own cancer since you caused it” was a prevalent idea for many. And there were those strong adherents of the notion that you could visualize immune cells killing cancer cells and thereby enhance the body’s powers to fight cancer. Lewis Thomas once said, “The immune system is so complex, I wouldn’t know which cells to tell to fight more.” These views persist today to a lesser extent.

The psychosomatic medicine movement later branched into a research area called psychoneuroimmunology and the clinical area of health psychology and consultation-liaison psychiatry. The work of Ader et al<sup>16</sup> established the beginnings of psychoneuroimmunology in 1975 when they reported a conditioned taste aversion to saccharin, which resulted in a conditioned immune response in rats. This area of work contributed to the research in cancer that led to the understanding of conditioned nausea and vomiting as a learned response in patients undergoing cycles of emetogenic chemotherapy. Studies have shown that patients, years after the completion of chemotherapy, remain sensitive to visual and olfactory stimuli that are reminders of the chemotherapy, such as the sight of the nurse or doctor, the smell of an antiseptic, or the perfume worn by the nurse. Patients unconsciously respond with transient nausea and anxiety.<sup>17</sup>

Psychoneuroimmunology utilized newer techniques that tracked biologic events and measured psychological phenomena in a far more precise way, truly embodying the biopsychosocial concept of Engel.<sup>18</sup> These researchers also explored the impact of stress and coping on immune function during the course of cancer treatment.<sup>19,20</sup> The significance of psychoimmune mechanisms as factors in cancer risk and survival remains unclear and investigators have been modest in their interpretation of the likelihood of its importance in cancer.<sup>21</sup>

Psychosomatic medicine has been viewed by some as a field that has been fragmented and weakened. A recent critique by Brown,<sup>22</sup> delivered at the New York Academy of Medicine, chronicled *The Rise and Fall of Psychosomatic Medicine* and the reasons for it. And Gottlieb,<sup>23</sup> in a paper titled *Whatever Happened to Psychosomatic Medicine?*, explored the demise of psychoanalytic psychosomatic medicine as psychiatry moved toward a neuroscience focus and medicine moved toward molecular biology.

Weiner, senior theorist in psychosomatic medicine, suggested that reports of its death are grossly exaggerated. His view is that psychosomatic medicine, as a field, has made and continues to make significant contributions to an integrative theory of medicine. “Psychosomatic medicine also recognizes that . . . disease is an abstraction and should not be the sole focus of the healer’s attention: the patient should be, a notion that is found in Hippocrates’ writings.”<sup>24</sup>

This inclusive view, which incorporates information from genetics, physiologic and psychologic, and social domains, well describes the principles on which psychosomatic medicine has developed and progressed with increasingly more scientifically sound research.

The second identifiable field which grew out of psychosomatic medicine was consultation-liaison psychiatry, which, in terms of cancer, focused on understanding and alleviating the psychological burden of patients with cancer. Eissler<sup>25</sup> (in 1955) and Norton<sup>26</sup> (in 1963) made detailed and sensitive observations of their patients, who, during psychoanalysis, developed cancer. These fortuitous studies provided rich material for those beginning to work in the field in the 1960s as to how patients coped with progressive stages of illness and approaching death.

In the early 1950s, several prospective studies began to examine the psychological response of hospitalized patients to cancer, done in a collaborative effort with the physicians treating cancer. The first reports of psychological adaptation to cancer and its treatment were made by the psychiatric group at the Massachusetts General Hospital, under the direction of Finesinger, and the psychiatric research group at Memorial Sloan-Kettering Cancer Center, under Sutherland, also a psychiatrist. By 1955, these two centers had published the initial papers documenting the psychological reactions to cancer and its treatment.<sup>27-30</sup> Guilt and shame were described by Abrams and Finesinger<sup>27</sup> as a prominent psychological response related to the stigma of cancer. Shands et al,<sup>28</sup> also at Massachusetts General Hospital, observed how patients’ communication patterns changed over the stages of illness, noting that communication became more limited as the disease progressed, likely as they responded to the expectation that progressing illness was not to be discussed.

Ruth Abrams, a social worker at the Massachusetts General Hospital, contributed to these early observations of patients, as did other social workers, including Ruth Dyk at Memorial Hospital, by providing the first psychosocial services to patients with cancer. Much credit goes to these pioneers. Nurses at the bedside, who intuitively provided psychological support, were equally effective early on. They were increasingly trained in the clinical and research areas of psychosocial care, guided by early nursing researchers such as Jeanne Quint Benoliel.

The group at Memorial Sloan-Kettering Cancer Center focused on the patients’ responses to the radical surgical procedures of the day for gynecologic, breast, and colon cancer. Major physical and functional deficits were the cost of possible cure. The group described, in two seminal papers, the responses to colostomy and radical mastectomy.<sup>29,30</sup> The psychiatric groups at these two hospitals (both comprised of psychiatrists, psychologists and social workers) began to forge clinical and research ties with treating surgeons, radiotherapists, and oncologists and thus, collaborative work began establishing the ties from which psycho-oncology emerged as a subspecialty in oncology.

