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Providing Care in the End of Life

Ethical and Therapeutic Considerations

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Abstract: As modern technology advances, people live longer and are more likely to face death later in life from chronic or degenerative diseases. The location of death has also changed, resulting in more people dying in impersonal settings. The final months in the life of George, a terminally ill 89-year-old Caucasian male are discussed from four perspectives: existential approach, the stage model of death and dying, the reinforcement model, and an integrated model. Therapeutic interventions, aimed toward assisting George in dealing with his medical condition and existential issues, consisted of the following three major components: family therapy, religiosity, and preparation for death. Ethical and therapeutic considerations related to issues of death and dying are addressed.

Keywords: end of life care, terminal illness, aging, religiosity, family therapy, competency evaluation

1 THEORETICAL AND RESEARCH BASIS

In 1900, the average life span was 47.3 years; by 1997, it had increased to 76.5 years, a gain of 29.2 years in less than a century. The age distribution of the population in the United States has also changed dramatically in the past century. The number of people under the age of 65 has tripled, whereas the number of people who are 65 or older has increased by a factor of 11 (Kevin & Velkoff, 2001). The location and the nature of death have also changed. Approximately 70% to 80% of the population in advanced industrial nations face death later in life from chronic or degenerative diseases characterized by late, slow onset, and extended decline. In the past, death occurred in more personal settings involving family and friends, whereas currently, nearly 60% of all deaths occur in impersonal settings. These dramatic changes should be taken into consideration when working with terminally ill elderly patients (American Psychological Association, 2001). The extension of life, at times beyond the physiological capacity of the body, raises ethical and therapeutic challenges that should be addressed.

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When working with terminally ill populations, it is essential to have a thorough understanding of the patient's medical condition to establish appropriate treatment goals and interventions. George, as were most patients in the particular hospital described, suffered from a complex medical condition. The most acute medical conditions with the greatest impact on George's medical course at the hospital were Chronic Obstructive Pulmonary Disease (COPD), followed by a respiratory failure that required connection to the mechanical ventilator.

COPD

COPD is the fourth most common source of death in patients older than 65. It affects more than 14 million people in the United States. This is a chronic and progressive disease of the lungs, largely related to smoking behavior, with a preclinical course of 30 to 40 years and a clinical course of approximately 10 years. Symptoms include increased airflow resistance, difficulty in breathing, and dyspnea (Labbot, 1998; Segal, 1996).

According to Frazer, Leicht, and Backer (1996), depressive symptomatology occurs in one quarter to one half of COPD patients. Denial and tolerance of symptoms of COPD may lead to restriction of activities and restriction of the social environment. In addition, guilt associated with previous smoking behavior often intensifies the depressive symptoms. Secondary symptoms of COPD, such as fear of not being able to catch one's breath, are strongly related to anxiety. Cognitive symptoms of COPD include a decrease in mental alertness and difficulties in tasks that require complex problem solving, motor coordination, and speed. The cognitive symptoms may be due to oxygen deprivation or due to CO₂ retention (Acosta, 1987; Frazer et al., 1996).

THE VENTILATOR PATIENT

A mechanical ventilator may be required in case of ventilatory failure due to pulmonary or cardiac diseases. A ventilator-dependent patient requires the mechanical ventilation over an extended period of time due to adaptation to the chronic need for a mechanical ventilator and due to fear of not being able to catch his or her own breath. Weaning is the gradual process of removing the patient from the ventilator machine.

There are about 11,419 chronic ventilator patients in hospitals in the United States (American Association for Respiratory Care, 1991). There are no epidemiological studies describing the characteristics of ventilator patients. The prognosis of ventilator patients is relatively poor, especially at older age and prior poor functional dependence. Carson, Bach, Brzozowski, and Leff (1999) reported that of 133 ventilator patients studied, 66 died prior to discharge. Of discharged patients, 70% were weaned. One year later,

77% of all patients had expired, typically after spending the majority of their days in intensive care units. Only 8% of 1-year survivors were fully functional.

Riggio, Singer, Hartman, and Sneider (1982) suggested that inability of the “ventilator” patient to produce sound speech often leads to feelings of loss of control that may trigger frustration and anger in the patient and the family. Interactions between patient and family and staff are likely to be hampered because of the communication difficulties of the patient. The staff is more likely than the patient or the family to perceive communication difficulties as problematic. The staff also tends to perceive the patient as more disoriented and as having more memory problems than perceived by the family. Both patients and staff notice more anger expressed by patients than family members do because the staff is likely to be the target of such anger.

