

Psychosocial End-of-Life Considerations for Healthcare Providers

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ABSTRACT

This article summarizes concepts related to psychosocial issues at the end of life with special attention directed to the rights of the mentally ill, issues related to mental capacity to consent, and suicidality and desire for hastened death in patients with a terminal illness. We discuss assessment tools and clinical decision-making strategies to guide the healthcare provider in dealing effectively with the often difficult situations involving patients facing the end of life.

BRIEF HISTORY OF MENTAL HEALTH CARE

Early conceptualization of the mentally ill was steeped in religious beliefs. Ancient Egyptian, Hindu, and Chinese literature attribute mental illness to demonic possession.¹ Early Greek philosophers identified mental illness as a madness plucked from heaven and humanized.² Hippocrates viewed mental illness as an imbalance of the bodily fluids, affecting the brain and leading to madness.¹ Treatment involved trepanning, boring a hole through the skull to release the evil spirit, or techniques such as blood-letting, purgatives, vomiting, and purulence to release fluids from the body.¹ Medieval mental health conceptualization continued with barbaric forms of treatment such as burning women at the stake or chaining an individual to the wall of a basement to remove the mentally ill from society.¹

During the 16th and 17th centuries, society shunned the mentally ill, and these individuals were

often beaten or incarcerated. Families often housed a mentally ill family member under the home in a hole less than 5 feet deep and covered with a cage where the afflicted person would eventually die.³ The 17th and 18th centuries introduced the asylum as a way to care for the mentally ill. Unfortunately, the use of chains and whips was still common.² Other treatment modalities included submerging patients into cold water to shock their minds,² strapping them to chairs to eliminate sensation, or pinning them down and pouring cold water over their faces, nearly drowning them.¹

Asylums in the 19th and 20th centuries attempted to humanize mental health care, but these institutions soon became infamous for their deplorable conditions. Patients received electroconvulsive therapy (ECT) without anesthesia, and poorly trained physicians performed frontal lobotomies. Negative clinical outcomes would soon stigmatize psychiatric care. Cold submersions, insulin-induced comas, restraints, and seclusion were common practices for patients with psychosis until the development of chlorpromazine in 1952. Many patients were forced into taking medication against their will and stripped of their civil rights and dignity.

Today, society continues to view psychiatric patients with outdated and stereotypical beliefs. These attitudes include the erroneous notion that all patients with mental illness are incapacitated, have no decision-making abilities, and must be treated against their will to maintain societal standards of safety.

RIGHTS OF THE MENTALLY ILL

Since the deinstitutionalization of the mentally ill in the 1960s, society has struggled with honoring the rights of these patients. A general misconception is that an individual receiving any type of psychiatric treatment is incapable of exercising his or her rights of citizenship.⁴ However, the United States Constitution guarantees any person, even one with a mental illness, equal civil rights. Despite this constitutional guarantee, discrimination and denial of equal justice are unfortunately common in our legal system and in the medical community. Because the stigmatization of mental health care persists even among healthcare providers, it is essential to promote accurate understanding of the rights of the mentally ill.

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Federal law now includes a bill of rights for persons receiving mental health treatment services. Title V, Section 501 of the Mental Health Systems Act 42 U.S.C. defines in United States law a Bill of Rights for Mentally Ill Patients.⁵ Table 1 summarizes the rights of the mentally ill set forth in the law.

The United States Constitution protects all individuals, regardless of mental health diagnosis. The 5th Amendment ensures due process as a means to safeguard against abuse during legal proceedings.⁶ Constitutional safeguards are particularly relevant when a healthcare provider is executing an involuntary commitment of a patient to a psychiatric facility. During involuntary commitment proceedings, the provider is required to uphold state legislation because commitment could be seen as an infringement to life and liberty as stated in the 14th Amendment.⁷ The rights of the mentally ill are often compromised by an overzealous use of paternalistic tendencies.⁸ Healthcare professionals should be aware of the medico-legal and ethical issues involved in the promotion of well-being and the right to self-determination and autonomy.⁸ Providers should monitor the possible imposition of their own values and beliefs so they do not compromise the rights of their mentally ill patients.

Eastman and Starling⁹ state that while all medical diagnoses are value laden, mental health diagnoses are quantitatively more so. Therefore, healthcare practitioners must maintain personal boundaries to uphold the dignity, respect, and autonomy of their patients with mental illness.