Another early area of psychological intervention occurred in the 1960s when the first debates began in this country about the wisdom of never revealing the diagnosis of cancer to the patient. Psychiatrists were active as participants (on the “do tell” side) of

these lively debates with some oncologists who were often on the “never tell” side. In a survey by Oken<sup>31</sup> in 1961, more than 90% of physicians in this country did not usually reveal the diagnosis to the patient. The argument that many people preferred to know the truth, and that more harm was done by telling a lie, began to be persuasive. The same questions asked in a survey in 1978 showed that 97% of the doctors in the same geographic area now told patients their cancer diagnosis.<sup>32</sup> Over the course of those intervening 17 years, the public’s knowledge about cancer increased and we saw patients, consumers, and women mount their respective rights movements. Also, as more types of cancer were cured, optimism about outcome made it easier to discuss these matters. However, the candor of American doctors in revealing cancer has still not been matched in many other countries where the custom of “seldom telling” continues.<sup>33</sup>

Another factor in the 1960s that heightened interest in psychological issues in cancer was the work of psychiatrist, Elizabeth Kubler-Ross. She challenged the taboo against talking to cancer patients about their impending death, and challenged doctors and nurses to stop avoiding talking with these patients and to allow them to express their concerns about death. Kubler-Ross galvanized both public and medical attention to the isolation of dying patients, in particular, patients with cancer and their need for dialogue about their situation.<sup>34</sup> Her contributions were crucial to the beginning of the thanatology movement in this country, to fostering the concept of hospice care, and to humanizing end-of-life care.

However, the attitudinal barrier against “all things mental,” even among medically ill patients, has not disappeared and must be recognized as a factor in the slow development and use of psychological and psychiatric services among patients with cancer. Even today, patients worry about being labeled not only as a person with cancer, but as a person who needs psychological help; “It means I’m crazy;” “I’m weak if I admit I need help.” They fear being labeled as “psychiatric” or “psychological” or “weak.” To overcome this barrier, psychosocial services developed today should ideally be seamlessly and fully integrated into the oncology services. When the mental health professional is a member of the medical team, rounding with them in the hospital, and when services are given in the outpatient clinics in the same place where oncologists see their patients, then these features reduce the barrier. When supportive mental health and psychosocial services are separate, distanced, and hence subject to the mental health stigma, patients are far less apt to utilize these frequently needed services.

#### *Beginning of Psycho-Oncology: 1975*

The subspecialty of psycho-oncology began formally around the mid 1970s when the barrier to revealing the diagnosis fell and it became possible to talk with patients about their cancer diagnoses and the implications for their lives. This coincided with several social changes. First, the public felt a greater sense of optimism about cancer, principally as a result of the presence of increasing numbers of cancer survivors who were vocal about their successful outcomes, in contrast to prior times when they

remained silent because of the illness’ stigma and fearing repercussions at their job. Secondly, celebrities began to permit the media to cover their illness, revealing both the diagnosis and treatment. Most notable examples were Betty Ford and Happy Rockefeller in 1975, as well as Betty Rollin with her account of breast cancer in, *First, You Cry*.<sup>35</sup> Lastly, this period saw the surging of powerful social movements championing human rights that were the legacy of the Vietnam era, directing the nation’s attention to groups whose rights were not fully acknowledged: women, consumers, and patients. As a result of all these factors, cancer came out of the closet and the door opened for exploration of its psychological dimension.

In 1975, a small group of clinical investigators gathered in San Antonio, Texas, for the first national research conference on psycho-oncology.<sup>36</sup> It addressed the major barrier posed by the absence of instruments to quantitatively measure subjective symptoms such as pain, anxiety, and depression. Instruments designed for study of physically healthy patients with psychiatric disorders were not calibrated finely enough to measure these types of distress in the medically ill. The ACS vigorously supported this initial research and sponsored several national conferences to improve research methods. Instruments were developed to quantitate subjective symptoms of pain, anxiety, nausea, depression, and delirium, and more recently, fatigue. The psychiatric group at Memorial Hospital, which was begun in 1951 and dispersed in 1961, was re-established in 1977 and began to develop clinical services, a postgraduate training program comprised of a didactic and clinical tutorial experience for psychiatrists/psychologists, and a research initiative.<sup>37</sup> As a critical mass developed, the group (collaborating with the ACS and the National Cancer Institute) became a force for national and international development of psycho-oncology.

By the mid 1970s, the consultation-liaison psychiatrists working on inpatient cancer floors or in psycho-oncology units were the first wave of investigators, and as such, explored the epidemiology of comorbid psychiatric disorders that most often complicated cancer care: depression, anxiety, and delirium.<sup>38</sup> The Psychosocial Collaborative Oncology Group under Schmale led to the multicenter, cross-sectional study by Derogatis et al<sup>39</sup> of the frequency and type of DSM-III diagnosis in cancer patients, showing 47% had suffered distress to qualify as a psychiatric disorder, primarily reactive anxiety and depression. Studies began to document the frequency of depression by site and stage of cancer, acknowledging the difficulties in separating physical from psychological symptoms; the causes and course of delirium; the causes, both functional and treatment-related, of anxiety; the relationship of all to the presence of pain; and impaired cognitive functioning. Clinical trials began of psychosocial and psychopharmacologic interventions. An account of this research literature and clinical experience appeared in the first textbook of psycho-oncology published in 1989.<sup>37</sup> The opportunity for teaching oncology staff about these issues increased as curriculum and research studies became available for use in teaching rounds, in-service workshops, and national conferences. Group sessions for oncology staff also grew in popularity as a place where doctors and nurses could express

their reactions to the stresses of clinical care and the symptoms of burnout.<sup>40</sup>

The behavioral medicine movement began around the late 1970s and brought a second wave of researchers to the psychosocial aspects of cancer. Health psychologists brought a new and valuable dimension to this research. They began to study theoretical models of coping, identifying those that were most effective. They brought cognitive-behavioral models of psychological interventions that have proved widely acceptable and efficacious. The development of theoretical models on which to build psychosocial and behavioral interventions has been critically important. Behavioral psychologists have given cancer prevention its strongest boost with their studies on how to change lifestyles in order to lower cancer risk by reducing sun exposure, changing dietary habits, increasing exercise, and most important, enhancing smoking cessation. Research has increasingly found little evidence for traumatic events and personality as contributing causes of cancer. However, lifestyles, social class, social ties, and adherence to treatment are major behavioral factors in the risk and survival of cancer (Table 2).

