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Jimmie C. Holland, MD, is recognized as the founder of the field of psycho-oncology. In 1977, she established the first committee in the CALGB to assess quality of life in clinical trials. In the same year, she became Chief of the Psychiatry Service and then Chair of the Department of Psychiatry and Behavioral Sciences at Memorial Sloan-Kettering Cancer Center to 2003, where she now holds the Wayne Chapman Chair in Psychiatric Oncology and is also Professor of Psychiatry at Weill Medical College, Cornell University. Dr. Holland is Founding President of both the International (1984) and the American (1986) Psycho-Oncology Societies. She edited the first textbook of psycho-oncology in 1989; a second reference text in 1998, and a new edition in 2010, (*Psycho-Oncology*, Eds). Dr. Holland is Co-Editor of the journal, *Psycho-Oncology*, begun in 1992. She co-authored *The Human Side of Cancer*, published in 2000 for patients and their families. Dr. Holland chairs the NCCN panel that published the first Clinical Practice Guidelines for management of distress in cancer. In 1995, she was elected Fellow in the Institute of Medicine. Dr. Holland received the Medal of Honor for Clinical Research from the American Cancer Society in 1994; the APA Presidential Commendation in 2000. She is a graduate of Baylor College of Medicine.

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Why Psychosocial Care is Difficult to Integrate into Routine Cancer Care: Stigma is the Elephant in the Room

This issue of *JNCCN* reviews the NCCN Clinical Practice Guidelines in Oncology: Distress Management for 2010, updated by the NCCN Distress Management Panel. The NCCN appointed this multidisciplinary panel, which met first in 1997, to address the barriers to psychosocial care and to develop clinical practice guidelines.¹ The panel members felt that the major barrier, for both physicians and patients, was the negative meaning and stigma attached to words implying the psychological domain, such as *psychiatric*, *psychological*, and *psychosocial*. The panel considered descriptive words that could encompass the range of fears, worries, and concerns of patients with cancer, and proposed the word *distress* because it could vary in severity from a normal response to a more significant level, consistent with a psychiatric disorder requiring intervention. The word *distress* also encompasses the range of fears, anxieties, and sadness that patients with cancer experience.

The panel then developed guidelines for the management of distress, recommending that patients be first screened for distress with a short, initial, rapid screening question, followed by a second phase during which the doctor or nurse asks about specific problems. This process should be repeated as clinically indicated as part of routine care. Learning from the success of pain management, the panel suggested using a 0 to 10 scale in the form of a Distress Thermometer (DT) to allow patients to indicate their level of distress, either verbally or with pen and paper. Those who scored above a cutoff score for “caseness” (≥ 4) were asked to identify the domains causing the distress and then were referred to a professional such as a social worker, nurse, psychologist, chaplain, or psychiatrist, depending on the problem.² These guidelines are updated annually. In Canada, an effort is being made to establish distress the sixth vital sign.³

In 2007, the Institute of Medicine (IOM) issued a landmark report noting that quality cancer care *must* integrate the psychosocial domain, because strong evidence shows the efficacy of a range of interventions, from psychological to psychopharmacologic.⁴ The model for integrating psychosocial services is based strongly on the NCCN Distress Management Guidelines. There is now an alliance of more than 30 professional and advocacy groups with the mission to assure implementation of these guidelines.

This issue of *JNCCN* contains important steps that have been taken to encourage the integration of psychosocial services in cancer care. As discussed, short screening instruments, particularly the DT, have been validated as a broad first screen.⁵ Touch-screen technology brings a rapid waiting room opportunity to screen for psychosocial problems.⁶ Jacobsen has developed a patient chart audit of quality care that is being used in the voluntary audit of community oncology practices.⁷

However, attitudinal barriers persist that reduce the implementation of quality psychosocial care. We propose that stigma is a major barrier that delays patients’ asking for help and oncologists’ integrating psychosocial care into their practice. Stigma has been associated with cancer for centuries. In the mid 1970s, health care professionals began to tell people their cancer diagnosis and cancer “came out of the closet” and into the public media. Today, it is hard to recall when the word *cancer* was not spoken. Nonetheless, stigma remains, and is attached more strongly today to some cancer sites than others, particularly where “blaming the victim” occurs, as with lung cancer.