CAPACITY TO CONSENT

Mental capacity and decisionmaking are part of a continuing debate among healthcare providers that becomes even more complicated when a patient has a psychiatric history. However, until a person is deemed incapacitated, both capacity and competency are to be assumed.¹⁰ Although lack of capacity is not uncommon in patients admitted to a psychiatric facility, providers cannot presume that all persons lack the capacity to make treatment decisions.¹¹ Mental capacity tends to vary according to diagnoses. Capacity is more commonly limited for those with mania and schizophrenia and less commonly limited for individuals diagnosed with depression or personality disorders.¹¹

Capacity to consent is unique for each individual in the context of both time and situation. Capacity is only related to a specific decision¹⁰ and is a dynamic

Table 1. Bill of Rights for Mentally Ill Patients⁵

A person admitted to a program or facility for the purpose of receiving mental health services should be accorded the following:
<ul style="list-style-type: none"> • The right to treatment and services under conditions that support the person's personal liberty and restrict such liberty only as necessary to comply with treatment needs, laws, and judicial orders. • The right to an individualized, written treatment or service plan (to be developed promptly after admission), treatment based on the plan, periodic review and reassessment of needs, and appropriate revisions of the plan, including a description of services that may be needed after discharge. • The right to ongoing participation in the planning of services to be provided and in the development and periodic revision of the treatment plan and the right to be provided with a reasonable explanation of all aspects of one's own condition and treatment. • The right to refuse treatment, except during an emergency situation or as permitted under law in the case of a person committed by a court for treatment. • The right not to participate in experimentation in the absence of the patient's informed, voluntary, written consent, the right to appropriate protections associated with such participation, and the right to an opportunity to revoke such consent. • The right to freedom from restraints or seclusion, other than during an emergency situation. • The right to a humane treatment environment that affords reasonable protection from harm and appropriate privacy. • The right to confidentiality of records. • The right to access, upon request, one's own mental health care records. • The right (in residential or inpatient care) to converse with others privately and to have access to the telephone and mails, unless denial of access is documented as necessary for treatment. • The right to be informed promptly, in appropriate language and terms, of the rights described in this section. • The right to assert grievances with respect to infringement of the Bill of Rights, including the right to have such grievances considered in a fair, timely, and impartial procedure. • The right of access to protection, service, and a qualified advocate in order to understand, exercise, and protect one's rights. • The right to exercise the rights described in this section without reprisal, including reprisal in the form of denial of any appropriate, available treatment. • The right to referral as appropriate to other providers of mental health services upon discharge.

factor. The healthcare provider must be aware that capacity to consent must be reassessed for each treatment decision and over time, as a patient's capacity can fluctuate.¹⁰ When assessing capacity, the healthcare practitioner should be especially focused on evaluating what the patient lacks. Lacking capacity refers to the inability of an individual who has an impairment or disturbance to understand, retain, use, or weigh information considered relevant to decisionmaking or communicating a decision.¹⁰

When assessing for capacity, the provider must recognize that an established diagnosis of a physical, mental, or developmental disorder does not constitute incompetence or mental incapacitation.¹² Collaborating with a psychiatric provider or initiating a formal ethics consult may be helpful in these scenarios.¹² Table 2 summarizes key concepts from multiple resources that may assist the healthcare provider when assessing for mental capacity.¹²⁻¹⁴

SUICIDALITY VS DESIRE FOR HASTENED DEATH

In addition to concerns related to a mentally ill patient's capacity to consent, both suicidality and desire for hastened death are relevant to the end-of-life literature. Healthcare practitioners who provide care for patients with a terminal illness realize that statements of a desire for hastened death are not uncommon. These statements may indicate a patient with depression and accompanying suicidality, or they may simply reflect the patient's method of coping with a terminal illness. Clarification is necessary because a broad spectrum of patient requests for hastened death exists.¹⁵ These requests range from a passive desire for death with no active plans to hasten death to overt suicidality with a specific plan in place. The term suicidality refers to thoughts and statements about intentionally ending one's life.

Desire-to-die statements include expressions of a desire for hastened death and are not unusual in patients coping with advanced disease states.^{16,17} The desire for hastened death is most common among patients with terminal cancer, human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS), or amyotrophic lateral sclerosis.^{18,19} Terminally ill patients may fear painful medical procedures, prolonged suffering, pain, or the burden of healthcare costs on their loved ones.²⁰ Although desire-to-die statements are often thought to underlie suicidal ideation, not all desires for hastened death fall within this category because not all statements are associated with a specific plan to expedite the dying process.²¹ The figure illustrates these concepts.