Although Shipper (an oncologist) et al<sup>41</sup> in Winnipeg developed a quality-of-life (QoL) scale in the early 1980s, it was the health psychologists who validated the multidimensional quantitative measurement of QoL (functional status) as an outcome measure in cancer clinical trials. Aaronson<sup>42</sup> in Europe (European Organization for Research and Training in Cancer) and Cella et al<sup>43</sup> in the United States have developed extensively used scales, made up of a core set of questions with modules to apply to specific tumor sites. Evaluation of a new drug or cancer treatment today assesses not only impact on length of survival, disease-free interval, but also QoL and, often, cost analysis. Combining QoL data with survival data now permits statistical approaches to determine quality-adjusted life-years. Many other instruments have been developed by others for symptom assessment, unmet patient needs, and screening for psychosocial distress.

Other important contributions to psycho-oncology have come from nursing researchers. This cadre of contributors combined their astute insights gleaned from bedside nursing with psychological research methodology to make unique contributions to symptom measurement and control,<sup>44</sup> palliative care,<sup>45</sup> pain management,<sup>46</sup> and psychosocial support.<sup>47</sup>

As mentioned earlier, social workers were the first, alongside nurses, to attend to the psychological and social problems of

cancer patients and their families. They have continued as the “front-line” in clinical care and as important researchers in psycho-oncology. Studies of children’s and parents’ reactions, distress management, caregivers’ burden, and, especially, palliative care, have been within their purview of contributions.<sup>48,49,50,51</sup> The *Journal of Psychosocial Oncology*, established in 1983, was the first journal dedicated to informing the field about current research.

Only in recent years have the contributions to psycho-oncology by clergy and pastoral counselors been acknowledged as a crucial component of supportive services, reflecting the recognition of the patients’ need to find a belief system that could contribute to finding a tolerable meaning to their existential plight. In fact, serious illness has been called a psychospiritual crisis by some.<sup>52</sup> Research in the religious domain can now be included in assessments of quality of life because of major contributions to methodology by Pargament,<sup>53</sup> a psychologist, and others. Scales to measure patients’ spiritual beliefs and reliance on them in coping with cancer have been developed, as well as spiritual assessment tools for clinicians.<sup>54</sup>

The contributions from psychiatry, behavioral medicine, health psychology, social work, nursing and pastoral counseling, as well as oncologists, ethicists, and patients themselves have created a richness and diversity of information, and theoretical models and approaches, both in research and clinical cancer care. The most successful psycho-oncology, psychosocial, and behavioral oncology units have been those able to use this diversity to their advantage by evaluating patients and referring them to the most appropriate resource. They function as truly multidisciplinary organizations, drawing on the knowledge of each to enrich the others, while remaining fully integrated in the patients’ total medical care. Jacobsen’s Psychosocial, Behavioral, Palliative Care Program at the H. Lee Moffitt Cancer Center in Florida is an example of integrative efforts, as is the program of Cancer Supportive Services led by Fleishman at the Beth Israel Medical Center in New York.

The range of areas of psycho-oncology, and the remarkably expanded range of interventions, have been described in the multi-authored textbook, *Psycho-Oncology*, published in 1998.<sup>2</sup> The journal, *Psycho-Oncology*, begun in 1992 to cover the psychological, social and behavioral dimensions of cancer, seeks to make new research findings available from each area, and, thereby, serves as an integrating force as the official journal of the International Psycho-Oncology Society, the British Psychosocial Oncology Group, and the American Psychosocial Oncology Society (APOS). Recent efforts have been made to establish APOS, founded in 1986, as the multidisciplinary organization to provide a network for all disciplines working in psychosocial services in cancer and to enhance collaboration with advocacy organizations ([www.apos-society.org](http://www.apos-society.org)). APOS has also established a toll-free help line to provide assistance to patients, families and advocacy organizations by identifying needed mental health services in their local communities (1-866-APOS-4-HELP).

**Table 2. Psychosocial and Behavioral Factors in Cancer Risk and Survival**

Factors
Weak evidence
Personality and coping
Loss, bereavement, depression
Strong evidence
Lifestyle
SES; social class
Social ties
Treatment adherence

Abbreviation: SES, socioeconomic status.

*"Suffering of the Mind"*

The diagnosis of an illness like cancer, with the fears attached to it and the threat to life itself, results in a complex set of issues that the individual must confront: physical symptoms (especially pain); psychological reactions of fear and sadness; concern for the family and their endangered future; facing the existential issues of life and death; and seeking a comforting philosophical, spiritual or religious belief system to help give a tolerable meaning to the new world of illness.

Shakespeare, in *King Lear*, eloquently expressed the totality of the issues raised by life-threatening illness: "...We are not ourselves when nature, being oppressed, commands the mind to suffer with the body."

The core of psycho-oncology addresses this "suffering of the mind" that occurs with cancer. It incorporates the psychological, social, spiritual, and existential dimensions, and seeks to help the patient find a tolerable meaning to the presence of the unwelcome intruder of serious illness and threat to the future and to life itself. Finding a theoretical model that could incorporate all aspects of "suffering of the mind" would serve as an integrative force in our work in psycho-oncology, and help to diminish the fragmentation that occurs when the oncology team addresses primarily the biologic "suffering."

