Demoralization:
A life-preserving diagnosis to make for the severely medically ill

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INTRODUCTION

Existential distress and suffering in terminally ill patients present challenges for palliative care providers who are attempting to help these patients achieve a good death. Such challenges are common and often unmet. Among those with a bountiful sense of life accomplishment, acceptance of dying becomes more probable as death approaches. Adaptive coping is facilitated by a perception of the meaning, value, and worth of life. However, when life appears futile, its meaning is lost and the worthiness of the individual is depleted, despair can result. The demoralization syndrome has been proposed as an important diagnosis that can guide management of these difficult circumstances (1). What remains unanswered is whether consensus can be reached about its diagnostic criteria, whether the construct can be shown to be empirically valid, how the demoralization syndrome can be differentiated from depression, and what utility the construct offers to the field.

For several decades, assessment for the presence of clinical depression and anxiety was the key clinical diagnostic task that healthcare professionals undertook to understand patients presenting with unhappiness, hopelessness, helplessness, and a desire for hastened death. This narrow lens created therapeutic difficulties when anhedonia was not present, when the patient's mood was reactive, and when the patient could laugh spontaneously in a humorous context. Clearly, suffering can occur within an existential frame and coping can be challenged, but the psychiatric classification system has proven unhelpful in directing the healthcare professional toward therapeutic strategies.

A relatively recent revision of the conventional Lazarus and Folkman model of coping has provided insight into this predicament (2). In 1984, conceptualization of the original coping model included a stressor-generating appraisal of any potential threat, with a choice of problem-based or emotion-based response pathways. Folkman became intrigued by the retention of joy among the caregivers she was studying, even though illness was causing a sad decline in their partners' well-being. The meaning they found in caregiving was the basis of their sustained happiness and resilience in the face of adversity. Folkman realized that meaning-based coping had been completely overlooked by the original coping model, yet it is a major adaptive pathway. As a corollary, loss of meaning and purpose precipitates loss of morale, a struggle to cope, and the potential development of despair and demoralization. The future is perceived as bleak, dark, and hopeless, and continuing to exist seems pointless (1).

THE DEMORALIZATION SYNDROME

In psychiatry, mood assessment has long been a central activity; appraisal of morale and sense of meaning has been neglected. Recognizing this deficiency, we proposed at the turn of this century that physicians give consideration to a new clinical diagnosis: the demoralization syndrome. Morale is a dimensional state of mind, ranging from optimism and confidence at one end of the scale to loss of morale at the other. Loss of morale can be further divided into a mild loss of confidence or disheartenment, a greater loss of hope and purpose causing early despondency, and a morbid state of mind characterized by a considerable loss of meaning, hope, and purpose. We named the latter state "demoralization."

The demoralization syndrome is described as a persistent mental state resulting from a stressor event, such as advanced illness. Over a period of two or more weeks, the patient in this state complains of: meaninglessness or purposelessness; hopelessness or helplessness; difficulty in coping with and meeting the expectations of self or others; and feelings of failure or pointlessness that can lead to a growing urge to give up, withdraw,

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or consider ending one's life because a worthwhile future is inconceivable (1). Demoralized patients may become very distressed, agitated, and desperate to resolve their predicament. While suffering from the symptoms of a prolonged and debilitating illness (such as cancer or Lou Gehrig's disease), they may also be afflicted with a comorbid anxiety or depressive disorder. Nevertheless, it is primarily the loss of morale that brings their mental state to our attention.

A thoughtful reader might ask, "Does this stigmatize a normal range of human responsiveness and unduly pathologize it?" I believe not. The power of a diagnosis is that it can permit due recognition of distress and suffering, lead patients to seek help and access services, and facilitate discussion about what can be done (3). Specifically, the triggering of therapeutic interventions can ameliorate suffering. Medicine's worthy aim is to promote the healing of those afflicted with illness, although symptoms and the mental states they engender do not specifically constitute the disease. It would clearly be useful for practitioners of palliative medicine to define the threshold for diagnosis of demoralization. This would assist palliative care teams to recognize when they should intervene clinically and help them to encourage patients to engage in life rather than passively accept death (4).