Hypnotically induced relaxation has been identified as a beneficial therapeutic intervention aimed toward assisting with the weaning process (Acosta, 1987; Bowen, 1989). However, research of the topic has suffered from empirical flaws, focusing mainly on case studies and involving heterogeneous samples without use of a comparison group.

OLD AGE

Prevalence of depression among the elderly is between 12% to 15%. Such prevalence is relatively similar to prevalence of depression in the general population. However, once the focus shifts to hospitalized medical patients, between one third to one half of the patients older than 60 are diagnosed with depression (Barusch & Abu-Bader, 1999). Late life depression is more likely to be chronic and is associated with higher mortality rates (Benazzi, 2000).

Physical disability and medical illness are the most prominent risk factors of depression in old age, especially among men. Depression is more likely to occur when a larger number of medical conditions are present. However, the relation between disability and depression could go both ways. Because disability may be the first observable feature of depression, it may be a stressful condition that increases the risk for depression, or depression may be considered as a risk factor for disability (Cadoret & Widmer, 1988).

Bereavement and loss are risk factors of depression in the general population. However, it was suggested that at old age, loss of loved ones and loss of social roles become less influential because of their familiarity to elderly people. Gender discrepancies between males and females diminish with age, possibly because of the fact that medical illness is more depressogenic for men than for women. Similarly, the relation between depression to low socioeconomic status or to family history of depression decreases in old age because of the high association between medical condition and depression (Wolfe, Morrow, & Fredrickson, 1996).

2 CASE STUDY

George was an 89-year-old male, Protestant, married, and father of two children. George retired at the age of 65 from his work as an accountant and was fully independent prior to hospitalization. When admitted to the hospital, he suffered from a complex medical condition, including past history of cardiomyopathy, prostate cancer, and COPD. Most recent medical history included a car accident due to a syncopal episode, pneumonia, respiratory failure, renal insufficiency, and proximal atrial fibrillation.

It is essential to view George's course at the hospital in a chronological fashion because the short period of hospital stay incorporated intense medical, emotional, cognitive, and social changes in his life. Figure 1 presents a graphical illustration of George's course at the hospital. Following the motor vehicle accident, he was transferred to the hospital for further weaning from the mechanical ventilator. His medical condition had slightly improved but eventually was followed by a setback associated with delirium. During this period, George's wife, who was his primary caregiver, broke her hip and died several weeks after her injury. George died 15 days after his wife's death.

3 PRESENTING COMPLAINTS

George was initially evaluated as part of the hospital requirements to evaluate every new admission. During the initial evaluation, George endorsed feeling depressed and expressed feelings of anhedonia and guilt over past smoking behavior. He denied any suicidal or homicidal thoughts or intents. George's vegetative symptoms included insomnia, loss of weight, psychomotor retardation, and loss of energy. Based on the initial evaluation, it was decided that George would benefit from supportive therapy. Later, during the course of his illness, George's level of awareness to the environment had declined, and he was placed in wrist restraints. Periods in which George slept throughout the entire day and was oriented only to type of place and person became more frequent.

4 HISTORY

George denied any personal or familial history of mental illness. Most patients in this particular hospital, including George, suffer from complex medical conditions and are unable to tolerate a long evaluation process. Ventilator patients, in particular, are limited in their ability to communicate and prefer to resort to close-ended questions. Most of the initial information about the patient is usually gathered through contacts with other informants, such as family members and friends. When George was first admitted to the hospital, no family member or friend accompanied him. Therefore, his evaluation did not include important details about his history that were essential to development of an appropriate therapeutic intervention. Only after George's death was the primary thera-

6/9/99	7/14/99	7/21/99	8/20/99	10/5/99	10/25/99	12/3/99	1/2/00	1/17/00
Motor Vehicle Accident	Hospitalization	Transfer for further weaning	Off the vent	Back on the vent	Delirium on/off	Wife admitted to hospital	Death of wife	Death of George

Figure 1: George's Course at the Hospital

pist informed that he was previously married twice. His wife at time of hospitalization had also been married in the past and had children from a previous marriage. It was unclear, however, whether George's biological daughters, who were most influential in his care, also were the biological children of his wife. Figure 2 represents George's family tree.

