

## ORIGINAL ARTICLE

**Psychosocial issues near the end of life**J. L. WERTH JR.,<sup>1</sup> J. R. GORDON<sup>2</sup> & R. R. JOHNSON JR.<sup>3</sup><sup>1</sup>The University of Akron, <sup>2</sup>University of Washington, & <sup>3</sup>American Psychological Association, USA**Abstract**

End-of-life care has received increasing attention in the last decade; however, the focus continues to be on the physical aspects of suffering and care to the virtual exclusion of psychosocial areas. This paper provides an overview of the literature on the intra- and interpersonal aspects of dying, including the effects that psychosocial variables have on end-of-life decision-making; common diagnosable mental disorders (e.g., clinical depression, delirium); other types of personal considerations (e.g., autonomy/control, grief); and interpersonal/environmental issues (e.g., cultural factors, financial variables). Six roles that qualified mental health professionals can play (i.e., advocate, counselor, educator, evaluator, multidisciplinary team member, and researcher) are also outlined. Because psychosocial issues are ubiquitous and can have enormous impact near the end of life, properly trained mental health professionals can play vital roles in alleviating suffering and improving the quality of life of people who are dying.

**Introduction**

End-of-life care has been receiving a significant and growing amount of attention from a variety of sources (e.g., Field & Cassel, 1997); however, much of the emphasis has been on the medical aspects of caring for the terminally ill, with significantly less attention on the relevant psychosocial issues (Working Group on Assisted Suicide and End-of-Life Decisions [Working Group], 2000). This is unfortunate because of the important role that psychological and interpersonal factors play during the dying process (e.g., Block, 2001; Cherny *et al.*, 1994a; 1994b; Emanuel & Emanuel, 1998; International Work Group on Death, Dying, and Bereavement, 1993; National Institutes of Health [NIH], 1997; Pasacreta & Pickett, 1998; Steinhauer *et al.*, 2000; Vachon *et al.*, 1995; Working Group, 2000). In fact, the World Health Organization (1990, p. 11) has stated that, 'control of pain, of other symptoms, and of psychological, social, and spiritual problems, is paramount' in palliative care.

Thus, although physical problems are important and should often take first priority, truly comprehensive end-of-life care requires that psychosocial matters be assessed and addressed. The purpose of this paper is to provide an overview of the degree to which psychosocial issues—psychological, 'emotional, intellectual, spiritual, interpersonal, social, cultural, and economic dimensions of the human experience' (International Work Group on Death,

Dying, and Bereavement, 1993, pp. 29)—are critical near the end of life, review those that commonly arise, and highlight some of the many ways in which mental health professionals can be a valuable part of multidisciplinary teams providing quality end-of-life care (American Geriatrics Society [AGS] Ethics Committee, 1998; Singer *et al.*, 1999). The focus will be on adults who have the capacity to make health care decisions or about whom such capacity is in question because (1) decisions regarding treatment of incapacitated adults involve other considerations (Buchanan & Brock, 1989; Karlawish *et al.*, 1999) and (2) end-of-life issues with children entail other legal, ethical, and clinical dimensions (Van der Feen & Jellinek, 1998; Wolfe *et al.*, 2000).

**The role of psychosocial factors in end-of-life decisions and care**

Research and clinical experience has demonstrated that psychosocial issues play important roles in end-of-life decision-making (Wilson *et al.*, 1998). Because over 70% of deaths in the United States occur after some sort of decision regarding treatment is made (In re L.W., 1992), we cannot write about end-of-life issues and care without talking about decisions that may affect the timing of death. Although most of the recent work has focused on factors influencing decisions to request assisted suicide (Sullivan *et al.*,

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2001), many have recognized that the psychosocial aspects associated with requests for, and decisions regarding, any action or inaction that results in a person dying sooner than may have occurred had such an action or inaction not taken place are similar (e.g., Cohen, 1998; Quill & Byock, 2000; Quill *et al.*, 2000; Rosenblatt & Block, 2001; Werth, 2000; Werth & Gordon, 1998). Thus, end-of-life decisions include both assisted suicide, and voluntary euthanasia (but not involuntary euthanasia as this action is universally condemned), as well as withholding or withdrawing treatment, voluntarily stopping eating and drinking, and terminal sedation (Cohen, 1998; Quill & Byock, 2000; Sullivan *et al.*, 1997; Werth & Gordon, 1998). The decisions that patients and their loved ones make near the end of life may affect not only the timing of death but also the care that is received.