Regrettably, the stigma attached to psychological issues has not appreciably diminished, even when the issue relates to a life-threatening illness such as cancer. This partially accounts for why the psychosocial domain has been slow to develop. A

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large proportion of patients in need of psychosocial interventions do not receive them,⁸ even though clinical depression has a marked effect on quality of life and adherence to cancer treatments if left untreated.⁹ Only a few services implement recommended screening procedures¹⁰ and, despite evidence for the benefits of communications skills training, these are not widely implemented.¹¹ Funding for psychosocial services has not yet matched the level of need, despite compelling evidence of cost benefits.³

This editorial briefly reviews this history, which will help those working with patients with cancer to understand how contemporary attitudes have formed and how recalcitrant fixed beliefs can be to change.

What is Stigma and Why is it Important?

Stigma is recognized as a powerful adverse influence on the responses of individuals, families, and communities to illness and disease.¹² It can be directed to individuals affected by illness, their families, and the institutions and people who care for them.¹³

Throughout history, the focus of disease-related stigma has varied, but it tends to be greatest for conditions that provoke the most fear and threat. Stigma may be greatest when cause is unknown, when beliefs about individual responsibility for illness are most firmly held, and when a risk for contagion is present or stigmatized behaviors are implicated. Illnesses carry deeply held personal and cultural meaning that may have an adverse impact on the affected individual's perception of themselves (e.g., decreased self-esteem, feelings of shame, loss of dignity).¹⁴ They can also have an adverse effect on the way people with illnesses are treated by others, from people in their immediate environment through to health systems (e.g., service availability, funding).¹⁵

Stigma and Mental Illness

For centuries, mental illness has been subject to fear and misunderstanding, and people with mental illness historically have been among the most marginalized. Implied personal culpability believed to reflect personal, social, or spiritual deficit is perhaps greatest in mental illness. This stigma is longstanding, often deeply held, and evident across many cultures.

Studies of community attitudes to mental illness clearly illustrate the problem.¹³ People with depression or other mental disorders are often viewed as personally responsible for their condition.¹⁶⁻¹⁸ There are worryingly low levels of confidence in the benefits of psychiatric and psychological treatments and in referral to mental health clinicians.¹⁹ Not surprisingly, these beliefs influence ways people seek help for distress and psychological problems.²⁰ Furthermore, greater levels of distress, such as depression and anxiety, reduce confidence in accepting the beneficial interventions available. It is generally accepted that in rural areas, where communities are smaller, concerns about the negative social consequences associated with having others know about a mental health problem may be a major disincentive for individuals to seek help.²¹

Stigma may be inadvertently reinforced by health professionals, who may be reluctant to diagnose depression because of concern about its stigmatizing effect, or they may convey unease in exploring distress or referring patients to mental health colleagues.^{22,23} This, in turn, often prevents patients from seeking proper mental health treatment.

Stigma of Cancer

Despite notable recent improvements in addressing it, the stigma of cancer remains by virtue of its threat to life, ongoing uncertainty about its causes in many cases,



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and perceived incurability. Personal attitudes and cultural beliefs about cancer are powerful factors influencing all aspects of cancer care (from prevention and early detection to treatment and how cancer is discussed between patients and doctors and among families).²⁴⁻²⁶ These culturally based models for cancer, when searching for explanations, can include an overemphasis on the role of past and present behaviors or the view of cancer as punishment, retribution, and “fate.”²⁴