5 ASSESSMENT

During the initial evaluation, a short neuropsychological screening aimed toward assessing cognitive deficits, is usually employed (i.e., Mini Mental Status Exam) in addition to a short informal interview. George's initial assessment did not reveal any cognitive deficits in his functioning. His cognitive functioning was at the superior level for his age.

George was evaluated three additional times toward the end of his life due to mental status changes associated with deterioration in his medical condition. The purpose of these evaluations was to determine whether George had decisional capacity to make end-of-life decisions. Capacity becomes an issue in situations in which a patient refuses a recommended medical treatment, when self-care is impaired, when there is evidence of mental status impairments, or when the family disagrees with the patient's wishes. There are no uniform criteria to assess competency. However, it is suggested that at least two evaluations should be conducted at different points in time because of possible fluctuations in the ability of older adults to comprehend and to make rational decisions. Evaluation of capacity incorporates several components: (a) The patient has to demonstrate ability to understand the possible choices and to retain information; (b) the patient has to demonstrate rational manipulation of choices; (c) the patient has to understand the implications of the choices made; and (d) the patient has to communicate a coherent and consistent choice over time (Mishkin, 1989; Searight & Hubbard, 1998).

During the first two evaluations, George was only able to nod his head in response to close-ended questions and to follow two-step commands. George indicated that he would prefer to go to a nursing home connected to the ventilator machine rather than go through terminal weaning. Based on these evaluations, it was decided that George had decisional capacity. Following a request of George's daughters, an additional evaluation was conducted. The daughters, accompanied by a case manager, assessed George's end-of-life decisions for the third time and determined that he would prefer to go through terminal weaning.

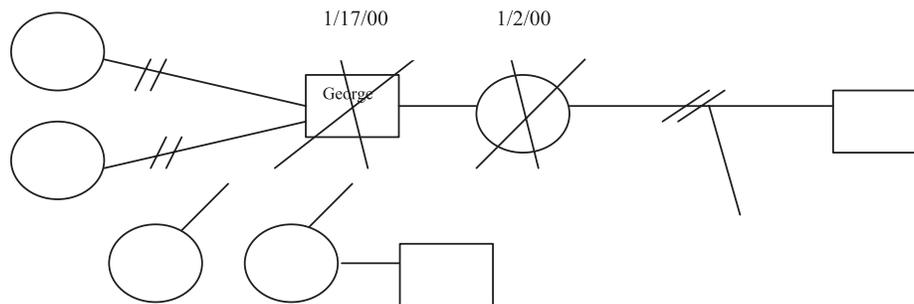


Figure 2: George's Family Tree

6 CASE CONCEPTUALIZATION

Several different DSM-IV diagnoses could be employed to describe George's mental condition. During the initial stages, the options of adjustment disorder versus mood disorder due to medical condition versus major depressive disorder were considered. Due to the fact that George's presentation met criteria for major depressive disorder, the other two disorders were ruled out.

Toward the end of George's life, his presentation met the criteria for delirium due to multiple etiologies. This diagnosis was supported by laboratory results. The diagnosis of major depressive disorder could not have fully explained his presentation at that point. Because George's initial evaluation did not suggest existence of cognitive deficits, the diagnosis of dementia was ruled out.

Several theoretical approaches can explain George's mental condition during his initial hospitalization period. The existential approach (Frankel, 1946; Yalom, 1980), the stage model of death and dying (Kubler-Ross, 1969), and the reinforcement model (Lewinsohn, 1974) were selected because each explains a different aspect of George's condition.

THE EXISTENTIAL APPROACH

The existential approach emphasizes the following four ultimate concerns: death, freedom, isolation, and meaninglessness. Confrontation with these concerns is inevitable, and it is likely to promote anxiety that increases the use of defense mechanisms (Yalom, 1980).