A wide variety of experts and commissions have stated that attending to psychosocial factors is a crucial aspect of good end-of-life care—which includes alleviating pain and suffering. Pain has been defined as ‘an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage’ (International Association for the Study of Pain [IASP] Task Force on Taxonomy, 1994). Therefore, it is not surprising that research has demonstrated that the presence of physical pain can lead to or exacerbate clinical depression and anxiety (e.g., Block, 2000; Block & Billings, 1998; Massie & Holland, 1992; Strang, 1997; Vachon *et al.*, 1995; Velkova *et al.*, 1995). Consequently, the alleviation of pain is important not only in terms of providing complete, quality care for the dying person but also in moderating the role psychosocial factors may play in end-of-life decisions. Because behavioral interventions and the involvement of mental health professionals can contribute much to pain management (AGS Panel on Chronic Pain in Older Persons, 1998; American Academy of Pain Medicine and American Pain Society, 1996; Eimer & Freeman, 1998; NIH, 1997; NIH Technology Assessment Conference Statement, 1995; Turk & Feldman, 1992), efforts to ameliorate pain should include mental health professionals.

Mental health professionals can play key roles in reducing suffering and therefore improving the quality of life of dying people and their loved ones. In fact, psychosocial issues are a key component of suffering, which has been described as:

‘... a more expansive concept than pain. It goes beyond unpleasant sensations or distressing symptoms to encompass the anguish, terror, and hopelessness that dying patients may experience. A dying person who experiences few if any physical symptoms may suffer greatly if he or she feels that life has lost any meaning.

‘... [subjective] perceptions [of suffering] may have significant emotional and spiritual dimen-

sions related to self-image, family relationships, past experiences, caregiver attitudes, and other circumstances of a patient’s life (Field & Cassel, 1997, pp. 26; see also Cassell, 1981).

Therefore, in order to truly alleviate suffering, the whole being (i.e., physical, psychological, spiritual, interpersonal) of the dying person must be taken into account.

To the extent that alleviating suffering and improving quality of living and dying are the goals of improving end-of-life care, an emphasis on physical pain and symptom management that ignores psychosocial aspects may be short-sighted or seriously limited in effectiveness. Further, such an emphasis neglects the factors that appear to be the primary reasons why people make many of the end-of-life decisions that they do. For example, virtually all of the research studying people who actually requested and died by physician-assisted suicide or euthanasia has indicated that psychosocial issues were the most frequent and important reasons for such actions (Emanuel & Emanuel, 1998; Wilson *et al.*, 1998). Studies from the United States (e.g., Back *et al.*, 1996; Chin *et al.*, 1999; Coombs Lee & Werth, 2000; Ganzini *et al.*, 2000; Hedberg *et al.*, 2002; Sullivan *et al.*, 2000; 2001) and the Netherlands (e.g., Booij, 1995; Groenewoud *et al.*, 1997) reveal that the loss of (or fears of losing) autonomy, control, and self-determination; perceptions of experiencing an ‘undignified’ dying process; and concerns or fears about being or becoming a ‘burden’ on loved ones were the predominant reasons why dying individuals used medication prescribed by physicians to end their lives. Similar results are found when examining reasons for dialysis discontinuation (Cohen, 1998; Cohen *et al.*, 2000; see also Rosenblatt & Block, 2001).

Thus, although fears of pain or suffering are frequently mentioned in studies examining hypothetical reasons why people would request assisted suicide (Foley, 2000; Sullivan *et al.*, 1997), research indicates that when people are actually facing death, these are not the primary motivators for these requests (e.g., Sullivan *et al.*, 2001). Neither is clinical depression—according to the records kept by those who evaluated the people who died (e.g., Back *et al.*, 1996; Chin *et al.*, 1999; Coombs Lee & Werth, 2000; Hedberg *et al.*, 2002; Preston & Mero, 1996; Reagan, 1999; Sullivan *et al.*, 2000; 2001)—even though clinical depression has been found to be correlated with desire for death in several studies of persons with terminal illnesses (e.g., Breitbart *et al.*, 1996; Brown *et al.*, 1986; Chochinov *et al.*, 1995). That is, some people with life-threatening illnesses who have a desire for death may be clinically depressed, but this desire does not necessarily lead to requests for assisted suicide. On the other hand, people in Oregon who qualified for physician-assisted suicide were not so depressed that their judgment was impaired or they would not have met the requirements for assistance (Chin *et al.*,

