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Psychological Distress in End-of-Life Care: A Review of Issues in Assessment and Treatment

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The psychological distress and other end-of-life issues experienced by the terminally ill patient are a focus of attention for both the medical and psychiatric communities. The arena has engaged a variety of voices, from those who medicalize end-of-life distress to others who view distress as a normative response within the biopsychosocial-spiritual framework. This article reviews issues in assessment and treatment and suggests that medicalization of distress and DSM-IV-TR criteria are insufficient to describe the dying patient's experience. A broader view is needed. End-of-life care is a rich field of practice where existential concerns impact physical and mental well-being. It is imperative that clinicians in the field equip themselves with psychosocial and spiritual clinical tools. Social workers may have a unique position in understanding and addressing end-of-life issues. Recommendations for social work education include increased training to equip medical social workers to address the specific needs of chronically or terminally ill individuals.

KEYWORDS assessment, clinical tools, end-of-life care, psychological distress, social work, spiritual, treatment

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INTRODUCTION

Life expectancy in the United States has increased from 49.3 years in 1900 to 77.4 years in 2003. This is largely due to decreases in mortality rates from heart, malignant neoplasms, and cerebrovascular diseases (Arias, 2006, p. 30) and to the reduction of infectious disease with the introduction of antibiotics. Today, Americans are living longer but are likely to be saddled with chronic or debilitating conditions in their later years. These population changes affect each individual as well as our social systems.

The impact is noticeably present in mental health aspects of end-of-life care as more attention is being paid to “psychiatric morbidity” (Shuster, Breitbart, & Chochinov, 1998) or “psychological distress” (Pessin, Rosenfeld, & Breitbart, 2002). The term varies depending on the practice framework. Terminally ill patients may find themselves diagnosed with a range of mental disorders from the DSM-IV-TR (American Psychiatric Association, 2000) including adjustment disorder, cognitive disorder (including delirium), depressive disorder (including suicidal ideation), anxiety disorder (including PTSD), exacerbation of personality disorder, substance-related disorder, eating disorder, and sleep disorder. Psychological issues that cause distress, yet fail to meet DSM-IV-TR criteria for a mental disorder, may be classified under V-codes such as bereavement or phase-of-life problems.

Prevalence rates for psychiatric disorders in terminal illness range widely, depending on the population, medical condition, and assessment methods used (King, Heisel, & Lyness, 2005). In reviewing published studies, the authors noted that prevalence rates for adjustment disorder, anxiety disorders, or depressive disorders in patients with terminal conditions varied from 1% to 76%, with no general consensus other than the common theme that mental disorders are probably under-recognized (Akechi et al., 2004).

Depression has received the most attention due to its tendency to complicate medical treatment of the dying patient by heightening the perception of pain and interfering with rational decision making (Pessin et al., 2002). Miovic and Block (2007) observed that depression has been tied to lower adherence to treatment, prolonged hospital care, and diminished quality of life. Depression can also be a risk factor for the patient’s desire to hasten his or her death (Miovic & Block). Policy statements published on behalf of both the American College of Physicians (Block, 2000) and the Academy of Psychosomatic Medicine (Shuster et al., 1998) advocated for increased attention to the assessment and diagnosis of depression in the terminally ill. The Academy of Psychosomatic Medicine, in particular, has requested legislative changes to permit the inclusion of psychiatrists on the interdisciplinary hospice team to provide “appropriately aggressive care for psychiatric complications of terminal illness” (p. 2). If the reader is wondering what it meant by “aggressive” psychiatric care at end-of-life, the Academy

gives two examples: the use of psychostimulants for depression, and sedation for “agitated and delirious patients...to relieve the emotional suffering of the patient and family” (p. 2).

While monitoring for psychiatric disorders is one aspect of good palliative care, the terminally ill patient experiences a confluence of stressors, any of which may lead to psychological distress. These stressors may include one or more of the following: a decline in physical appearance, energy, weight, mobility, physical function; cognitive changes such as delirium or confusion; decrease in social support or opportunities for socialization; dependence upon others for personal care or management of one’s affairs; loss or alteration of social roles within the family and community; loss of income or earning power combined with increased expenses; loss of future in this world and fear of the unknown; concern about caregiver burden; and sense of one’s life being controlled by others and/or the medical profession. Since these stressors are possible and probable occurrences at the end-of-life, it may be worthwhile to view them as normal rather than pathological. Thus, as an alternative to declaring psychological distress at the end-of-life as pathological, a significant number of medical professionals have begun to view this distress as a normative response to a very difficult developmental phase. Psychiatry, in particular, has begun to suggest that DSM categories and criteria be expanded to include end-of-life mental health concerns, with more attention to psychosocial and existential issues. Thus, the medical model of illness and DSM-IV-TR criteria may be increasingly seen as inadequate and inappropriate to address mental health concerns in the dying patient.