Healthcare providers should feel professionally and compassionately comfortable responding to

desire-to-die statements.²² However, healthcare professionals are more frequently concerned or confused and struggle with how to respond appropriately. Practitioners should assess patients who verbalize these statements to evaluate whether their intention is a request for hastened death, a sign of depression and/or suicidality, or merely a comment not intended to be heard literally as a plan for expedited death.²³

Currently, research suggests that occasional desire-to-die statements may be common in the palliative care population, while pervasive expressed desires for expedited death are relatively infrequent.²⁴⁻²⁷ In one such study, 27% of terminal cancer patients thought about seeking assistance with suicide, but only 2% actually discussed this idea with their healthcare provider.²⁸ Although statements regarding desire for death are not uncommon in the advanced disease population, thoughts about hastened death appear to be more common than verbalized statements. Hudson et al suggest that this incidence might be higher if healthcare professionals encouraged patients at the end of life to freely express their wishes.¹⁵ Overall, the available literature suggests that desire to die may represent a transient experience for patients with terminal illness and that stable or persistent desire for death with depression as an associated factor may exist for a minority of patients.¹⁶

ASSESSMENT OF DESIRE TO DIE

Current clinical assessment tools can help healthcare providers assess patient desire for hastened death. The Desire for Death Rating Scale²⁶ was first developed as a single-item clinician-rated scale for use with terminally ill patients. This scale is comprised of a single 0-6 numeric rating based on a series of open-ended questions regarding thoughts, beliefs, and attitudes toward terminal illness. This unvalidated assessment tool relies only on the judgment of the healthcare provider and has a restricted range of possible scores. Both the subjectivity and the restricted score range limit the utility of this measure.²⁹

More recently, a 20-item self-report measure called the Schedule of Attitudes Toward Hastened Death (SAHD)^{29,30} was developed to measure the desire for hastened death in patients with terminal illness. The questionnaire's true/false format of 20 items captures several constructs related to desire for death, including quality of life concerns (eg, fear of pain or emotional suffering), psychosocial factors (eg, religion, family obligations), and thoughts related to facilitating one's death.³⁰ The SAHD has produced desirable reliability and validity in samples of ambulatory and terminally ill patients with HIV/AIDS³⁰ and in terminally ill cancer patients.²⁹ The SAHD is intended

Table 2. Assessment Techniques for Determining Mental Capacity

1. Assessment and attention	
a. Level of arousal or consciousness	<p>“Can you speak to me?”</p> <p>“Can you follow my pen with your eyes?”</p> <p>“Can you write your name for me?”</p>
b. Orientation to time, place, person, and situation	<p>“Can you please tell me the month, day, and year?”</p> <p>“What is the name of this building?”</p> <p>“Who is the president of the United States?”</p>
c. Ability to focus and concentrate	<p>“Can you spell the word WORLD for me? Can you spell it backwards?”</p> <p>“Are you able to subtract 3 from 20?” (continue with 3 from 17, from 14...)</p>
2. Information processing	
a. Short- and long-term memory	<p>“Please repeat these 3 words: ball, tree, and flag.” (ask to repeat in 5 minutes)</p> <p>“What was the last thing you had to eat?”</p> <p>“When did you graduate from high school?”</p> <p>“What is your birthday?”</p> <p>“Who was president in the 1980s?”</p>
b. Recognition of familiar objects and familiar persons	<p>“Can you tell me what this is?” (point to your watch or your pen)</p> <p>“Who is that person standing next to you?”</p>
c. Ability to understand and appreciate quantities	<p>“How many eggs are in a dozen?”</p> <p>“If a woman has twins, how many babies is that?”</p>
d. Ability to reason using abstract concepts	<p>“What is the same about a car and a boat?”</p> <p>“What is different about them?”</p> <p>“Which of the following does not belong: a cat, a bird, or a baseball?”</p> <p>“Why?”</p>
e. Ability to plan, organize, and carry out actions in one’s own rational self-interest	<p>“How would you start to bake a cake?”</p> <p>“How do you address an envelope?”</p>
f. Ability to reason logically	<p>“What would you do if you smelled smoke while at the library?”</p> <p>“If you bought a greeting card for \$1.50, how many quarters is that?”</p>
3. Thought processes (deficits in these functions may be demonstrated by the presence of the following)	
a. Severely disorganized thinking	<p><u>Disorganized thought processes</u> can be assessed by listening to the patient’s speech for sentence structure or asking for a writing sample. Monitor for rapid, pressured speech or nonsensical sentence structure.</p> <p><u>Flight of ideas</u> reflects a stream of thoughts that moves abruptly from idea to idea rapidly with an odd connection (eg, “You’re the apple of my eye, New York is the big apple, I want apple pie”).</p> <p><u>Looseness of associations (derailment)</u> refers to a breakdown in both the logical connection between ideas and the overall sense of goal-directness (eg, “What’s the temperature on Venus, where is my bridesmaid, I want an iguana”).</p>
b. Hallucinations (involve the 5 senses)	<p>Use open-ended questions:</p> <p>“When was the last time you heard voices?”</p> <p>“Tell me about the things only you can see.”</p>
c. Delusions (disturbances of thought or fixed or false beliefs)	<p>Listen for themes that are persecutory or paranoid, grandiose, jealous, somatic, or erotic:</p> <p>“Tell me about any special powers you may have.”</p> <p>“I notice you mentioned the Messiah many times.”</p>