1999; Coombs Lee & Werth, 2000; Ganzini *et al.*, 2000; Hedberg *et al.*, 2002; Reagan, 1999; Sullivan *et al.*, 2000; 2001).

Because research and clinical practice has documented that psychosocial issues have a significant impact on people's quality of life and end-of-life decision-making, these matters should be at the forefront when providing services to people who are dying. However, this is not the case. In an effort to bring together the psychosocial issues that affect care and decisions near the end of life, the next section outlines the pertinent areas identified in the literature.

## Psychosocial issues

There are a number of psychosocial issues that must be assessed for and, if present, addressed in order to alleviate the suffering a dying person experiences and maximize his or her quality of life. A complete discussion of all of them is beyond the scope of this paper, but the most common, debilitating, and/or amenable ones are highlighted (see, e.g., Chochinov & Breitbart, 2000; Steinberg & Youngner, 1998).

### *Diagnosable mental disorders*

Several conditions listed in the *Diagnostic and Statistical Manual of Mental Disorders, IV* (American Psychiatric Association, 1994) can be present in people who are dying, and research has indicated that some of the diagnoses may be fairly common in this population. This section highlights those diagnoses that have been documented through research, or proposed in theory, to be especially relevant when a person is dying. The focus will be on conditions associated with the dying process as opposed to pre-existing diagnoses.

*Anxiety disorders.* Anxiety disorders commonly accompany terminal illness due to apprehension about symptoms, including pain, and about treatment, care-taking arrangements, and fears about the dying process (Barraclough, 1997; Block, 2001; Strang, 1997). Symptoms of unresolved past losses, acute stress, and even post-traumatic stress disorder may occur when a person is facing the end of life. Dying individuals and their loved ones may also experience death anxiety during the dying process (e.g., Neimeyer & Van Brunt, 1995). For some, information may alleviate anxiety, but others will need to discuss their concerns with a knowledgeable and sensitive mental health professional. In addition, medication may be necessary for some individuals.

*Clinical depression and other mood disorders.* The condition that is most commonly mentioned when discussing psychosocial issues near the end of life is depression (Baile *et al.*, 1993). Clinical depression

must be differentiated from the lay definition of depression and from grief and mourning (Block, 2000; 2001). Such subtle distinctions are difficult to make by non-mental health professionals or therapists who are inexperienced with people near the end of life and should be made by a trained clinician (Peruzzi *et al.*, 1996; Sullivan & Youngner, 1994; Zaubler & Sullivan, 1996). Further, clinical depression is neither an inevitable nor a normal part of the dying process and, when it does occur, there are a variety of therapeutic interventions that can ameliorate it (Barraclough, 1997; Block 2000, 2001; Wilson *et al.*, 2000).

Although relatively high levels of depression (and anxiety) have been associated with decreased complex problem-solving abilities, the presence of clinical depression does not necessarily make a person incapable of making health care decisions (Sullivan, 1998; Sullivan & Youngner, 1994; Werth *et al.*, 2000; Zaubler & Sullivan, 1996). Further, some research has indicated that end-of-life decisions that are made while in the midst of mild to moderate clinical depression may not change after the depression has lifted (Ganzini *et al.*, 1994b; Lee & Ganzini, 1992; 1994).

Bipolar disorder has not been reviewed in the context of end-of-life decisions. However it seems highly likely that the same incidence of bipolar disorder is found in dying individuals as in the general population. Thus, differential diagnosis is critical because some of the treatments for clinical depression may exacerbate the manic symptoms of bipolar disorder. Both the depression and the mania associated with these conditions can compromise decision-making.