ASSESSMENT OF PSYCHOLOGICAL DISTRESS IN TERMINAL ILLNESS

Current literature on end-of-life care utilizes the term “psychological distress” to identify a range of common psychiatric conditions in terminally ill patients and their families. The National Comprehensive Cancer Network’s (NCCN) recent publication of *Distress Management Guidelines* (Holland et al., 2008) provided the following definition:

Distress is a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis. (p. DIS-2)

The NCCN panel writes that the term “distress” was specifically chosen because “it is more acceptable and less stigmatizing than “psychiatric,”

“psychosocial,” or “emotional,” sounds “normal” and less embarrassing, [and] can be defined and measured by self-report” (p. DIS-1). The term “distress” thus broadens the scope of attention beyond the confines of DSM-IV-TR criteria to include signs and symptoms of the physical, psychosocial, and spiritual states that converge during the terminal phase of illness. Consequently, DSM classification, and the usual psychiatric assessment instruments and evaluation protocols may be seen as inadequate for identifying the particular manifestations of anxiety, depression, delirium, and suicidal ideation near the end-of-life. Constructs being discussed in end-of-life literature include anticipatory or preparatory grief, existential distress, hopelessness, demoralization, despair at the end-of-life, loss of dignity, loss of meaning, and the desire for hastened death. A discussion running parallel to these terms involves a debate as to whether the DSM needs to be expanded to include newly created definitions of psychological distress. Operating outside or ahead of the DSM system, the new definitions of mental states may represent a challenge to the medicalization of end-of-life care and a challenge to the validity of the current DSM model of classification. It is not clear, however, whether the driving force behind a model of mental health more inclusive of existential experience is an attempt to normalize or to medicalize a broader range of human experience.

The DSM: Advantages, Limitations and Adaptations

The DSM system of classification of mental disorders provides a conceptual framework for studying, comparing, and differentiating between the various presentations of mental states. It has the effect of simplifying complex sets of behavior into recognizable patterns, so as to facilitate diagnosis and treatment. However, the DSM reinforces Western cultural values of individuality, productivity (Crowe, 2000), and secularism, possibly making application with non-Western and/or marginalized clientele problematic.

In addition, DSM criteria are meant to describe physically healthy, psychically unhealthy individuals (Breitbart & Heller, 2003), and therefore are often inapplicable to the terminally ill population, for whom there is considerable overlap in symptoms between psychiatric and medical conditions (King et al., 2005). Pessin and colleagues (2002) noted that psychological distress, even that below the clinical threshold for major psychiatric disorders, may be a significant factor in the emotional experience at the end-of-life, both for patients and their families.

Cohen-Cole and Stoudemire (1987) described three approaches to adapting DSM criteria for use with a medically ill population: the exclusive approach that eliminates somatic symptoms that overlap with symptoms of a medical condition; the substitutive approach that exchanges somatic symptoms for additional psychological symptoms; and the inclusive approach that includes all symptoms of a disorder regardless of possible

overlap with those of the medical condition. For example, Endicott (1984, as cited in Noorani & Montagnini, 2007) substituted cognitive or social symptoms for somatic symptoms in assessing for depression in cancer patients. However, the use of exclusive or substitutive criteria may result in underdetection of mental disorders in the medically ill population, while the use of inclusive criteria may result in false positives when somatic symptoms of a medical condition are confounded with those of a psychiatric disorder (King et al., 2005). It is not clear whether adapting DSM criteria for atypical populations will lead to improved mental health care in those populations.

Barriers to Diagnosis or Recognition of Psychological Distress

Aside from the difficulty of distinguishing between somatic and psychological symptoms in end-of-life medical and psychiatric conditions, other barriers exist to the recognition of significant psychological distress in the terminally ill patient. For one, it is common for psychological distress to be accepted as a normal part of the dying process by the patient and both formal and informal support systems (Shuster et al., 1998). This may be due to lack of training or experience in the members of the medical team, lack of education in the general public, or sometimes lack of access to qualified mental health professionals. Sub-clinical levels of depression and anxiety, as seen in adjustment disorders or V-code diagnoses, are not reimbursable by health insurance, and therefore physicians and mental health professionals see no financial incentive to diagnose or treat "psychological distress."

Symptoms of comorbidities, medication side effects, or substance abuse may also distract medical professionals from recognizing treatable psychiatric conditions. Additionally, the uncertain and limited life expectancy in the terminally ill patient may lead clinicians to disregard obvious psychological symptoms, thinking that there is insufficient time for either pharmaceutical or psychotherapeutic interventions to have a therapeutic effect. From the medical standpoint, the prevailing attitude may be: "Why bother? He's going to die anyway!"

Cultural and lifestyle factors in the patient and family have the potential to present barriers to the diagnosis and treatment of psychological distress. It is not uncommon for ethnic populations or the current cohort of older adults to fail to mention significant psychological distress they experience, as they are not comfortable with or accustomed to openly expressing their thoughts or feelings. The reticence to talking about one's mental state is reinforced by the cultural stigma attached to psychiatric evaluations or psychotherapy among the general public, causing patients and families alike to decline anything other than the most cursory evaluative process.

Even in the best of scenarios, when the terminally ill patient voices his distress, has access to a mental health professional trained in end-of-life care, and is not too ill to undergo a psychiatric evaluation; the assessment surveys,

scales, and instruments utilized may not be appropriate. These tools likely were not designed for a patient's end-of-life experience. Therefore, there is a great need for simplified screening questionnaires or instruments that are specific to the experience of patients at the end-of-life (Periyakoil et al., 2005).