(continued)

Table 2. Continued

d. Uncontrollable, repetitive, or intrusive thoughts	Listen for preoccupations, obsessions, or compulsions: <i>“Tell me about the thought you can’t get out of your head.”</i> <i>“What behaviors do you have to do over and over in a certain or order?”</i> (eg, checking locks or doors, washing hands excessively)
4. Ability to modulate mood and affect	
a. Mood (emotional response felt by the patient)	<i>“Tell me how you feel inside today.”</i> Be direct with questions regarding suicidality: <i>“When was the last time you wanted to hurt or kill yourself?”</i>
b. Affect (outward expression of mood)	It is appropriate to state the obvious: <i>“You tell me you are happy, yet you are tearful and crying.”</i> Listen for anger, anxiety, fear, depression, hopelessness, helplessness, or indifference. Make note of <u>insight</u> (awareness and understanding of illness) and <u>judgment</u> (behaviors that are harmful to the patient or minimizing negative behaviors and consequences).

for use in studies examining the desire for hastened death, the underlying constructs, and the impact of palliative care interventions on the desire for death.²⁹

A recent study using the SAHD explored the relationships between desire for hastened death, depression, and hopelessness in patients with terminal cancer.³¹ Results revealed that the desire for hastened death was significantly associated with a diagnosis of depression and with hopelessness and that both depression and hopelessness independently contributed to the prediction of desire for hastened death.³¹ This study suggests that interventions aimed at addressing depression and hopelessness may be particularly valuable in the palliative care setting.

QUALITY OF END OF LIFE

When a terminally ill yet competent patient expresses a request for hastened death, healthcare professionals may feel torn between respecting

patient autonomy and preserving life.³² However, advanced medical technology designed to prevent premature death may unintentionally prolong life regardless of patient wishes.³³ Humane care at the end of life is essential, even if a patient’s choices differ from typical healthcare practices.³⁴ Circumstances can also vary from state to state; for instance, physician-assisted suicide is legal in Oregon in some situations under the Death with Dignity Act.

Appropriate end-of-life discussions can promote healthy coping because they give patients the opportunity to express their concerns and to request support for specific issues (eg, pain control).³⁵ The end-of-life literature emphasizes the utility of establishing a professional relationship with terminal patients that allows for open discussion of treatment desires, feelings, and fears.¹⁶ Patients’ relationships with their healthcare providers appear to play a vital role in how patients perceive their end-of-life experience.³⁶

Patients with a terminal illness who meet the criteria for clinical depression may benefit from a number of pharmacological and psychological interventions¹⁶ to enhance their end-of-life experience. Interventions that include cognitive-behavioral components such as targeting self-defeating patterns of thinking^{37,38} or interventions that include a spiritual component to address existential concerns³⁹ may help to decrease hopelessness in these patients.

The following strategies can promote discussions and enhance end-of-life care for patients dealing with a terminal illness.