Cancer-related stigma can extend to strongly held views about the distress experienced by people with cancer. Prevailing myths exist about the link between people’s level of stress and their style of coping as a cause of the development and progression of cancer. In this way, patients with cancer are held responsible for their own survival in a way that other patients are not. This overstatement of personal capacity to control cancer (e.g., cancer can be controlled by remaining positive) becomes a considerable burden to patients and families. Furthermore, patients may be subject to expectations that “good” cancer patients are those who remain “brave” at all times,²⁷ often with related expectations of an unrealistic stoicism (which is frequently associated with patients’ avoidance of or embarrassment about discussing distress for fear that this will reflect badly on their coping abilities).²³

Clinicians, as well as patients, may also mistakenly believe that even severe levels of depression and anxiety are normal or expected consequences of cancer. Therefore, they unfortunately believe that this distress will not require nor benefit from psychosocial or psychiatric interventions,²⁸ or that it will inappropriately “medicalize” a person’s feelings to receive this assistance. Consequently, stigma is then manifested and expressed in the prejudicial views about the benefits that can come from these interventions.

Studies conducted among patients with cancer indicate that those with the highest levels of distress, least social support, lower levels of illness knowledge, and more avoidant coping styles have the lowest interest in psychosocial care and are least likely to accept psychooncologic interventions, but paradoxically are those most likely to benefit from treatment.^{29,30} Perceived stigma of referral is an important influence on this reluctance.²³ Therefore, the people most likely to benefit from interventions are those who need the greatest support and encouragement from cancer clinicians to receive this help.

Stigma and Specific Cancer Sites

Heightened social stigma is associated with specific cancer sites based on the origin of the disease, the perceived role of health behaviors or lifestyle and prevailing views about its preventability (i.e., lung cancer and smoking, cervical cancer

and sexual activity), and the effects of the disease (i.e., prostate and breast cancer and their impact on sexuality).

Lung Cancer

Because lung cancer is so closely associated with smoking, it probably carries the greatest stigma among cancers; some have even deemed it the “Smoking Stigma.” Public health interventions that aim to reduce behaviors such as smoking may inadvertently accentuate this stigma.³¹ Even though stigma has not been widely published in the cancer literature, the greatest numbers of citations to stigma are in regard to lung cancer. For smokers and non-smokers alike, stigma has been found to be high among this population.^{32,33} At diagnosis of lung cancer, patients are often immediately asked “Did you smoke?” Reactions to patients may differ depending on their answer, reflecting a “blame the victim” stance and perhaps a reassurance on the part of the questioner, who may believe “it won’t happen to me.”

Cervical Cancer

Human papillomavirus (HPV) is a sexually transmitted disease that leads to cervical cancer. Similar to smoking and lung cancer, cervical cancer therefore has a behavioral component to its etiology, one that may also be subject to prejudicial attitudes and their personal consequences. Evidence showing that persistent high-risk HPV can cause cervical cancer has increased cervical screening in the United States.³⁴

Breast, Gynecologic, and Prostate Cancers

Stigma is also high for patients who have cancer sites that impact on their sexuality. For example, some investigators have found that stigma associated with prostate cancer is perhaps higher than for any other cancer site³⁵ because of the sexual dysfunction associated with the disease and its treatment. Given the increased media attention and recent public figures who have been outspoken about the disease, prostate cancer is becoming more openly and publicly discussed, which may eventually help decrease the associated stigma. This has been seen with the gains achieved through advocacy for women with breast cancer. Unfortunately, women with ovarian and uterine cancer experience profound effects on their sexuality, yet less advocacy and attention has been given to them. Regrettably, men with breast cancer, though much fewer in number, experience more social stigma than women with the disease.