Differential Diagnosis in Terminal Illness

CLINICAL DEPRESSION AND PREPARATORY GRIEF

Recent studies that distinguish between clinical depression and anticipatory or preparatory grief are a significant and welcome contribution to the classification of mental conditions near the end-of-life. Clinical depression, as described by the DSM-IV-TR, and preparatory grief share somatic symptoms—primarily the vegetative signs such as difficulty sleeping, poor appetite, loss of energy, psychomotor retardation, or diminished concentration. Preparatory grief tends to come in waves (Block, 2000), whereas clinical depression is persistent, profound, and marked by anhedonia and a desire for hastened death (Breitbart & Heller, 2003). The patient experiencing preparatory grief retains some capacity for pleasure (Miovic & Block, 2007) and may find new meaning and hope in the midst of profound sadness and grief surrounding her or his eventual death. As such, preparatory grief is considered “a normal reaction to the loss that occurs during the terminal illness process, as perceived by the patient” (Periyakoil et al., 2005, p. 203). It facilitates the patient’s transition through the last developmental stage in preparation for death. Clinical depression, however, is considered maladaptive and has the potential to impede the transition to a peaceful death, to heighten physical and psychic pain, and to disrupt social relationships between the patient and his support system. While research findings suggest that depression is more prevalent in the terminally ill population than in the general population, these results may highlight classification problems, with preparatory grief being misdiagnosed as depression (Periyakoil et al.).

ANXIETY, DELIRIUM, PANIC, AND PTSD

Anxiety disorders experienced in terminal illness must likewise be distinguished from depression and delirium and from specific presentations of anxiety such as PTSD and panic disorders. Anxiety in end-of-life care may be a symptom of a mental disorder, or may be a response to medications, medical treatments, pain, or even illness-related stressors (Pessin et al., 2002). Stiefel (1994, as cited by Block, 2006) provided refreshing clarity to the discussion by categorizing anxiety states according to their context: situational, organic, psychiatric, or existential, with each context suggesting a specific course of treatment. Miovic and Block (2007) reported that patients with situational anxiety present with cognitive symptoms, like confusion,

while those with organic anxiety display the more somatic symptoms, such as restlessness or elevated blood pressure.

Delirium, although similar in presentation to anxiety disorders, is distinguished from anxiety by the presentation of cognitive impairment including memory loss, disorientation, and an inability to concentrate (Pessin et al., 2002). Delirium may also share symptomatology with psychotic disorders and mood disorders, and can lead others to assume that the patient suffers from a mental disorder instead of a treatable condition of organic etiology.

Finally, panic disorder and post-traumatic stress disorder (PTSD) share symptoms with anxiety disorder, and are observed in patients with terminal cancer, or in terminally ill patients with previous exposure to violent trauma or physical/sexual abuse. It is thought that the fear, anxiety, or even dyspnea experienced in terminal illness may trigger panic attacks or the flashback/avoidance/hyperarousal clusters of behavior in PTSD (Feldman & Periyakoil, 2006). Periyakoil (2007), using the substitutive approach, suggested that the affective symptoms of panic disorder (fear of loss of control, de-realization, or depersonalization) are more useful indicators of the disorder in terminal illness than somatic symptoms.

Psychosocial and Spiritual Components of the Assessment

Medical social workers performing the psychosocial assessment with a terminally ill patient may find themselves dealing with conflicting expectations: those of the medical profession and those of the patient and family. The medical profession has an expectation that the psychosocial assessment will uncover possible barriers to continued treatment and service delivery and will support the patient's adaptive response to diagnosis, prognosis, and treatment. The patient and his or her family system, however, may have psychosocial or spiritual needs that take precedence over recommendations of the medical team. The social worker in a medical setting may thus serve as the bridge between the medical team and the patient's world in developing the plan of care.

Pain and symptom management are generally the initial step to assessing psychological distress and to ensure that treatable medical conditions are not mistaken for psychiatric disorders (Block, 2000). The patient's cognitive function is assessed next, to rule out dementia or other cognitive disorders that may hinder the patient's ability to participate in the psychosocial assessment process or to make sound end-of-life decisions. An attempt is then made to gather information through the clinical interview that encourages the patient to self-report. Some patients, due to illness, pain, or distress, may not always be reliable historians of their own life experience. Clinicians may, therefore, find it necessary to collect information for a thorough assessment from the patient's family, friends, medical records, or possibly service providers. As with any psychosocial assessment, all aspects of the patient's experience

are assessed—including the history of illness, substance use/abuse, trauma, coping style, risk of suicide, and cultural considerations. The authors' experience is that a discussion around advance directives has the potential to reveal a wealth of information about the patient and his/her family, their experience of illness and loss, coping strategies, family conflict, unresolved personal issues, cultural preferences, and desires for the future. Each of these factors has the potential to shape the course of a terminal illness.

The developmental stages of both the patient and the family members are also commonly assessed but less frequently discussed in end-of-life literature. Patients face specific challenges in adjusting to the terminal illness process depending upon their placement within the eight developmental stages described by Erik Erikson in 1950. This is relevant to the psychosocial assessment, as psychological distress at the end-of-life may represent unfinished tasks from earlier developmental stages. Pain, depression, or anxiety at end-of-life that does not respond to treatment may indicate unresolved developmental conflicts (Knight, 2004).

A spiritual assessment is particularly crucial to understanding the patient's worldview, values and beliefs, and cultural tradition. Spirituality and/or religion are usually essential aspects of the client's coping strategy near end-of-life (Hodge, 2003). For clients who have no religious affiliation or spiritual belief, assessment of the sense of meaning in life serves a similar purpose to the spiritual assessment. The ability to find meaning and hope within the dying experience and a strong sense of spiritual well-being may protect individuals from depression and a desire for hastened death (Breitbart et al., 2000). The spiritual assessment is performed primarily through a narrative format, with open exploration of the client's spiritual history, beliefs, and practices. Spiritual genograms and maps may also be utilized to organize the information and encourage further recognition of the role spirituality has played throughout one's life (Hodge).