Recently, interest has grown in the role of meaning as an important aspect of coping with illness and loss, fostered by Folkman<sup>55</sup> in a coping paradigm that includes "making meaning". Developed from studies of patients with AIDS and their partners, the model provides a framework for understanding coping with life-threatening illness and loss. Folkman suggests that each individual has a "global meaning," composed of beliefs, values, goals, and a self-image persisting over a lifetime. This personal construct is challenged by a catastrophic event like cancer, which makes coping with the process of reconciling global (life-long) values/goals with the new existential meanings created by the illness. A new balance is sought between the global and the situational that permits continued coping and gives a new meaning to life. Spiritual and religious beliefs are often helpful in finding meaning. An example is the young long distance runner who requires an amputation of the leg for osteosarcoma. He must reconcile the loss to fit his life-long goals, or alter his life-long goals to incorporate the loss.

*Accomplishments: 1975 to 2003*

Psycho-oncology is presently defined as the subspecialty of cancer dealing with two psychological dimensions: the psychological reactions of patients at all stages of their cancer illness and the stresses on their families and clinical staff; and studies of the psychological, social, and behavioral factors that contribute to cancer cause and survival.

There have been truly revolutionary improvements in the understanding of cancer biology and development of new cancer treatments in the past two decades. However, each new therapy carries with it new psychological challenges for patients with significant neuropsychiatric and psychological complications.<sup>14</sup> Preclinical cancer, in which positive markers

are present in the absence of clinical findings, is the challenge for healthy people, as is genetic counseling, which has implications for the family as well.

Because of this, the close interaction with cancer clinicians and investigators has been critically important. Our field's strength, and the reason for its fascinating and challenging nature, is that it simultaneously addresses the universal issues that cancer raises, but also the new psychological challenges specific to individual patients. It also seeks to apply and test new approaches in psychotherapies, behavioral interventions and psychopharmacologic agents, coming from general psychiatry, consultation liaison psychiatry, health psychology and behavioral medicine. It ensures that psycho-oncologists have a keen interest in both oncology and psycho-oncology.

Figure 1 shows the research model that has guided our work through the 1990s. Cancer (and its treatment) is the independent variable; quality of life (in all its dimensions, including psychological) and survival are the outcome variables. The mediating variables (and our interventions to affect them) are the core of psycho-oncologic research. Our studies explore: the personal variables of sociodemography, personality and coping style, beliefs, and prior adjustment; the variables associated with stage of illness, rehabilitation options, illness-related behaviors, and the relationship to treatment team; the availability of social supports (family, friends, community, and socio-cultural influences); and concurrent stresses related to illness that add to the psychological burden, such as loss of a spouse.

For the first time, cancer mortality fell in the United States in 1998. Cancer survivors, long out of the closet and strong advocates for better psychological care, now number almost 9 million. Most oncology care today is given in clinics, not in hospitals, leading us to focus on the need for more psychosocial services in ambulatory settings. Psycho-oncology has a role throughout the continuum of cancer: from prevention (lifestyle changes); preclinical cancer (known genetic risk, or positive cancer markers for a specific cancer in the absence of clinical disease); through diagnosis, curative treatment, survivorship, and cure; and palliative and end-of-life care. Recurrence after a treatment attempt at cure will lead today to noncurative, but

### RESEARCH MODEL FOR PSYCHIATRIC & QUALITY OF LIFE RESEARCH IN ONCOLOGY

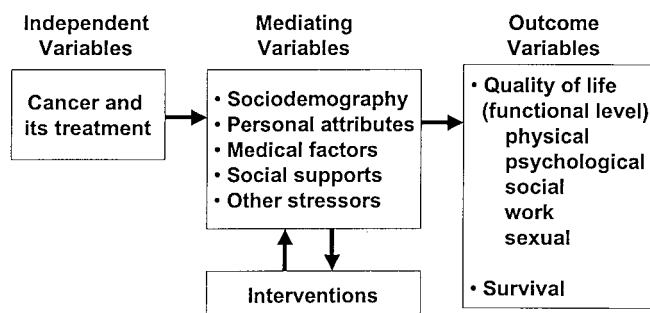


Fig 1. Research model for psychiatric and quality of life research in oncology.

life-extending therapies for a stage of illness that can be called chronic disease, best recognized in breast and prostate cancer, where patients live for long periods receiving second- and third-line chemotherapies that extend survival. Palliative and end-of-life care characterize the phases of illness in which care is directed toward maximal comfort and symptom control, which requires particular attention to pain, depression, anxiety, and delirium.

Primary prevention of cancer depends on changing behaviors and lifestyle. Smoking prevention and cessation research in psycho-oncology has resulted in models for planning rational interventions for smoking cessation.<sup>56</sup> The relationship between depression and smoking has emerged. Prevention and treatment of obesity and attention to exercise and diet are the cornerstones of prevention for both cancer and heart disease.

The genetic basis of increasingly more tumors is becoming known. While genetic testing is going forward with appropriate attention to counseling, there is still much need to study its psychological and social consequences on patients and their families. The viral cause of more cancers is emerging, particularly the human papilloma virus in cervical cancer, suggesting the need to educate women about exposure and possibly earlier recognition of disease by viral markers and treatment by vaccines. All represent new challenges and areas for behavioral and psychological research.