STUDIES OF DEMORALIZATION

Our first step in facilitating empirical studies of demoralization in palliative care was to develop a measure of demoralization (5). The scale permitted researchers to conduct a series of observational studies in order to demonstrate the presence of the condition. In the past decade, the demoralization scale has been translated into eight languages. A recent systematic review found 25 studies of demoralization involving 4,545 participants in 10 countries (6). This demonstrated a prevalence of clinically significant demoralization in the range of 13 to 18 percent of patients. Demoralization is real, discernable, and worthy of clinical focus because of the inherent morbidity that it reflects.

There is a range of factors that show particular vulnerability to the development of demoralization. These include being single (unmarried, widowed, separated, or divorced), being unemployed, being socially isolated or alienated, having reduced social functioning, having poorly controlled physical symptoms, receiving inadequate treatment for depression and anxiety, and having comorbid substance dependence (6). Spirituality and religious beliefs have been found to be protective; spiritual problems have resulted in greater demoralization (7). No clear relationship has yet emerged between demoralization and age, gender, or education level. Indeed, results related to these factors have been mixed, and so definitive conclusions cannot be drawn.

There are few data on illnesses other than cancer, but demoralization was found to be higher in patients with motor neuron disease, systemic lupus, and heroin/methadone dependence than in patients with cancer (6). There is no association between time since diagnosis, stage of disease, and type of treatment. Findings related to cancer site are inconsistent, but demoralization may be higher among those with some disfiguring cancers, including cancers of the head and neck (6). A wide range of physical symptoms is implicated in aggravating demoralization. These include pain, dyspnea, fatigue, reduced mobility and overall loss of independent functioning, constipation, confusion, memory change, and reduced quality of life. Future investigations of whether certain diseases and symptom clusters are likely to induce more prevalent and intense demoralization are warranted.

COMORBIDITY WITH OTHER MENTAL ILLNESSES

Consistent correlations have been found between demoralization and depression, anxiety, and a desire for hastened death. As clinical depression becomes more severe, the likelihood increases that comorbid demoralization will develop. However, demoralization can certainly occur when anhedonic depression is not present, and moderate demoralization without depression may be relatively common. For instance, in one German study of 516 patients with cancer, while 5 percent showed severe demoralization without evidence of clinical depression, many in the cohort were afflicted with mild-to-moderate levels of demoralization and no formal psychiatric disorder (7). The latter subgroup may be considered a major therapeutic target for psychotherapeutic interventions without in any way detracting from the urgent requirement to address the needs of acutely suicidal and severely demoralized patients.

Clarke and colleagues conducted an important series of studies of depressive phenomenology in the medically ill (8, 9). Using latent trait analyses to define discrete clusters, they showed a clear distinction between anhedonia (the loss of pleasure), demoralization (the loss of hope), and grief (emotions associated with loss). An important clinical activity is to tease out these differences because we direct our therapeutic response accordingly. The dominant psychiatric view of clinical depression is based on anhedonia, in

which lowered mood accompanies loss of interest or pleasure. The *Diagnostic and Statistical Manual of Mental Disorders*, fifth edition (DSM-5), does not list a sense of meaninglessness or a sense of hopelessness as key diagnostic criteria for a major depressive disorder (10).

Major depression is thus solidly grounded in the experience of loss of interest and pleasure, inducing lowered mood. In contrast, a sense of entrapment in a predicament that removes anticipated meaning and purpose most aptly characterizes demoralization. Important questions nevertheless remain. Further studies are needed to better distinguish demoralization from depression.

In the setting of medical illness, an inability to cope, the presence of significant distress and impaired functioning will meet DSM-5 criteria for a diagnosis of adjustment disorder (10). This disorder has quite broad and subjective diagnostic criteria, it is not well understood by clinicians, and its diagnosis does not necessarily trigger optimal interventions. My contention is that physicians understand the concept of demoralization intuitively and also appreciate the benefit of meaning-centred interventions. In the short term, when clinicians are about to diagnose adjustment disorder with depressed mood, they should consider whether adjustment disorder with demoralization would be more accurate.