Social workers also assess for caregiver distress and burden, as psychological distress experienced by family caregivers may have a serious effect on the mental health of the terminally ill patient. Koenig (2002) noted that unresolved psychological issues in caregivers can result in a family's inability to accept a terminal prognosis and insistence on aggressive treatment that neither the patient nor physician support. Psychological distress in caregivers in end-of-life situations may also lead to the resurrection of conflicts that will persist long after the death of the patient.

Assessment Instruments: Comparisons, Limitations, and Recent Additions

There is a growing collection of quantitative measures being used in end-of-life care. The measures mentioned below assess for psychological distress. Periyakoil et al. (2005) developed the Terminally Ill Grief or Depression Scale

(TIGDS) consisting of grief and depression subscales. This measure is designed to differentiate preparatory grief from clinical depression. Other scales of note are the Hospital Anxiety and Depression Scale (HADS), which distinguishes between anxiety and depression; the NCCN Distress Management Scale, a single-item distress thermometer; the Structured Interview Assessment of Symptoms and Concerns in Palliative Care (SISC) scale; Mini-Suffering State Examination (MSSE); Missoula-Vitas Quality of Life Index (MVQOLI); Schedule of Attitudes toward Hastened Death (SAHD); and the Functional Assessment of Chronic Illness Therapy- Spiritual Well-Being (FACIT-Sp) scale (Kelly, McClement, & Chochinov, 2006). All of the aforementioned measures can be completed by self-report or utilized in a semi-structured clinical interview.

As mentioned previously, the use of some assessment instruments to measure somatic, psychological, and functional symptoms at the end-of-life may generate false results and therefore lack reliability and validity with this population (Periyakoil et al., 2005). Terminally ill persons may also lack the energy or mental clarity to complete lengthy assessment instruments or to participate in complex semi-structured interviews, as in the Structured Clinical Interview for DSM Disorder (SCID). For these reasons, qualitative assessment methods, such as the clinical interview, are considered the “gold standard” in assessment and are widely used and preferred, as they capture more of the biopsychosocial and spiritual factors that bear on the patient’s sense of well-being (Hodge, 2003).

Of all the instruments reviewed, the simplest and easiest to use and score is the single-item interview assessing depressed mood in terminally ill patients, which consists of a single question: “Are you depressed?” This question alone outperformed other brief scales in assessing for depression at end-of-life (Kelly et al., 2006). The superiority of simply asking the patient, directly, about his experience may call into question the utility of additional research to develop measures with potentially lower validity and reliability, and less specificity than a single direct question. This implies that a social worker may ask the client a direct question about depression and receive valuable assessment information.

TREATMENT OF END-OF-LIFE DISTRESS

Understanding that distress at the end-of-life may be variously defined by the patient and may include physical, psychological, social, and existential sources of discomfort, it seems helpful to identify exactly what is to be treated and by whom. What is the goal of treatment? Is there evidence to support one particular treatment over another? Do treatment protocols change as the patient gets nearer to death? At what point does distress become pathological, or warrant a psychiatric diagnosis?

If it is agreed that palliation is one of the choices that is preferable at the end-of-life, and that the goal of palliative care is comfort, then “comfort” needs to be defined. Some professionals have said that controlling physical pain ensures comfort, and others have stated that controlling physical pain and depression insures comfort. In either case, if the above can be ensured, the patient’s experience is sometimes referred to as a “good death.” Breitbart and Heller (2003) have found that patients continue to experience distress, even when pain and depression have been successfully treated. Terminally ill individuals may continue to desire hastened death, express hopelessness and a loss of meaning and dignity in the absence of physical pain or psychiatric diagnosis (Breitbart & Heller). However, when spiritual or existential well-being and a sense of meaning were addressed alongside physical and psychological needs, patients showed the greatest improvement in psychological well-being. They exhibited less distress, less depression and hopelessness, less desire for death, and improved social support (Breitbart & Heller), even as their medical condition worsened. True comfort, or palliation, may thus entail a patient-centered, holistic, integrated model of care that includes attention to existential well-being and the sense of meaning experienced in the dying process.

Barriers to Treatment

Treatment of distress in terminal illness is challenging because care providers tend to focus on symptoms that are easiest to treat, with interventions that are inexpensive and readily available. The goal of such therapy is to make the patient less aware of his suffering throughout the dying process (Chochinov et al., 2005). In practical terms, this means that the patient may be given a prescription for antidepressants, anxiolytics, or antipsychotics. Hansen, Rosholt, Gichangi, and Vach (2007) found that the use of antidepressants in older adults peaked in the 6 months prior to their death. In the study, 33% of females and 25% of males were prescribed antidepressants compared to 5% of the general population under 65 years. Unfortunately, the use of antidepressants in this population also brings an increased risk for falls and upper gastrointestinal bleeds, and other side effects. The authors’ experience is that physicians, psychiatric nurses, and clinical social workers may assume that end-of-life despair is normal and unavoidable. The frailty and isolation of the terminally ill patient, depending upon the proximity to death, also limits the range of suitable interventions. In addition, there may be financial considerations, as end-of-life care can be expensive depending on the insurance situation since it is reimbursed with limitations by private insurance or Medicare/Medicaid.