Cancer therapies create a range of psychiatric and neuropsychiatric disorders, and new ones will likely continue to present similar issues. Fatigue, peripheral neuropathy, dyspareunia, infertility, incontinence, impotence, and chronic pain syndromes are complications of some chemotherapy treatments. Interferon, standard treatment for chronic myelogenous leukemia and metastatic melanoma, creates severe mood and cognitive problems. Other cytokines cause fatigue and significant mood changes. Subtle cognitive loss is becoming apparent as a side effect of standard adjuvant breast chemotherapy.<sup>21</sup> Effects of these agents on brain function will be important, since some basic neurochemical mechanisms may be elucidated by their study. In addition, as new therapies are tested, patient-reported quality of life must be included as an outcome measure in more clinical trials in which an arduous treatment appears efficacious but carries with it a high price in quality of life. Quality-of-life information is important in helping them choose.

Survivors are now numerous and they have psychological baggage first described extensively in 1981 by Koocher and O'Malley.<sup>57</sup> Side effects of therapies lead many to experience symptoms of posttraumatic stress disorder (PTSD) and conditioned responses. Around 10% to 20% of bone marrow transplant survivors have full blown PTSD, but a larger percent have PTSD-like symptoms.<sup>58</sup> Those who have gone through the most arduous treatment, such as high-dose chemotherapy or stem-cell transplant with total-body irradiation, are most vulnerable. Anxiety is a frequent problem for most patients, especially before follow-up visits when anticipatory anxiety is high.<sup>59-61</sup>

Management of cancer care in this decade has moved from the hospital to ambulatory clinics and offices and home. More treatments can be given in the clinic and more palliative care

**Table 3. Standards of Care for Distress Management**

Standards of Care
Distress should be recognized, monitored, documented, and treated promptly at all stages of disease.
All patients should be screened for distress at their initial visit, at appropriate intervals, and as clinically indicated especially with changes in disease status (ie, remission, recurrence, progression).
Screening should identify the level and nature of the distress.
Distress should be assessed and managed according to clinical practice guidelines.
Multidisciplinary institutional committees should be formed to implement standards for distress management.
Educational and training programs should be developed to ensure that health care professionals and pastoral caregivers have knowledge and skills in the assessment and management of distress.
Licensed mental health professionals and certified pastoral caregivers experienced in psychosocial aspects of cancer should be readily available as staff members or by referral.
Medical care contracts should include reimbursement for services provided by mental health professionals.
Clinical health outcomes measurement should include assessment of the psychosocial domain (eg, quality of life and patient and family satisfaction).
Patients, families, and treatment teams should be informed that management of distress is an integral part of total medical care and provided with appropriate information about psychosocial services in the treatment center and the community.
Quality of distress management should be included in institutional continuous quality improvement projects.

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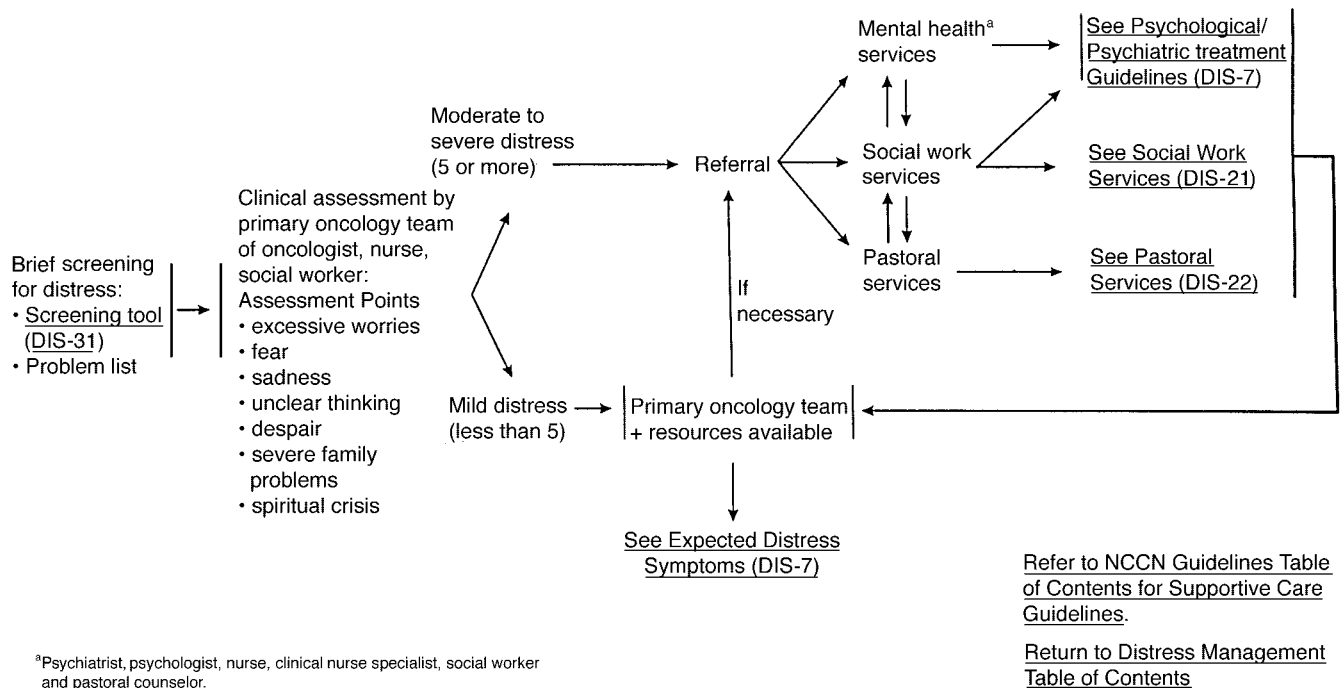
interventions for symptom control, especially for pain, can be managed in the home. With this shift of cancer treatments into the clinics, the need is obvious for the psycho-oncologist to move to the clinics, as well as to provide psychiatric/psychological support in the same or an adjacent space. The need to refer a cancer patient to a psychiatric clinic away from the cancer clinic, and especially to a place marked "psychiatric," loses many people who still feel the stigma of psychiatric care. Psychiatrists and psychologists at Memorial Hospital are assigned to work directly in the gynecology, breast, prostate, and pediatric areas to provide the ideal model of psychological care integrated into the medical care. Our outpatient center, seeing over 1,200 patients per year, is called the Counseling Center. Over two-thirds of our work is now with outpatients, as compared to 20 years ago when it was largely inpatient consultations and treatment.