Fear of death was George's main concern. According to the existential approach, fear of death represents the tension between the inevitable and the wish to continue to be. Being in the hospital in a critical condition and abruptly losing his independence served George as a constant reminder of his own mortality. The search for meaning is often influenced by the fear of death. The logotherapy approach suggests that neurosis is a failure to find meaning and responsibility in life (Frankel, 1946). George, who faced

his upcoming mortality, was actively searching for meaning that would account for his life prior to admission to the hospital and for his upcoming death. God was George's source of meaning. Praying to God, talking about God, talking with God, and experiencing God provided George with meaning. George perceived himself as blessed because he "had seen God." The strong connection with God also increased George's belief in his immortality. George, who had never attended church before hospitalization, became religiously involved while in the hospital.

STAGES OF DEATH AND DYING

The stages of death and dying, identified by Kubler-Ross (1969), can also explain George's mental condition at the hospital. The model describes the stages of coping with death. All stages are considered adaptive and serve as defense mechanisms against death anxiety. Although this is a stage model, people can go back and forth through the stages.

In the case of George, some stages captured a more prominent role during certain periods, but oftentimes, several stages co-occurred. During the initial stage, denial and isolation exist. Shock and denial protect the mourner from experiencing the total extent of reality. Denial is often accompanied by isolation from family and friends (Kubler-Ross, 1969). It is possible to view the initial period of George's therapy as representing the stage of denial and isolation. During the first period of George's stay at the hospital, his communication was extremely limited because he was connected to the ventilator machine, which prevented him from producing sound speech. George's hearing problem also impaired communication. Each of the first four meetings with George lasted less than 20 minutes. He did not discuss any personal issues, and the conversation focused mainly on vegetative symptoms of depression. During the fifth session, he had noticed the therapist's name tag and commented on the unusual name. Learning that the unusual name originated from Israel had increased his interest in the therapist because he apparently had a strong political interest. The fifth session lasted longer than the first four sessions, and the topic of discussion was the political situation in the Middle East. Only during later sessions did George discuss his emotional experience at the hospital. The last period in his life, which was characterized by disorientation and inattention to the environment, can also be viewed as a period of denial.

During the second stage, anger is present; when denial cannot be maintained, the question, *Why me?* arises. Anger is displaced in all directions and reduces the availability of social support. Guilt is another common theme at this stage because, often, people express the feeling that their actions caused or failed to prevent the upcoming death (Kubler-Ross, 1969). George expressed guilt related to previous smoking behavior and blamed himself for his medical condition. In addition, George directed his anger toward his daughters, whom he perceived as not caring for his wife as much as he would have liked.

The third stage, bargaining, represents an attempt to enter an agreement with God to postpone the inevitable (Kubler-Ross, 1969). George, who was relatively secular

before admission to the hospital, reported an increase in religiosity and spirituality following his admission. This can be considered as an attempt to prevent the inevitable.

Depression was George's main complaint, endorsed throughout his stay in the hospital. The fourth stage represents a sense of loss that cannot be denied or transformed any longer. This preparatory grief is aimed toward separation from the world (Kubler-Ross, 1969).

Last, acceptance occurs when the patient is no longer angry or depressed about his or her fate. During this stage, the family may need more support than the patient (Kubler-Ross, 1969). It is possible that the last month in George's life, during which levels of orientation and attention declined, represents his acceptance of his fate.

Critics of the model argue that it was developed on middle-aged cancer patients and does not necessarily apply to the elderly. Middle-aged people perceive death as untimely and have to adjust to the dramatic change in roles, whereas elderly people perceive loss of friends and change in roles as familiar and timely (Retsinas, 1988). Despite this criticism, the stages of death and dying model describes George's experiences adequately because he was functionally independent before hospitalization.

THE REINFORCEMENT MODEL

The reinforcement model addresses a different angle of George's mental condition. Depression is considered by the model as a response to loss or lack of response-contingent positive reinforcements. Insufficient reinforcements are said to lead to reduction in behaviors, whereas other symptoms such as low self-esteem or hopelessness are a result of reduced level of functioning (Lewinsohn, 1974). Williamson and Shaffer (2000) studied 228 geriatric outpatients with a variety of illness conditions. They found that illness and disability are life stressors and depression is a reaction to such stressors. However, activity restriction is the mediator that connects between life stressors and depression. Restricted activity is said to prevent people from obtaining positive reinforcements and to lower people's feelings of self-efficacy. In the case of George, a combination of low levels of reinforcements provided by the hospital setting, restricted activity, and few attempts to obtain available reinforcements were responsible for a reduction in his functioning level and for an increase in his depressive symptomatology.