Financial considerations are tied to the discussion as to who should provide the holistic intervention aimed at distress management in end-of-life

care. The authors have read recommendations from several professional disciplines each advocating that they are necessary and appropriate to provide psychosocial/spiritual support to the terminally ill. Physicians assert that they are the primary, most influential medical professional with access to the isolated, terminally ill individual. They suggest that they be trained to initiate and sustain client-centered discussions and to refer patients for further supportive therapy. Psychiatrists insist that they have more expertise with pharmaceuticals and with identifying, diagnosing, and treating mental disorders. They advocate that they be included on the hospice inter-disciplinary team or at least as consultant-liaisons to the medical team. However, patients and families do not generally seek hospice or palliative care for the purpose of receiving mental health treatment. Social workers appear to be in the better position to provide ongoing, client-centered, holistic care. They are required by law to be part of the Medicare hospice team, can be further licensed to provide specialty mental health services, and are trained in the systems approach to identify both strengths and stressors impacting the client. Social workers may also be in the best position to refer clients and families to available community resources.

Research Issues

When considering the research on psychological issues and end-of-life care, two issues must be taken into account. The first issue is the lack of uniformity in definition of the constructs surrounding the patient's end-of-life experience. Experts in the field, therefore, call for uniform consensus about what defines distress at the end-of-life and what components constitute the distress model. Questions also exist as to whether the distress experienced at the end-of-life differs significantly from mental states already deconstructed in the DSM-IV model of classification.

The second issue is the lack of substantial research on the terminally ill population and their psychological distress. Although treatment protocols for distress in terminal illness often recommend a combination of pharmaceutical and supportive therapies, along with patient and caregiver education, there is a paucity of research involving randomized controlled clinical trials with the terminally ill population (Block, 2000). The lack of published studies may be due to several factors including a lack of funding for non-pharmaceutical research, a difficulty in recruiting patients for studies, the plethora of illnesses that shape the experience of distress, and the hesitation to intrude into the last few weeks or months of a patient's life for sake of research. Additionally, much of the research to date involves studies conducted with patients with cancer or HIV, which may or may not be generalizable to experiences of patients with other life-threatening illness or chronic conditions (Block).

Treatment Guidelines

Treatment approaches must take into consideration the life expectancy of the terminally-ill patient, along with severity of psychological symptoms, the practicality of the intervention, and the need for regular reassessment and ongoing modification of the intervention as the patient's physical condition declines. The National Comprehensive Cancer Network (NCCN; Levy, Back, Bendetti, Billings, & Block, 2008) published a stage-based intervention model for palliative care in cancer patients. Among the recommendations are that patients be grouped according to how long patients expect to live: years to months; months to weeks; and weeks to days. The NCCN further triages patients according to their level of distress. Specifically, those scoring low on the Distress Thermometer, a brief screening tool, are seen by the primary medical team that includes a medical social worker. Patients with a higher level of distress are referred to the next level of care—possibly necessitating a referral to a psychiatrist, clinical social worker, or pastoral counselor, depending upon the problem areas identified by the patient (Holland et al., 2008). Patients who do not experience stable or diminished distress after treatment are reassessed for pain and physical symptoms, and then reassessed for distress, with a possible referral to a higher level of psychiatric or spiritual care.

Block (2000) suggested that there are times when a referral to a psychiatrist may be immediately indicated, such as when “the physician is uncertain about the psychiatric diagnosis, the patient has a history of a major psychiatric disorder, the patient is suicidal or requests assisted suicide, the patient is psychotic, or the patient does not respond to the first-line psychotropic medications” (p. 216). It is not uncommon for patients or families to refuse psychiatric care and treatment. In these situations, it is the responsibility of the social worker to suggest alternative approaches—including counseling, spiritual support, complementary and alternative medical therapies, and/or interventions that are culturally-specific.

What is the protocol when all interventions for end-of-life distress have proven ineffective and the patient's suffering is profound and intractable? At this point, terminal distress, depression, or anxiety is seen as a terminal illness in itself (Block, 2006). Treatment of any type, pharmaceutical or psychological, is discontinued, and a discussion with the patient and/or family ensues as to whether to leave the distress untreated or to offer the patient “sufficient sedation to relieve the emotional suffering” (Shuster et al., 1998, p. 2). This is a method of last resort; however, that may be utilized more than the public realizes.

Psychotherapeutic Interventions

Standard psychotherapeutic models, such as cognitive behavioral therapy, supportive-expressive therapy, narrative therapy, existential therapy, or

insight-oriented psychotherapy do not differ significantly in implementation with the terminally ill population as compared to the healthy population. In end-of-life care, the overall treatment approach may be more important than the actual psychotherapeutic model.

Block (2006) and others advocate for a client-centered eclectic approach that is supportive, emotionally expressive, flexible, strengths-based, psycho-educational, and includes life review and an exploration of the patient and family's fears and concerns. In the interventions to follow, the end-of-life is not seen as a disease, and distress in terminal illness is not viewed as abnormal or evidence of a mental disorder. More importantly, the focus of the intervention is to facilitate the discovery of a sense of meaning and closure, along with a reduction in distress, in the life of the terminally ill patient, by whatever method is appropriate. As leading experts in the field suggest that distress cannot be adequately addressed at end-of-life except through a mind-body-spirit approach, several interventions that favor this approach will be highlighted.