These moves to clinic and home have created a new burden on families that did not exist before and which demand study and development of better psychosocial services to this largely neglected, yet critically important sector.<sup>62</sup> There are an estimated 24 million homes in which a chronically ill person is being cared for, often without adequate resources, and many in underserved communities. Models of intervention directed at the family of the patient with cancer are needed.

Psychiatric complications of palliative care have received more attention as end-of-life care has received a greater focus nationally. The study of depression has been important since much of the debate about physician-assisted suicide has failed to

## EVALUATION

## TREATMENT



**Fig 2. Overview of evaluation and treatment process.** Reprinted with permission from the National Comprehensive Cancer Network (NCCN), Practice Guidelines in Oncology, Distress Management.

recognize the issue of treatable depression as a factor in requests for help with suicide. Several studies have given a clearer picture of depression in advanced cancer and AIDS.<sup>63,64</sup> Research has also addressed the clinical evaluation and measurement of the severity of the delirium and its pharmacologic management.<sup>65</sup> This remains a major issue for psycho-oncologists who are doing inpatient work. As patients in the hospital represent the sickest of the sick (others are discharged), the care of delirious patients becomes a more frequent and urgent problem.

The psychological and psychiatric aspects of pain control have emerged more clearly recently. The cognitive-behavioral interventions of meditation, hypnosis, and relaxation are useful adjuncts to medication.

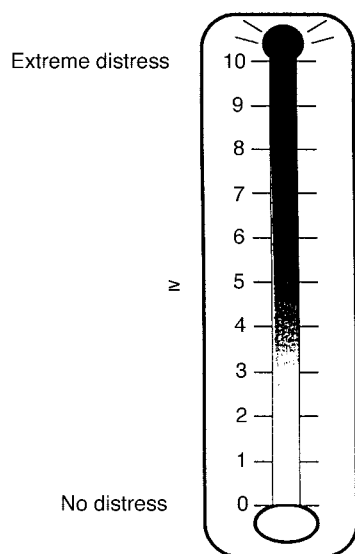
An interesting issue has risen in psycho-oncology as alternative and complementary therapies have entered mainstream medicine and especially oncology. Behavioral interventions, based on strong empirical data, are being widely presented as alternative therapies, blurring the lines between traditional interventions and alternative/complementary regimens, especially in cancer. One of the reasons this is happening is the trend to classify every intervention in cancer as "alternative/complementary" if it is not surgery, radiation, or chemotherapy. Dietary changes, prayer, and common sense, approaches people use all the time, including group and individual psychotherapy, are

placed in this category. This accounts in part for the inflated figures on the use of alternative/complementary approaches. A study by Burstein et al<sup>66</sup> of women a year after their initial treatment for breast cancer found that the women who reported using alternative/complementary therapies had more distress, were more depressed, had poorer sexual function, and poorer quality of life than their counterparts who had not used them. This suggests that patients may be turning to alternatives as a way to treat their distress, which may be due, in part, to the oncologist not asking about their distress and not referring them. But, it may also be that using an alternative treatment is viewed as a nonstigmatizing way to deal with the distress.<sup>67</sup>

These changes are occurring at the time when the range of psychosocial, psychotherapeutic, and behavioral interventions is broader than it has ever been. Group therapies are widely available for patients with cancer, organized by disease site, stage, and often sex. A major impetus to their use was the study of Spiegel et al<sup>20</sup> in 1989, which reported that group sessions for breast cancer impacted positively on survival. A well-designed study by Goodwin et al,<sup>47</sup> which controlled medical variables and replicated the Spiegel intervention, did not show a survival advantage, though there was a reduction of distress and better quality of life. The need for well controlled, prospective clinical trials is imperative to bring the field forward with the highest

Instructions: First please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.

Second, please indicate if any of the following has been a cause of distress in the past week including today. Be sure to check YES or NO for each.