Patient-Focused Care

Healthcare that is focused on the patient and that emphasizes quality of end of life is essential in

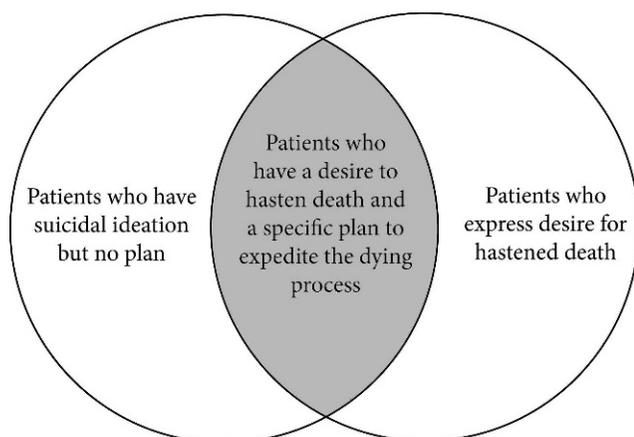


Figure. Venn diagram illustrating constructs of suicidality and desire for hastened death.

Table 3. Factors Suggestive of a Need for Psychiatry Referral

a. Preexisting Factors	History of previous suicide attempts History of psychiatric illness Substance abuse
b. Mental Status Changes	Agitation Disorientation Out of touch with reality Psychosis Delirium
c. Factors Related to Mood	Suicidal ideation Desire-to-die statements Depressed affect Hopelessness Feelings related to loss of control
d. Information Related to Medical Status	Deterioration of function Change in treatment due to futility Awareness that symptoms are intractable
e. Psychosocial Issues	Social isolation Caregiver burden Conflict between family members regarding treatment decisions

the palliative care setting. Physicians and patients both value communication about end-of-life care although studies suggest that these conversations happen infrequently.⁴⁰ A competent patient may seek to hasten death; when this situation occurs, education about end-of-life treatment and advocacy are essential.³³ Healthcare providers have a clear opportunity to enhance patient autonomy by focusing on communication of patient desires and concerns.

Sociocultural Considerations

Cultural factors can certainly influence patients' reactions to terminal illness as well as decisions about their end-of-life care.⁴¹ Various ethnic groups may differ in their use of advance directives or desire for autonomy in decisionmaking because they may conflict with family-centered values or religious beliefs.³³ Healthcare providers' personal biases may also impact their therapeutic responses to their patients' requests. Asking patients about their sociocultural beliefs as they relate to end-of-life care is vital, in addition to a commitment to respect competent patient requests even if they conflict with the healthcare provider's personal values.

Communication Skills

Interactions that convey empathy, provide comprehensive information, and reduce psychosocial concerns are the goal for all healthcare providers treating a patient coping with terminal

illness.²³ Responding to emotional cues, including verbal and nonverbal signs of distress, monitoring one's own attitudes and responses, and expressing continued commitment to symptom management are all essential components of effective communication. The healthcare provider should be especially cognizant of allowing patients adequate time to express concerns, ask questions, and obtain support.

Involvement of Family Members

The experience of family members coping with a loved one's terminal illness can be understandably difficult. Family members may feel torn between their feelings that death would be both a blessing and a tragedy.³³ While the healthcare provider is treating the patient and not the family, it is certainly appropriate to involve family members in discussion and treatment planning consistent with patient requests. Family involvement may also be necessary when capacity to consent becomes relevant. Family members often desire reassurance that they are acting in the best interest of their loved one and confirmation that they did everything possible to prevent premature death or suffering.³³

Referral to Psychiatry

Evaluation of mental health status and screening for depression are warranted in patients coping with end-of-life issues. Assessment of depression among the terminally ill is vital given depression's implication

in producing the desire for death.¹⁶ Psychological assessment is a dynamic process, and patient mental health needs may change over time. If patients become agitated, are disoriented, or appear to be out of touch with reality, a psychiatric consultation should be immediately initiated.³³ Patients expressing desire-to-die statements, suicidal ideation, or a sense of hopelessness could also benefit from mental health services, particularly from interventions focused on establishing a supportive environment and enhancing a sense of personal control. Often, patients are simply seeking help, reassurance, or the opportunity to express their thoughts about their experience.¹⁶ However, patients who are depressed and express overt suicidality require immediate psychiatric attention.¹⁶ Table 3 summarizes a list of factors that suggest a mental health referral is appropriate.

CONCLUSIONS

Providing healthcare to the terminally ill patient is challenging, from both the biomedical and the psychosocial perspective. We reviewed issues related to the rights of the mentally ill, capacity to consent, and suicidality and the desire for hastened death in patients with terminal illness. We also presented strategies for providing quality end-of-life care. In summary, healthcare providers have a clear opportunity to enhance end-of-life care for patients coping with terminal illness if they appropriately manage the relevant psychosocial issues.

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