MEANING-CENTERED GROUP PSYCHOTHERAPY

Brietbart and Heller (2003) designed an 8-week experiential group therapy to assist terminally ill patients with recovering and sustaining a sense of meaning and hope as they approach death. The manual-driven intervention is based upon the work of Frankl (1959, as cited in Breitbart & Heller), who suggested that maintaining a sense of meaning in mind, body, and spirit engenders "a sense of well-being, peace, and contentment and facilitates a self-transcendence and a sense of connectedness with others" (Breitbart & Heller, p. 981). Participants progress through a series of experiential exercises about important life issues. The exercises identify sources of meaning and areas of responsibility in the participants' lives. At midintervention, the focus of the exercises shifts from the past to the reality of the present and uncertainty of the future. The question is raised, "How will meaning and hope be sustained up to the point of death?" The study revealed that each participant was able to identify significant hopes for the remainder of their lives. They also experienced a greater sense of connectedness to others in their lives. Breitbart and Heller (2003) found that this intervention appealed especially to men, who tend to avoid supportive-expressive group therapy. However, the length of the intervention and stamina required to participate made it impractical for sicker individuals. Breitbart and Heller, therefore, plan to develop a three-session version in a brief, individual format that can be administered at bedside.

DIGNITY THERAPY

Dignity therapy (Chochinov et al., 2005) is a brief, individualized intervention. It builds upon the aforementioned work of Breitbart, and is designed

to enhance a sense of meaning and facilitate dignified closure in a simple, single session. The therapist follows an interview guide, asking questions based on the dignity model of palliative care. The dignity model covers the following themes: continuity of self, role preservation, maintenance of pride, hopefulness, and aftermath concerns (Chochinov et al.). Sessions can be conducted at bedside, in the facility or home setting, and can be as brief as one session, lasting between 30 minutes to an hour. The sessions are taped, then transcribed and read back to the patient for corrections or additions. The final edited transcript is returned to the patient. The beauty of this intervention, besides its brevity and simplicity, is the creation of a lasting, “tangible product” that can be gifted to others, covering aspects of the patient’s life that were most meaningful, history that she wants to be remembered, and messages or instructions for the survivors (Chochinov, 2006). Other positive aspects of the intervention were that it fostered multi-generational relationships, increased the participant’s will to live, and can be administered very close to death. Further, it was perceived as being beneficial to patients in the most distress (Chochinov et al.).

Complementary and Alternative Medicine (CAM) Interventions

Integrated palliative interventions for end-of-life distress are treatment options that are considered complementary to conventional medical care. In reality, many mainstream treatment modalities were once considered “complementary” or even “alternative.” As their use becomes more widespread and accepted, they may be integrated into conventional medical care. The use and integration of CAM therapies into palliative or end-of-life care is supported by a growing number of medical professionals. Scanning the website of the Integrative Medicine Service at Memorial Sloan-Kettering Cancer Center (<http://www.mskcc.org/mskcc/html/1987.cfm>), found a variety of offerings under the categories of touch, mind-body, creative, and acupuncture therapies; many of which are currently being utilized with terminally ill patients. Many medical programs offer various forms of massage, aromatherapy, reiki, reflexology, meditation, mindfulness-based stress reduction, guided imagery, hypnosis, biofeedback, spinal manipulation, dance/art/music therapies, writing therapy, yoga, and spiritual practices such as prayer and scripture reading, to relieve distress and enhance healing and a sense of well-being in critically ill persons. Less accepted but also used treatments include herbal, vitamin, heat, and energy therapies; and alternative systems of medicine, like homeopathic, naturopathic, Ayurvedic, and Traditional Chinese Medicine.

Medical, psychiatric, and psychotherapeutic treatments work on the principle of targeting the so-called source of the problem: an organ, a disease process, a thought, or a maladaptive behavior. Groopman, in his book, *The Anatomy of Hope* (2004), advocated that research investigate the body-mind

connection to understand how therapy aimed at the peripheral parts, like massage, acupuncture, or even exercise, sends signals to the brain and may alter the brain chemistry thereby generating feelings of hope and well-being. Based on his life experience as well as his observations of his patients' lives, Groopman concluded that hope can break the cycle of pain and despair, thus leading to increased hope that can further decrease pain and distress. For terminally ill patients isolated in nursing homes or in the community, interventions such as massage and music therapy were observed to interrupt the cycle of pain and distress, enhancing a sense of connection and well-being. Body work, as it is popularly described, could therefore be used alone or in conjunction with psychotherapeutic interventions to relieve depression, anxiety, and the sense of hopelessness that arises at the end-of-life (Groupman).

In a pilot study conducted at a Connecticut nursing home, late-stage AIDS patients receiving a combination of metta (loving kindness) meditation and massage interventions over a 4-week period showed higher quality of life (Missoula-Vitas QOLI) scores than patients receiving either intervention alone or no treatment (Williams et al., 2005). The investigators were further surprised that the improvement in the perceived quality of life in the combined meditation-massage group far exceeded the additive effects of the two interventions, "implying a synergy" (p. 947). The suggestion is that massage improves the individual's receptivity to the benefits of meditation, while meditation enhances the physical benefits of massage. The improvement in overall quality of life and spiritual scores was maintained at 8 weeks and at monthly assessments up to the last assessment point at 68 weeks, despite an overall worsening of medical symptoms. While this preliminary evidence needs to be substantiated by additional studies, it may offer possibilities for interventions in other settings. For certain patients, complementary and alternative treatments for distress may be their preference, when compared to psychotropic medications and psychotherapy.