*Delirium.* A common and often misdiagnosed condition in people with terminal illnesses is delirium (Barraclough, 1997; Lawlor *et al.*, 2000; NIH, 1997). Delirium poses difficulties for the professional both in differential diagnosis with dementia and clinical depression (Farrell & Ganzini, 1995) as well as in how to ameliorate its effects. Because it is often iatrogenic (Inouye *et al.*, 1999), treatable (Block, 2001; de Stoutz *et al.*, 1995), and can compromise capacity to make health care decisions, it is essential that an experienced clinician evaluate the cause of compromised faculties.

*Dementia.* Various forms of dementia are becoming increasingly common as people continue to live longer, especially within the context of chronic and debilitating conditions (Larson & Imai, 1996; Working Group on the Older Adult, 1998). Dementia creates significant problems for the end-of-life treatment team because it can wax and wane, leading to alternating states of capacity and incapacity (Teresi *et al.*, 1994). As a result, a person with dementia periodically may be capable of making and changing health care decisions. Thus, health care

team members may need to check with dying individuals when they are lucid, to determine if their desires have changed. A related problem in the elderly is 'pseudodementia', a syndrome of reversible objective or subjective cognitive problems caused by a non-organic disorder, such as clinical depression (Bulbena & Berrios, 1986; Farrell & Ganzini, 1995; Working Group on the Older Adult, 1998).

*Personality disorders.* Little theoretical or empirical work has examined the impact of personality disorders on end-of-life decisions (Baile *et al.*, 1993; Farrenkopf & Bryan, 1999; Ganzini *et al.*, 1994a), and no definitive work has linked the desire for death with one or more personality disorders. It is unlikely that these disorders would lead to incapacity to make health care decisions (Ganzini *et al.*, 1994a). However difficult interpersonal styles or personalities can affect the responsiveness of caregivers or possibly bias professional judgment, assessment, or treatment planning (Block & Billings, 1998; Gutheil, 1985).

*Substance abuse.* The use of different substances can affect the ability to make decisions. Substance abuse is correlated with personality characteristics of impulsivity, inadequate coping skills, and an inability to tolerate intense affect (Block & Billings, 1998) and can lead to cognitive impairment. Therefore, the abuse or use of illegal, legal, and prescription medications may cause the person to be unable to fully consider his or her situation, options, and treatment implications. Fortunately, such effects are usually reversible. Because of the persistent misperception about this matter, it is important to emphasize that the use of high doses of morphine or other analgesics to control pain should not be equated with addiction or substance abuse (American Academy of Pain Medicine and American Pain Society, 1996).

#### *Other intrapersonal issues*

There are a variety of psychosocial issues that are not mental disorders but are often prominent aspects of end-of-life situations.

*Autonomy/control.* Research has indicated that issues of independence, autonomy, and control (alternatively referred to as 'self-determination') are of primary importance when people are considering end-of-life options and when they actually decide that death is their best option (Back *et al.*, 1996; Chin *et al.*, 1999; Cohen *et al.*, 2000; Coombs Lee & Werth, 2000; Ganzini *et al.*, 2000; Hedberg *et al.*, 2002; Rosenblatt & Block, 2001; Singer *et al.*, 1999; Sullivan *et al.*, 2000; 2001). As a result, exploration of such matters and the range of actions that allow for the maximization of personal control are often an important part of the decision-making process (however, see 'Cultural factors', below).

*Decision-making capacity.* Already mentioned several times, capacity to make health care decisions is vitally important in end-of-life situations (Peruzzi *et al.*, 1996; Sullivan & Youngner, 1994; Werth *et al.*, 2000; Youngner, 1998; Zaubler & Sullivan, 1996). The literature associated with defining and assessing capacity is extensive and doing these evaluations can be difficult (Baker *et al.*, 1998); however, a recent publication provides a set of guidelines for assessing capacity (Veterans Affairs National Center for Cost Containment, 1997). Given the complexity and importance of a capacity determination, an experienced professional should be consulted.

*Dignity.* An individual's personal definition of dignity and which conditions or situations lead to indignity can have a tremendous impact on end-of-life decision-making (Cohen *et al.*, 2000; Kade, 2000; Lavery *et al.*, 2001). What may be considered undignified for one person can be acceptable to another, or what was unacceptable to a person at one point may become acceptable after some time has passed. Issues of dignity are a function of the person's culture and unique value structure and should be reviewed repeatedly, as new challenges and changes occur.