YES	NO	Practical Problems	YES	NO	Physical Problems
<input type="checkbox"/>	<input type="checkbox"/>	Housing	<input type="checkbox"/>	<input type="checkbox"/>	Pain
<input type="checkbox"/>	<input type="checkbox"/>	Insurance	<input type="checkbox"/>	<input type="checkbox"/>	Nausea
<input type="checkbox"/>	<input type="checkbox"/>	Work/school	<input type="checkbox"/>	<input type="checkbox"/>	Fatigue
<input type="checkbox"/>	<input type="checkbox"/>	Transportation	<input type="checkbox"/>	<input type="checkbox"/>	Sleep
<input type="checkbox"/>	<input type="checkbox"/>	Child care	<input type="checkbox"/>	<input type="checkbox"/>	Getting around
		Family Problems	<input type="checkbox"/>	<input type="checkbox"/>	Bathing/dressing
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with partner	<input type="checkbox"/>	<input type="checkbox"/>	Breathing
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with children	<input type="checkbox"/>	<input type="checkbox"/>	Mouth sores
		Emotional Problems	<input type="checkbox"/>	<input type="checkbox"/>	Eating
<input type="checkbox"/>	<input type="checkbox"/>	Worry	<input type="checkbox"/>	<input type="checkbox"/>	Indigestion
<input type="checkbox"/>	<input type="checkbox"/>	Fears	<input type="checkbox"/>	<input type="checkbox"/>	Constipation
<input type="checkbox"/>	<input type="checkbox"/>	Sadness	<input type="checkbox"/>	<input type="checkbox"/>	Diarrhea
<input type="checkbox"/>	<input type="checkbox"/>	Depression	<input type="checkbox"/>	<input type="checkbox"/>	Changes in urination
<input type="checkbox"/>	<input type="checkbox"/>	Nervousness	<input type="checkbox"/>	<input type="checkbox"/>	Fevers
		Spiritual/Religious Concerns	<input type="checkbox"/>	<input type="checkbox"/>	Skin dry/itchy
<input type="checkbox"/>	<input type="checkbox"/>	Relating to God	<input type="checkbox"/>	<input type="checkbox"/>	Nose dry/congested
<input type="checkbox"/>	<input type="checkbox"/>	Loss of faith	<input type="checkbox"/>	<input type="checkbox"/>	Tingling in hands/feet
			<input type="checkbox"/>	<input type="checkbox"/>	Feeling swollen
			<input type="checkbox"/>	<input type="checkbox"/>	Sexual
Other Problems: _____					
_____					
_____					

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**Fig 3. Screening tools for measuring distress.** Reprinted with permission from the National Comprehensive Cancer Network (NCCN), Practice Guidelines in Oncology, Distress Management.

level of scientific rigor. Fox,<sup>68</sup> in a reanalysis of the Spiegel study,<sup>20</sup> found that the intervention group actually had the same survival time as other women in California with stage 4 breast cancer at that time using the National Cancer Institute's Surveillance, Epidemiology, and End Results database. The control group, for unexplained reasons, had shorter than expected survival, which led to the spurious conclusion that the intervention group had lived longer. A meta-analysis by Meyer and Mark<sup>69</sup> did not show a survival benefit across a number of intervention studies, though improvement of quality of life was readily apparent.

The integration of psychological care into total medical care has been difficult due to the attitudinal barriers mentioned earlier on the part of patients and physicians. Also, another attitudinal barrier today has been created by the move of cancer care to busy, often understaffed, clinics where managed care has forced shorter visits that focus on physical symptoms, but do not allow time for patients to mention distress. The National Comprehensive Cancer Network (NCCN), an organization of 18 comprehensive cancer centers, established a multidisciplinary panel to develop the first standards for psychosocial care in cancer (Table 3), and the first clinical practice guidelines for evaluating and treating patients with severe distress (Fig 2).<sup>70</sup> The standards, based on those developed for pain, require that all patients be

evaluated initially and monitored for the level and nature of their psychosocial "distress." The word "distress" was chosen because patients would consider it less stigmatizing than psychological terms, and, also, they would understand that it is normal to be "distressed" if one has cancer. Thus, the word "distress" does not have a negative connotation. However, patients could also recognize that "normal" distress could become more severe and result in significant problems. The NCCN defines distress in cancer as "a multifactorial, unpleasant experience of an emotional, psychological, social, or spiritual nature that interferes with the ability to cope with cancer, its physical symptoms, and its treatment. Distress extends along a continuum ranging from normal feelings of vulnerability, sadness, and fear to disabling conditions such as clinical depression, anxiety, panic, isolation, and existential or spiritual crisis".<sup>70</sup>

A rapid screen, taken from the 0 to 10 scale used in evaluating pain, is recommended for screening in the waiting room along with a list of possible physical, psychological, social, and spiritual problems (Fig 3 shows the Distress Thermometer [0 to 10 scale] and the Problem List). Preliminary testing of the Distress Thermometer against the Hospital Anxiety and Depression Scale (HADS) and Brief Symptom Inventory finds it acceptable to patients and staff and identifies a score of 5 or greater as equivalent to "caseness" using the HADS scale.<sup>71</sup>