DISCUSSION AND RECOMMENDATIONS

Since the publication of Kubler-Ross' book, *On Death and Dying*, in 1969, palliative and end-of-life care has grown into a critical field for research and practice. Within the field, the nature of distress at the end-of-life, how it is treated, and how it differs from recognized psychiatric disorders will undoubtedly continue to be studied and discussed for years to come. At this time, it is understood that the assessment and treatment of psychological or spiritual distress at the end-of-life involves multiple systems of health and well-being: biological, psychological, social, and spiritual. End-of-life distress appears to be best treated within the palliative care model, which includes the concept of healing and caring from a holistic, multi-disciplinary,

patient-centered approach. Palliative and end-of-life research and practice will continue to evolve over time due to "advancements in medical technology, rising rates of chronic illness, increasing number of elderly persons, and longer life spans" (National Association of Social Workers, 2004, p. 7). It may be that the palliative model of care will gain wider acceptance as a model for health care across the life span because it complements both professional and personal concepts of well-being, and has the potential to conserve financial and professional resources for the wider distribution of services. Unfortunately, at this time, terminally ill individuals have limited access to palliative or complementary treatment. In our current system of care (get sick, get treated, and get well), chronic or psychological conditions receive limited coverage from Medicare, Medicaid, and private insurance. The medical, pharmaceutical, and political lobbying interests that keep this system in place are formidable and hardly patient-centered.

There is a tremendous need for education in end-of-life care and in the nuances of end-of-life distress for both public and professional audiences. In 1999, 80% of surveyed persons 45 years or older did not know the meaning of hospice; only 18% of medical students and residents in a 2003 survey reported receiving formal end-of-life training (Keslar, 2007, p. 31).

Advocacy efforts aimed at reducing barriers to assessment and treatment of distress in terminal illness, increasing culturally-informed services, and improving access to a wider variety of care are representative of the ethical principle of justice in the social work profession. It should not be, as one study found, that popular complementary therapies are mainly accessed by upper-class, wealthy white females between the ages of 40 and 64 (Beider, 2005, p. 4).

To meet the increasing need for medical social workers trained in end-of-life issues and care, the social work profession has generated a number of initiatives. The National Association of Social Workers published the *NASW Standards for Social Work Practice in Palliative and End-of-life Care* (2004). The standards offer a complete guide to essential knowledge, skills, and competencies that are utilized in end-of-life care and could serve as an outline to develop corresponding social work courses. A new certification is jointly offered to social workers by NASW and the National Hospice and Palliative Care Organization (NHPCO). Walsh-Burke and Csikai (2005) reviewed available programs such as end-of-life courses, training manuals, and certificate programs and found that the numbers and varieties of educational resources was growing. Another initiative is the field rotation model of the social work practicum employed by the Hartford Partnership Program for Aging Education (HPPAE), is an excellent model for integrating coursework and the practicum. It is especially appropriate in palliative and end-of-life care, where the community need is evolving faster than the development of social work curriculum. The HPPAE exposes the social work student to the entire range of social work competencies with the aging

population, from counseling and case management through program planning and advocacy work (New York Academy of Medicine, 2008).

While the social work profession is responding to the need to train social workers, additional efforts need to be made. Training as broad as the HPPAE model should be available in more locations. The graduate level social work student should have the opportunity to take elective courses in medical social work since the medical setting is one of the primary settings for clinical social work practice. Finally, increasing the knowledge base through research on end-of-life issues is essential to better inform social work practice. An essential role of social work education and continuing education should be to better inform social workers who will serve as palliation providers in end-of-life care and further expand beyond the boundaries of current thinking to a truly holistic, integrated approach.

AUTHOR'S NOTE

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REFERENCES

- Akechi, T., Okuyama, T., Sugawara, Y., Nakano, T., Shima, Y., & Uchitomi, Y. (2004). Major depression, adjustment disorders, and post-traumatic stress disorder in terminally ill cancer patients: Associated and predictive factors. *Journal of Clinical Oncology*, 22(10), 1957–1965. doi:10.1200/JCO.2004.08.149.
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders*. (4th ed., text revision). Washington, DC: Author.
- Arias, E. (2006). United States life tables, 2003. *National Vital Statistics Report*, 54(14). Hyattsville, MD: National Center for Health Statistics.
- Beider, S. (2005). An ethical argument for integrated palliative care. *Evidence-based Complementary and Alternative Medicine*, 2, 227–231. doi:10.1093/ecam/neh089.
- Block, S. D. (2000). Assessing and managing depression in the terminally ill patient. *Annals of Internal Medicine*, 132(3), 209–218. Retrieved March 22, 2008, from <http://search.ebscohost.com.proxy.lib.fsu.edu/>
- Block, S. D. (2006). Psychological issues in end-of-life care. *Journal of Palliative Medicine*, 9(3), 751–772. doi:10.1089/jpm.2006.9.751.
- Breitbart, W., & Heller, K. S. (2003). Refraining hope: Meaning-centered care for patients near the end-of-life. *Journal of Palliative Medicine*, 6(6), 979–988. doi:10.1089/109662103322654901.
- Breitbart, W., Rosenfeld, B., Pessin, H., Kaim, M., Funesti-Esch, J., Galietta, M. et al. (2000). Depression, hopelessness, and desire for hastened death in terminally ill patients with cancer. *JAMA*, 284(22), 2907–2911. Retrieved August 16, 2009, from <http://jama.ama-assn.org/cgi/content/full/284/22/2907>