*Existential issues and spiritual beliefs.* Many dying people have existential and spiritual concerns (Block & Billings, 1998; Daaleman & VandeCreek, 2000; Strang, 1997). Exploring the meaning of life and death, the purpose of one's life, the legacy one leaves behind, and how to reach a sense of completion are often issues with which terminally ill people struggle (Block, 2001). These existential issues are often intertwined with spiritual beliefs related to one's place in the world, how one should go through the dying process, beliefs about reward and punishment in an afterlife, surrender to or anger at a Higher Power, and what happens after death. Existential and spiritual attitudes and values are shaped by cultural background, personal experience, and/or individual beliefs and therefore are likely to diverge from what members of the health care team believe, but must be recognized and respected. Quality end-of-life care should include exploration of these domains.

*Fear.* Associated with diagnosable anxiety disorders is fear, because the latter can lead to the former. Fear associated with an uncertain future are often listed by people as reasons why they would consider taking an action that would affect the timing of death (Strang, 1997). Fears of loss of control, intractable suffering, and being a burden are among the most common specific concerns mentioned by people desiring death (Coombs Lee & Werth, 2000; Ganzini *et al.*, 2000; Hedberg *et al.*, 2002; Sullivan *et al.*, 2000; 2001). However, as will be mentioned below, research indicates that the dying person's fear of becoming burdensome to loved ones often is not matched by concomitant reluctance of significant others to be caretakers (e.g., Beery *et al.*, 1997).

*Grief.* Loss is at the core of terminal illness (Block, 2001; Rando, 1984). The terminally ill person faces an array of losses that commonly give rise to psychological suffering severe enough that death may appear to be preferable. In addition to the anticipated loss of relationships, as the world narrows with disease progression, the patient also loses current relationships. Further, the person loses social and occupational roles, and expectations and hopes for the future (Block & Billings, 1998). Similarly, loved ones will be grieving over the loss of the dying person (Beder, 1998; Rando, 2000; Werth, 1999b). As mentioned above, differentiating grief and depression can be difficult.

*Hopelessness.* An impressive research literature has documented that suicidality and completed suicide among the medically well are more closely associated with hopelessness than with clinical depression (Beck *et al.*, 1985; Hill *et al.*, 1988). Related work on the presence of hopelessness has been done with people who are seriously or terminally ill. Several research teams have found that ill individuals who have a desire for death or an interest in dying appear to have serious levels of hopelessness (Breitbart *et al.*, 2000; Chochinov *et al.*, 1998; Ganzini *et al.*, 1998). Although some may argue that hopelessness is logical for someone who is in the end stages of a terminal illness, it is important to distinguish between accepting that there is no realistic hope for a cure and believing that there is no hope for a decent quality of life and death. Neither clinical depression nor hopelessness are inevitable aspects of the dying process (Block, 2000).

*Psychodynamic issues and counter-transference.* Some theorists have explored the potential role that psychodynamic issues may play in end-of-life decision-making (Muskin, 1998). Clinicians have stated that some dying individuals have neither the time nor the energy to fully explore or resolve deep-seated psychodynamic matters (Levy, 1990). The effects of counter-transference by members of the treatment team related to dying and their acceptance of death by clients, including those who have not 'worked through' their issues, have not been as fully explored (Dinwiddie, 1999; Jamison, 1997; Maddi, 1990). Nonetheless, the treatment team should be aware of their own, the dying person's, and the significant others' beliefs and unresolved issues or conflicts including, but not limited to, feelings about death that may affect treatment decisions (Block & Billings, 1998).

#### *Interpersonal/environmental issues*

*Being a burden.* Ill individuals may perceive themselves to be burdens (Ott, 1998; Singer *et al.*, 1999) while significant others have very different perspectives. In fact, some research has indicated that being a caretaker can give meaning to some people (Beery

*et al.*, 1997; Cooke *et al.*, 1998; Rapp & Chao, 2000). Other investigations show that there can be significant negative effects on caregivers (Covinsky *et al.*, 1994; Emanuel *et al.*, 2000; Schulz & Beach, 1999). There also is concern that overwhelmed caregivers may subtly or overtly send the message that speeding up the dying process would be the best for all involved (King *et al.*, 2000; Ott, 1998). In such situations, interventions to support the caregivers may be necessary to reduce the likelihood that such signals will be sent.