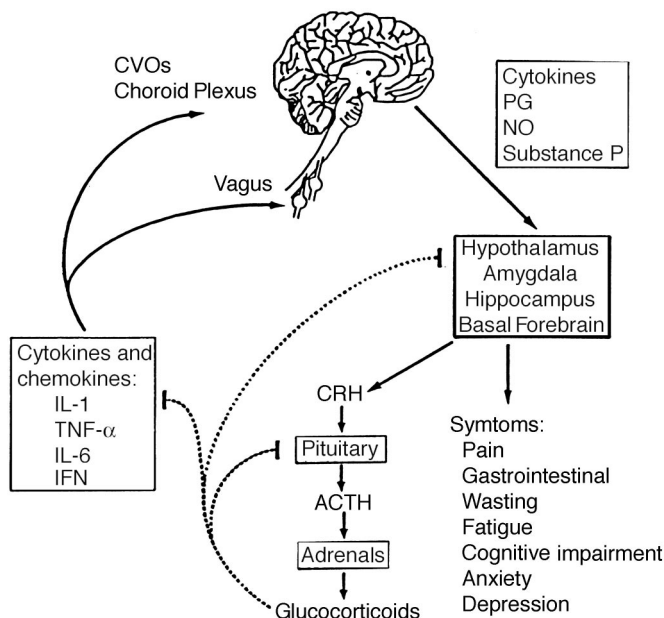


Fig 4. Biologic/physiologic mechanistic framework for cytokine-induced sickness behavior. In the afferent arm (solid lines), proinflammatory cytokines and chemokines (interleukin [IL]-1, tumor necrosis factor [TNF]- $\alpha$ , IL-6, interferon [IFN]- $\alpha$ , and IFN- $\gamma$ ) are released in the periphery by activated immunocytes. They exert their effects on peripheral nerves and directly on the brain to induce various aspects of the sickness response. These behavioral/physiologic changes are elicited by mediators acting downstream from the cytokines. Glutamate, nitric oxide, prostaglandins, and substance P act on brain regions, including the paraventricular nucleus of the hypothalamus and the amygdala. Turnover of monoamines (serotonin, dopamine, norepinephrine) in these brain regions is affected. Availability of monoamine precursors (eg, tryptophan) may be decreased. The hypothalamic-pituitary-adrenal axis is activated, with up-regulation of the plasma concentrations of corticosteroids, which in turn can provide feedback (dotted lines) to limit cytokine production. Other mediators, such as the antiinflammatory cytokine IL-10, also have roles in activation and regulation of responses. ACTH: adrenocorticotrophic hormone; CRH: corticotropin-releasing hormone; CVO: circumventricular organ; NO: nitric oxide; PG: prostaglandin. Reprinted with permission from the American Cancer Society: Cleeland et al. Are the symptoms of Cancer and Cancer Treatment due to a Shared Biologic Mechanism? *Cancer*, 2003, Volume 97, Number 11, p 2922.

Similar to the experience of pain, asking the question “How is your distress today?” verbally, or with pencil and paper, opens a dialogue that would probably not otherwise occur. Fleishman (personal communication) found the most common problems mentioned by patients on their problem list were fatigue, pain, worry, sleep, and sadness.

A score of 5 or more on the Distress Thermometer triggers the oncology staff to refer the patient for psychosocial services and the Problem List indicates the nature of the problem and whether the patient is referred to mental health, social work, or pastoral counseling (Fig 3). A multicenter trial for validity and feasibility has found the Distress Thermometer to be a valid instrument with a score of 4 to 5 as significant distress compared to the HADS and Brief Symptom Inventory (Jacobsen, personal communication). Clinical practice guidelines were written by the NCCN Panel for psychiatric disorders common in cancer patients and included the first treatment guidelines for social work and pastoral counseling.<sup>70</sup> ([www.nccn.org](http://www.nccn.org))

These NCCN standards and guidelines provide the first “gold standard” for psychosocial care arrived at jointly by oncologists

and all supportive care disciplines. The American College of Surgeons' Commission on Standards and the Association of Community Cancer Centers have adapted their standards to incorporate these concepts. The goal is now to approach regulatory agencies, such as JCAHO and HEDIS, to ensure that quality of psychosocial care is monitored against the benchmark of established standards.

## Summary

At the beginning of a new millennium, the good news is that a psycho-oncology unit exists in virtually all cancer centers and community hospitals, usually comprised of a multidisciplinary group who offer psychosocial services and maintain the staff's awareness of these issues in patient care. The base of information is far broader and more accessible today. And collegiality across disciplines is also far better now than in the past because mental health disciplines are more integrated into new units and with the general oncology staff. Some cancer clinics have mental health professionals available during clinic hours for consultation, which is the ideal model so that patients perceive their psychological care as fully integrated into their total care. A major problem remains the woefully small reimbursement for services, an issue that health policy must address.

The training of psycho-oncologists and the encouragement of young clinicians and investigators into the field remains critically important to ensure an adequate pool of excellent candidates to develop new psycho-oncology units in community hospitals and cancer centers and to address clinical and research needs. Continuing efforts to set standards for education in psycho-oncology have now developed an online core curriculum available online ([www.apos-society.org](http://www.apos-society.org)). Trainees from psychiatry are needed in psycho-oncology, particularly in the areas where a knowledge of medicine and psychiatry is important, as in palliative care and symptom control. Psychologists interested in health continue to form the central cadre of researchers and investigators, especially in cancer prevention, early detection, and genetic testing. The need for training young investigators and clinicians will grow as the National Cancer Institute places greater emphasis on prevention research, palliative care, communication research, and psychiatric/neuropsychiatric/cognitive consequences of cancer treatment.

The research agenda is both exciting and challenging, with many questions that beg for study. One of the emerging issues is the role of proinflammatory cytokines in producing “sickness behavior” in animals and a range of symptoms that are frequent with cancer: fatigue, pain, weakness, cognitive loss, depression, and anxiety. It is of interest that several key symptoms that we treat may be cytokine or immunologically related. Cleeland et al<sup>72</sup> has outlined these emerging concepts as possible explanation for this cluster of common cancer-related symptoms. Figure 4 is a diagram of the immunologic changes and cytokines released, which may account for these symptoms in patients with cancer.

Prevention of cancer becomes an increasingly important goal in the United States and worldwide. Behavioral scientists in psycho-oncology can contribute to the cancer control effort by their expertise in changing lifestyles to reduce cancer risk, particularly the use of tobacco, which accounts for 15% to 30% of worldwide cancer cases.<sup>73</sup> The next 25 years should see further expansion of this new, but important field in cancer

which explores the human elements of behavior and emotions as they relate to cancer cause and treatment.

### AUTHOR'S DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author indicated no potential conflicts of interest.

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