Editorial

Demoralization Syndrome: New Insights in Psychosocial Cancer Care

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The psychological reactions of patients in response to cancer have been the object of psycho-oncology research since the first studies carried out by Arthur M. Sutherland in the middle of the last century.[1] Subsequent better designed investigations were carried out in many parts of the world using standardized psychiatric interviews according to the *Diagnostic Statistical Manual for Mental Disorders* (*DSM*) of the American Psychiatric Association and the *International Classification of Diseases* (*ICD*) of the World Health Organization. Meta-analyses of these studies are now available[2] and indicate that approximately 30% to 40% of patients with cancer meet the criteria for a psychiatric diagnosis—especially depressive disorders—that have extremely negative consequences for the patients and their families (eg, impairment of quality of life, longer rehabilitation processes, risk of suicide, reduction in adherence to treatment).

It is clear that having a system to codify the psychiatric disorders observable in oncology, including depression, is extremely important for a whole-person–centered approach that includes psychosocial aspects as mandatory targets. However, the psycho-oncology literature has demonstrated that many other psychosocial dimensions not detectable with classical psychiatric nosology (ie, *ICD* and *DSM*) are extremely common and have a remarkable role in negatively influencing a patient's quality of life.[3,4] Demoralization is one of the most important among the aforesaid constructs. It can be clinically separated from depressive disorders, has a high prevalence in medical disorders, and thus needs to be carefully examined, correctly measured, and treated. There have been several recent reports about the importance of demoralization, particularly in the settings of cancer and palliative care.[5-7]

In this issue of *Cancer*, Robinson et al[8,9] explore the application of a new, refined, 16-item, self-report measure of demoralization (Demoralization Scale-II [DS-II]) in patients with cancer or other progressive diseases who were receiving palliative care. The analyses by Robinson and colleagues highlight the need for clinicians to consider demoralization as a significant clinical entity to be taken seriously into account in cancer settings.

Demoralization Syndrome and its Assessment

The concept of demoralization

The concept of demoralization is not new. It was introduced into the clinical setting by psychiatrist and psychotherapist Jerome D. Frank in the 1960s and 1970s to define a syndrome of existential distress ("disturbance," "suffering") occurring in patients with severe conditions, such as physical ilnesses or mental disorders, specifically those that threatened life or the integrity of being. Demoralization denotes a persistent failure of coping with internally or externally induced stress and is one of the most common reasons individuals seek psychotherapeutic treatment.[10] Its characteristic features, not all of which need to be present in any one individual, are feelings of impotence, isolation, and despair. The individual's self-esteem is damaged, and he or she feels rejected by others because of his or her failure to meet their expectations. In a more articulated conceptualization, de Figueiredo and Frank[11] suggested that demoralization is a combination of distress (anxiety, sadness, discouragement, and resentment) and subjective incompetence (a feeling of being trapped or blocked because of a sense of inability to plan and initiate concerted action toward one or more goals), which coexist when assumptions relevant to self-esteem are disconfirmed. Patients with major depression perceive that the source of distress is within them, have feelings of guilt and anhedonia, and do not perceive any motivation; in contrast, those with demoralization perceive

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the source of distress outside of themselves and do not feel guilty (but do feel subjectively incompetent to cope). Also, they do not present with anhedonia but with an uncertainty about the direction their actions should take while the magnitude of their motivation is intact.[12] By integrating George Engel's giving-up/given-up construct,[13] which identifies the sense of psychological impotence, hopelessness, and helplessness (in which previously used strategies, whether psychological or social, no longer seem to be effective for dealing with changes in the environment), and Frank's concept of demoralization, Fava et al[14] proposed a further definition of demoralization. Those authors suggested that, in the medically ill, demoralization can be diagnosed if they meet a series of criteria, including feelings of helplessness and hopelessness and the perception of diminished competence and control in one's own functioning. Patients' relationships with other individuals or their roles in life may feel less secure or gratifying. The external environment or their own performance does not fulfill patients' expectations given their previous experiences. They also feel the loss of a sense of continuity between past and future, with diminished hope and confidence in projecting themselves into the future, and are prone to revive previous unsuccessful or frustrating experiences.

More recently, Clarke and Kissane,[15] and Kissane et al[16] studied patients in oncology and palliative care settings and suggested that the demoralization syndrome is a specific clinical entity characterized by a series of symptoms, including existential distress; encompassing hopelessness or loss of meaning and purpose in life; cognitive attitudes of pessimism, helplessness, sense of being trapped, and personal failure; absence of drive or motivation to cope differently; associated features of social alienation or isolation and lack of support; and fluctuation in emotional intensity. All these phenomena should persist for more than 2 weeks, and a major depressive or other psychiatric episode should not be present as the primary condition.

Demoralization is reported as a spectrum or a gradient that starts with disheartenment (as a mild loss of confidence), despondency (starting to lose hope), despair (lost hope), and full-blown demoralization syndrome (lost purpose and given up), which is a pathologic condition causing significant impairment in important areas of functioning.[17]

Demoralization syndrome in clinical and cancer settings

Thus, the correct assessment of demoralization, including application of the DS-II as developed in the reports by Robinson et al, in this issue, is extremely important. The prevalence of demoralization, as a clinical syndrome separated from major depression, among 807 medically ill Italian patients who were recruited from different settings (eg, gastroenterology, cardiology, endocrinology, oncology), was reported as 30.4% by Mangelli et al,[18] whereas major depression (according to the *DSM*) was present in 16.7% of patients. Also, 69% of patients who had demoralization did not satisfy the criteria for major depression, and 43.7% who had major depression were not classified as demoralized. Similar data were reported in a study of 721 patients who had severe medical illness, including motor neuron disease and advanced cancer, by Clarke et al,[19] who demonstrated that demoralization is a specific construct that can be distinguished from anhedonic depression.