*Cultural factors.* The cultural self-identification of the person who is dying as well as that of those around the terminally ill individual are important factors. Beliefs about the appropriate role of family, how to interact with health care providers, how medical treatments and advance directives are perceived, and the utilization of alternative and complementary therapies may all impact the provision of care and therefore affect end-of-life decision-making.

Although the majority culture in the United States places great emphasis on autonomy, some cultures within the USA place much less value on self-determination and instead emphasize collective decision-making (Blackhall *et al.*, 1995; Hallenback *et al.*, 1996). In addition, some cultures (e.g., some Native American tribes) believe that speaking of death at all, or telling the terminally ill person that she or he may die, is harmful (Blackhall *et al.*, 1995; Carrese & Rhodes, 1995). Further, there are some potentially vulnerable groups (e.g., older adults, women, persons with disabilities) about whom there is grave concern regarding the possibility of direct or indirect coercion to die (Bickenach, 1998; Canetto, 1995; Gallagher-Thompson & Osgood, 1997; Gill, 2000; Ott, 1998; Wolf, 1996). There are other groups (e.g., African-Americans and Hispanics) who appear to be less willing to engage in any activities that might affect the timing of death (e.g., they are less likely to use advance directives; Braun *et al.*, 2001; Caralis *et al.*, 1993; Cicirelli, 1997; Morrison *et al.*, 1998). Therefore, it is important to assess the culture and values of each patient and to be aware of how diversity can influence decision-making and requirements for care near the end of life (Braun *et al.*, 2000; Crawley *et al.*, 2000; Irish *et al.*, 1993; Kagawa-Singer & Blackhall, 2001; Koenig, 1997; Taylor & Box, 1999).

*Financial variables.* Given the nature of the health care system in the USA, the potential impact of the cost of care nearly inevitably enters into debates about end-of-life decision-making (Field, 1998; Gallagher-Thompson & Osgood, 1997). Research indicates that financial issues are often considerations for people who are dying and their loved ones (Covinsky *et al.*, 1994; Covinsky *et al.*, 1996; Emanuel *et al.*, 2000) and that there is variability regarding the degree to which they influence end-of-

life decision-making (Ott, 1998). These matters must be explored fully to avoid undue influence of economic factors.

*Presence/absence of significant others.* A significant factor in the suicides of non-terminally ill elders may be isolation and loneliness (Pearson, 2000). Some argue that lack of significant others could be a reason for wanting to die (Breitbart *et al.*, 1996) and others have found that social support is an important component of elders' quality of life (Newsom & Schulz, 1996). Because of the clear impact that support, or the lack of it, can have on quality of life, this area should be explored fully (Block, 2001; Qualls, 2000; Working Group, 2000).

*Pressure/coercion.* Legitimate concern has been expressed that outside agents (e.g., significant others, health care providers, insurers) may directly or indirectly, intentionally or accidentally, influence a person's end-of-life decisions (Hendin, 1998; Richman, 1987; Tilden & Lee, 1997). Such pressures may be subtle and therefore difficult to identify but they can be powerful. Although it is impossible not to be influenced to some degree by others, the question is whether this pressure is influencing decision-making or if it is not being acknowledged and therefore is unaddressed. This is a delicate area, but one that deserves careful attention (King *et al.*, 2000).

### **Roles of mental health professionals**

There are several ways that mental health professionals can be involved in situations when people are facing the end-of-life and decisions are being made. This section reviews six possible roles: advocate, counselor, educator, evaluator, team member, and researcher.

#### *Advocate*

Mental health professionals who know the dying person and/or significant others can serve as powerful advocates within a health care system by helping to improve communication between health care team members and patients or significant others (Goold *et al.*, 2000; Tulskey *et al.*, 1998), or between patient and loved ones; and by assisting in mediating conflicts that arise among any of the people who are providing care for the dying person (Block & Billings, 1998).