Prostate cancer, like many other cancers, is often hidden. It is often affected by a “double stigma”: that of a life-threatening illness and a disease that affects sexual organs and sexual function, which are factors that discourage a man from disclosing his experience with prostate cancer.³⁵

HIV-Related Cancer

HIV-related cancer (such as Kaposi’s sarcoma) is associated

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with another set of specific conditions that are highly stigmatized because of their close association with AIDS, sexuality, stigmatized behaviors, and lifestyle choices. Patients with these cancers are often ashamed of their illnesses, and try to hide them from their friends and family. The presentation of widespread skin changes in Kaposi's sarcoma increases the potential for stigma through disfigurement. Clinicians have noted that many patients prefer to reveal the disease as cancer without noting that it is HIV-related, thereby avoiding the second stigma.

What Can Be Done?

To address the many levels at which stigma occurs, attention must be given to reducing the impact of this stigma on people directly affected by cancer; altering services to be more focussed on the psychosocial needs of this population; and addressing ways of countering the broader cultural beliefs and attitudes that discourage people from seeking and receiving help for their distress.^{36,37}

Among patient-focused approaches, resources and interventions have been promoted for all patients to address the universal need for information about cancer and its consequences, including distress and available treatments. These are recommended in the routine care for all patients.³⁸ A clinical approach to patients with cancer that promotes their esteem and sense of dignity despite the personal and social meanings of cancer is important in routine care, and can be an important dedicated focus of individual and group-based psychosocial interventions.^{39,40}

Substantial evidence now shows that training cancer clinicians (including doctors and nurses) in communication skills has significant benefits to not only patients but clinicians, including improved confidence of clinicians in responding to emotional cues, recognizing poor self-esteem as a consequence of stigma, eliciting patients concerns, and having an improved attitude to psychosocial care, especially when training and support in these skills is continued over time.^{41,42}

Training and education alone have only a limited impact unless they are matched by changes in models of services.³⁸ The IOM report of 2007 strongly asserts that "psychosocial care must be integrated in quality cancer care," in keeping with the NCCN guidelines. By integrating psychosocial care within patient's medical care, stigma is reduced because patients feel their mental health needs are as important and require equal attention as their medical needs. They perceive a fully integrated care system that focuses on the whole person, not just the tumor. This is essential for overcoming the stigma of having psychosocial needs identified. Patients should have a seamless process of screening for distress, an appropriate treatment plan,

and referrals provided as needed. This field needs to better implement this report. An alliance of advocacy and professional organizations in cancer is pursuing this goal.

Translation of guidelines into practice must address the considerable organizational barriers, including attitudes,¹¹ and therefore projects are needed to show the efficacy and cost-effectiveness of guidelines. An important role for psychooncology research is to investigate how health systems can change to better meet these needs.

The impact of socioeconomic disadvantage on cancer outcomes is well established. Interventions must be accessible and appropriate to patients and families in diverse geographic, cultural, and socioeconomic settings if they are to promote use.

Finally, at the level of the general community, several multifaceted stigma-reduction strategies have been successful, with evidence of gradual improvement in attitudes and knowledge about mental health problems.¹⁶ Efforts to improve public understanding of achievements in cancer treatments have played a major role in the substantial changes in public perceptions of cancer. The same needs to be done with psychosocial interventions in cancer care. Public health education and prevention campaigns must highlight behavioral risks to cancer in a manner that does not further stigmatize individuals with related cancers or those who engage in these behaviors.³¹

Conclusions

As we enter the second decade of the 21st century, stigma remains a major barrier to both detecting psychological distress in patients with cancer and improving psychosocial and mental health service use among these patients. Although great strides have been shown with the NCCN Distress Management Guidelines and the IOM's landmark report, and by researchers worldwide, much remains to be done. The fact that quality care today now demands integration of psychosocial in routine care is of great importance at the policy level, but practical changes in the day-to-day experiences of patients will require more time. To improve psychosocial standards among patients with cancer, their psychosocial needs must be entirely met. Improvements are undoubtedly unfolding, but novel interventions, better screening measures, and targeted community-based approaches need to continue to be developed to decrease stigma at all levels.

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