In another Italian study of 146 recently diagnosed patients with cancer who had a good performance status, almost 33% presented symptoms that met the criteria for demoralization, and there was an overlap between patients who had a definite psychiatric diagnosis and those who had demoralization in only $<$50% of the sample.[20] Interestingly, demoralized women with breast cancer (28.6% of the whole sample) reported poorer quality of life and higher levels of worries and preoccupation related to cancer (eg, the illness itself, feeling different from others, the impact on sexual life) compared with nondemoralized women, along with less effective coping styles, including a tendency to adopt a pessimistic and hopeless-helpless attitude toward cancer.[21] Confirmatory data were more recently reported among German patients with cancer in whom the prevalence of moderate-to-severe demoralization, as assessed using the first version of the Demoralization scale (DS), was 20% Loss of dignity significantly mediated 81% of the effect of the number of physical problems on demoralization and, conversely, demoralization mediated 53% of the association between physical problems and loss of dignity.[22] Likewise, in a study of 200 patients with cancer in Taiwan, demoralization, as measured using the DS, was negatively associated with the possible positive change that emerges after struggling with highly challenging life crises (ie, posttraumatic growth), sense-making (ie, the sense made of cancer experience), and benefit-finding (ie, a positive change from the experience of cancer).[23] Demoralization, especially in its subcomponent of loss of meaning, was also a more significant predictor of suicidal ideation than clinical depression itself.[24]

Instruments for Assessing Demoralization

Given the need for clinicians to pay attention to demoralization, a series of instruments has been proposed.

Some of them are general measures of a sense of well being and life satisfaction (eg, the demoralization scale from the Minnesota Multiphasic Personality Inventory-II Restructured Clinical Scales)[25] or nonspecific distress (eg, the demoralization scale of the Psychiatric Epidemiological Research Interview).[26] More specific instruments are represented by the Subjective Incompetence Scale[27] and the demoralization module within the Diagnostic Criteria for Psychosomatic Research, a clinically oriented interview developed by Fava et al[14] to examine the various psychosocial dimensions that affect the medically ill and are not present in the classic psychiatric taxonomy.

As mentioned, the first version of the Demoralization scale (DS) has also been demonstrated to be a complete and psychometrically sound tool.[28] It was originally validated among 100 patients with advanced cancer, and it consists of 5 subscales corresponding to the core dimensions of demoralization as proposed by Clarke and Kissane,[15] specifically: loss of meaning, dysphoria, disheartenment, helplessness, and sense of failure. In the oncology setting, the DS has been translated and validated in several countries, including Germany,[29] Ireland,[30] Spain,[31] and Taiwan.[32]

The study by Robinson et al presented in this issue of *Cancer* offer the possibility to use for clinical and research purposes a shorter version of the original DS. Through a sophisticated and well performed statistical analyses, the authors were able to reduce the original 24-item version of the DS in an easier-to-fill-in, 16-item version, the DS-II, which measures demoralization through 2 factors. The first, called Meaning and Purpose, examines the core related to the dimensions of loss of meaning and purpose as well as helplessness (eg, "I am not a worthwhile person," "I feel hopeless," "My life seems to be pointless"); the second, called Distress and Coping Ability, examines the core related to dysphoria, disheartenment, and sense of failure (eg, "I no longer feel emotionally in control," "I feel trapped by what is happening to me"). An interesting point is that a correlation was observed between demoralization and psychological symptom burden, depression, and the desire to die; and an opposite association was observed with quality of life, social support, existential well being, and the will to live. Also, it appears that patients with low and or moderate levels of demoralization were more likely not to have a major depressive disorder, whereas this difference was less likely in severely demoralized patients, who had a greater chance of being diagnosed with a major depressive disorder.

Conclusions

On the basis of the reports by Robinson et al, demoralization is confirmed as a significant clinical dimension that needs to be part of the vision physicians should have when treating patients with cancer. It is not a psychiatric disease; rather, it is the expression of an unfolding, situational existence already involved in an irreducibly complex social world in which cancer and its consequences, as traumatic stressors, impact the patient's experience and feelings, inducing profound emotional suffering.[33] A significant issue has been raised by Kissane[34] with respect to the hypothetical risk that demoralization syndrome can become a further psychiatric diagnosis that stigmatizes a normal range of emotions by medicalizing and pathologizing them. That author correctly suggests that this is not true, since it is the role and the power of a diagnosis (in the Greek etymologic sense of knowing thoroughly) to recognize human suffering and distress, thus favoring patients' access to services for help and proper therapeutic interventions, which, in turn, can ameliorate his or her quality of life. Indeed, the mandate of oncology is to promote the healing of individuals afflicted with cancer in an environment of global, person-centered care. Robinson and colleagues have provided further support for this vision and the urgent need to sensitize physicians about how to improve their discernment of cancer patients' psychosocial dimensions by going further with the assessment of general emotional distress to more specific aspects of suffering, such as demoralization.

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