THE CONTAGIOUS NATURE OF DEMORALIZATION

Loss of morale is readily transmitted across teams, affecting patients' family members and healthcare staff, including treating physicians. Psychoanalytic thinking about suicidality has long recognized complex interactional processes, including projective identification (in which one unconsciously projects an intolerable emotion onto another person for them to enact) and identification with the aggressor (in which one takes on another person's anger and acts violently as a result) (11). Classically, when a psychiatrist begins to think that a suicidal patient might be better off dead, the risk of suicide is very high indeed. In a telling study of demoralized palliative care patients, Kelly and colleagues showed a parallel lowering of their general practitioners' morale (12).

The transmission of morale among palliative care team members may be an unconscious process and thus indicate reduced insight. For the individual patient, however, intensification of morale promotes deeper awareness. Are there qualitative differences that future research might explore between demoralization as experienced by the patient and demoralization as experienced by caregivers and team members?

Decision-making processes are greatly influenced by the views of team members. When a multidisciplinary team becomes demoralized, this affects decisions regarding active versus conservative anticancer therapies. The informed consent process is also exquisitely sensitive to morale (13).

MANAGEMENT OF DEMORALIZATION

While mild demoralization may be ameliorated by empathic listening and supportive therapy, moderate and severe forms call for existential and meaning-centred psychotherapies. Recent trials of meaning-centred therapy have shown enhanced spiritual well-being and a sense of meaning in life (14, 15). Indeed, supportive-expressive group therapy for patients with cancer, as developed by Yalom and further propagated by Spiegel and Classen, has long had an existential orientation and has sought to help patients develop new priorities and life goals (16-18). A new intervention — dignity therapy — makes use of the life narrative to affirm accomplishments and significant roles and to create a legacy of meaning for the patient's family (19). Dignity therapy has been shown to enhance spiritual well-being and improve a range of secondary outcomes. Brief psychotherapy sessions at the bedside make use of key questions to open up discussion of existential concerns arising from demoralization (20). Another concise intervention fosters intentionality of purpose along with perceptions of what is meaningful to deepen a patient's appreciation of what is beautiful about his or her life (21). Thus we see that a number of psychotherapies are available to treat demoralized patients and to provide support for their families. In the everyday clinical encounter, affirmation of each person's creativity and each person's successes and accomplishments protects against lowered morale by emphasizing the individual's inherent sources of resilience and strength.

CALL FOR FIELD TRIALS

What we now need is a series of field trials, run across several countries, to better define the threshold for abnormality, the diagnostic criteria that will operationalize the demoralization syndrome, and the boundaries that will help differentiate it from other forms of mental illness. These studies should, in turn, lead to definitive trials of targeted interventions to complete the necessary validity criteria for acceptance of the utility of a diagnostic category. Chronic grief has long been recognized by bereavement researchers as falling outside the lexicon of psychiatric classification; we

have come a long way toward recognizing prolonged grief disorder as a form of complicated grief that can be differentiated from other conditions and that warrants a refined and specific model of therapy (22). A comparable journey of empirical research is needed to win full recognition of the demoralization syndrome.

CONCLUSION

What one might experience during a midlife crisis is a pale reflection of what one must grapple with at the end of life. A series of challenges arises from the givens of our existence: death and its many related losses, the continuity and meaning of life, our basic aloneness, our autonomy and how we control it, and the great mystery of what life is really all about (23). Based on the dearth of literature on the phenomenon of loss of meaning and its resolution at various stages of the life cycle, it appears that psychiatrists have had relatively little to say about these existential challenges ([24]). In this opinion piece, written on the occasion of the thirtieth anniversary of the *Journal of Palliative Care*, I highlight demoralization as a substantial cause of suffering, yet the ruptured threads of the life of the person who suffers from it can be rewoven in celebration of that life lived.

There are still many unanswered questions about the merit of this construct. What diagnostic criteria should be applied, and at what threshold of severity? How do we understand the complex comorbidity that may exist when depression, anxiety, and demoralization co-occur? What cultural and religious factors influence this? Which treatments are optimal? Not all pain and regret can be assuaged, but much can be done to contain distress and sustain attention on valuing meaning for whatever period of life remains. By recognizing and giving our attention to demoralization, we can realize major therapeutic benefits.

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