- Chochinov, H. M. (2006). Dying, dignity, and new horizons in palliative end-of-life care. *CA: A Cancer Journal for Clinicians*, 56(2), 84–103. doi:10.3322/canjclin.56.2.84.
- Chochinov, H. M., Hack, T., Hassard, T., Kristjanson, L. J., McClement, S., & Harlos, M. (2005). Dignity therapy: A novel psychotherapeutic intervention for patients near the end-of-life. *Journal of Clinical Oncology*, 23(24), 5520–5525. doi: 10.1200/JCO.2005.08.391.
- Cohen-Cole, S. A., & Stoudemire, A. (1987). Major depression and physical illness: Special considerations in diagnosis and biologic treatment. *Psychiatric Clinics of North America*, 10(1), 1–17.
- Crowe, M. (2000). Constructing normality: A discourse analysis of the DSM-IV. *Journal of Psychiatric and Mental Health Nursing*, 7(1), 69–77. doi:10.1046/j.1365-2850.2000.00261.x.
- Feldman, D. B., & Periyakoil, V. S. (2006). Posttraumatic stress disorder at the end-of-life. *Journal of Palliative Medicine*, 9(1), 213–218. doi:10.1089/jpm.2006.9.213.
- Groopman, J. (2004). *The anatomy of hope: How people prevail in the face of illness*. New York: Random House.
- Hansen, D. G., Rosholt, J., Gichangi, A., & Vach, W. (2007). Increased use of antidepressants at the end-of-life: Population-based study among people aged 65 years and above. *Age and Ageing*, 36(4), 449–454. doi:10.1093/ageing/afm056.
- Hodge, D. R. (2003). *Spiritual assessment: Handbook for helping professionals*. Botsford, CT: North American Association of Christians in Social Work.
- Holland, J., Anderson, B., Breitbart, W., Dudley, M., Fleishman, S., & Fulcher, C. D. (2008). *NCCN clinical practice guidelines in oncology: Distress management*. Retrieved August 16, 2009, from http://www.nccn.org/professionals/physician_gls/PDF/distress.pdf
- Kelly, B., McClement, S., & Chochinov, H. M. (2006). Measurement of psychological distress in palliative care. *Palliative Medicine*, 20(8), 779–789. doi:10.1177/0269216306072347.
- Keslar, L. (2007). *At home in hospice: Hospice's growing pains*. Retrieved April 5, 2008, from http://www.protomag.com/issues/2007_spring/pdfs/hospice.pdf
- King, D. A., Heisel, M. J., & Lyness, J. M. (2005). Assessment and psychological treatment of depression in older adults with terminal or life-threatening illness. *Clinical Psychology: Science and Practice*, 12(3), 339–353. doi:10.1093/clipsy.bpi029.
- Knight, B. G. (2004). *Psychotherapy with older adults* (3rd ed.). Thousand Oaks, CA: Sage Publications.
- Koenig, H. G. (2002). A commentary: The role of religion and spirituality at the end-of-life. *The Gerontologist*, 42(Special No. 3), 20–23. Retrieved August 16, 2009, from http://gerontologist.gerontologyjournals.org/cgi/reprint/42/suppl_3/20.pdf
- Levy, M., Back, A., Bendetti, C., Billings, J. A., & Block, S. (2008). *NCCN clinical practice guidelines in oncology: Palliative care*. Retrieved August 16, 2009, from http://www.nccn.org/professionals/physician_gls/PDF/palliative.pdf
- Miovic, M., & Block, S. (2007). Psychiatric disorders in advanced cancer. *Cancer*, 110(8), 1665–1673. doi:10.1002/cncr.22980.

- National Association of Social Workers. (2004). *NASW standards for social work practice in palliative and end-of-life care*. Washington, DC: Author.
- New York Academy of Medicine. (2008). *Social work leadership institute—Hartford partnership program for aging education*. Retrieved April 5, 2008, from <http://socialwork.nyam.org/nsw/ppp/about.php>
- Noorani, N. H., & Montagnini, M. (2007). Recognizing depression in palliative care patients. *Journal of Palliative Medicine*, 10(2), 458–464. doi:10.1089/jpm.2006.0099.
- Periyakoil, V. S. (2007). Panic disorder at the end-of-life #145. *Journal of Palliative Medicine*, 10(2), 483–484. doi:10.1089/jpm.2006.9977.
- Periyakoil, V. S., Kraemer, H. C., Noda, A., Moos, R., Hallenbeck, J., Webster, M. et al. (2005). The development and initial validation of the terminally ill grief or depression scale (TIGDS). *International Journal of Methods in Psychiatric Research*, 14(4), 202–212. doi:10.1002/mpr.8.
- Pessin, H., Rosenfeld, B., & Breitbart, W. (2002). Assessing psychological distress near the end-of-life. *American Behavioral Scientist*, 46(3), 357–372. doi: 10.1177/000276402237769.
- Shuster, J. L., Jr., Breitbart, W., & Chochinov, H. M. (1998). Psychiatric aspects of excellent end-of-life care: A position statement of the academy of psychosomatic medicine. *Journal of Palliative Medicine*, 1(2), 113–115. doi:10.1089/jpm.1998.1.113.
- Walsh-Burke, K., & Csikai, E. L. (2005). Contributions of the project on death in America's social work leadership development program. *Journal of Social Work in End-Of-Life & Palliative Care*, 1(2), 11–26. doi:10.1300/J1457v1301n1302_1303.
- Williams, A., Selwyn, P., Liberti, L., Molde, S., Njike, V., McCorkle, R. et al. (2005). A randomized controlled trial of meditation and massage effects on quality of life in people with late-stage disease: A pilot study. *Journal of Palliative Medicine*, 8(5), 939–952. doi:10.1089/jpm.2005.8.939.