#### *Counselor*

An experienced mental health professional can be of invaluable assistance in helping dying individuals and their loved ones as they struggle with any of the

matters discussed in this paper, as well as many unique issues that may arise for a particular person and his or her loved ones. By assisting people through the dying process, the mental health professional can help improve the quality of life of the terminally ill individual and his or her intimate network (Block, 2000; 2001; Jamison, 1995; Levy, 1990; Maddi, 1990; Pasacreta & Pickett, 1998; Peruzzi *et al.*, 1996; Rothchild, 1998; Singer *et al.*, 1999; Werth, 1999b; Werth & Gordon, 2002).

#### *Educator*

Providing information and resources (Doka, 1993; Pasacreta & Pickett, 1998) to answer questions, alleviate fears, and reduce confusion should be a part of the role of each member of the interdisciplinary team. However, because of scheduling and competing demands, the mental health professional may be the team member who is in the best position to be able to devote the time and attention to the educative aspects of patient care. Such a role must be performed within the limits of professional competence. Another educational role is to train others about how to evaluate for the presence of the conditions described in this paper.

#### *Evaluator*

An obvious role that properly trained (Werth, 1999c) mental health professionals can play is in evaluating the narrow issue of the dying person's decision-making capacity and, more broadly, evaluating whether the person's judgment is impaired and, if so, to what degree (Sullivan & Youngner, 1994; Zaubler & Sullivan, 1996). Because evaluations of decision-making capacity are necessarily narrow and do not consider the potential affects of a variety of issues that may impact decisions, a comprehensive assessment should entail reviewing the psychosocial variables discussed above (Werth *et al.*, 2000). Research has demonstrated that non-psychiatric medical professionals are not well trained or proficient at conducting such assessments (Peruzzi *et al.*, 1996), and thus having a mental health professional perform these evaluations seems appropriate. Several protocols have been set forth that address areas covered in this paper (e.g., Block, 2000; 2001; Block & Billings, 1998; Cohen, 1998; Cohen *et al.*, 2000; Farrenkopf & Bryan, 1999; Goldblum & Martin, 1999; Miller *et al.*, 1998; Rosenblatt & Block, 2001; Werth, 1999a; Werth *et al.*, 2000; Working Group, 2000).

#### *Multidisciplinary team member*

Mental health professionals can be valuable members of multidisciplinary treatment teams, which are

becoming the standard of care for providing services to terminally ill individuals (AGS Ethics Committee, 1998; Cummings, 1998; Quill & Byock, 2000; Quill *et al.*, 1998). They can help patients, significant others, and health care providers by bringing knowledge and experience about the various psychosocial issues discussed in this paper to discussions and decision-making. Further, they can bring important skills and perspectives to pain treatment (Simon & Folen, 2001). Ongoing involvement would allow informal counseling and evaluation to be continuous and would make a transition to more formal assessment processes and interventions easier for all parties if they become indicated.

In addition, mental health professionals can bring important perspectives and skills to ethics committee reviews and deliberations. Given the prevalence of psychosocial issues in end-of-life care and decision-making, formal inclusion of mental health professionals on ethics committees appears both appropriate and useful. Finally, such professionals could assist team members with resolving grief and other feelings after a death (Block & Billings, 1998).

#### Researcher

The dearth of research on many aspects of end-of-life care has been frequently noted (Field & Cassel, 1997; NIH, 1997; Quill *et al.*, 1998; Rosenfeld, 2000; Vachon *et al.*, 1995; Wilson *et al.*, 1998; Working Group, 2000). Many mental health professionals are ideally suited to design and conduct investigations of the care of dying people and their loved ones, as well as to identify and develop appropriate instruments. In addition to specialized training in research design, they are also able to conduct the interviews, analyze the data, and disseminate results.

#### Conclusion

Psychosocial factors are nearly always significant near the end of life and addressing these issues is essential to comprehensive quality end-of-life care. However, most discussions of appropriate care near the end of life have not incorporated the psychological, interpersonal, or societal aspects of the dying process as necessary components. In addition, to the degree that these variables are included in treatment planning, they are most commonly addressed by medical professionals providing pharmacological interventions. The valuable contributions of mental health professionals have not been fully recognized. If quality end-of-life care is synonymous with appropriate holistic care, then it is imperative that psychosocial issues be acknowledged and addressed more fully, and that professionals with relevant and specialized experience and training be involved more often.

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