AN INTEGRATED MODEL

Figure 3 represents an integrated etiological model of George's condition. A combination of a deteriorating medical condition and high self-expectations were responsible for his inability to meet his expectations. This promoted thoughts of worthlessness and hopelessness. Feelings of self-anger were influenced by these thoughts. George's self-anger was then redirected at others, who did not meet his increasing expectations. The fact that other people did not meet George's expectations and the hospitalization of George's wife, promoted perception of the world as an unfair place. This thought had

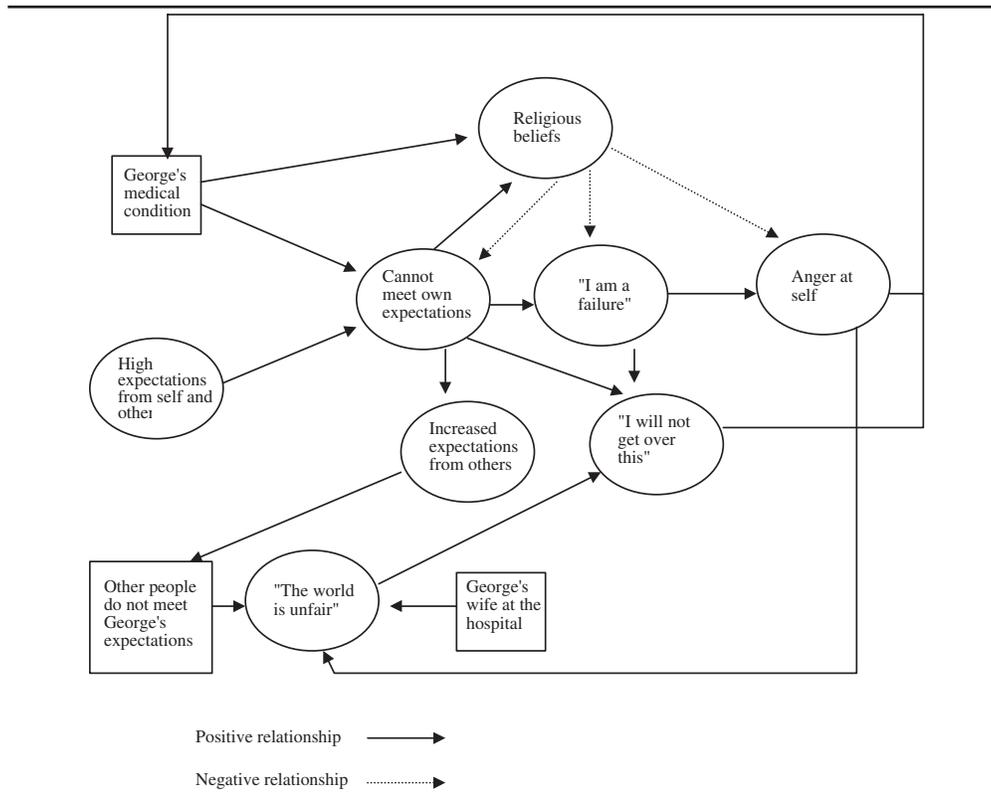


Figure 3: An Integrated Etiological Model

increased George’s hopelessness. Hopelessness and anger had a negative effect on his medical condition. George’s religious beliefs served as his main coping mechanism, which slightly ameliorated his thoughts of worthlessness and feelings of anger.

7 COURSE OF TREATMENT AND ASSESSMENT OF PROGRESS

George’s treatment incorporated the following three main aspects: family therapy, religiosity, and preparation for death. These aspects do not represent the conventional treatment for major depressive disorder. However, even though George met all the criteria of major depressive disorder, his mental condition was viewed in the context of his medical condition and existential issues.

FAMILY THERAPY

It is likely that the death of George’s wife was at least partially related to the stressors associated with her role as his primary caregiver. Even when formal care services are utilized, family members remain a crucial component of the overall care plan. The impact

of caregiving is well documented and ranges from loss of financial resources to emotional and physiological stress (Schulz & Beach, 1999).

The dying person should never be considered in isolation. Treatment should strive to improve the health of the patient and the caregivers and to help the family identify supportive resources. Once the patient receives enough emotional support from the family, the role of the therapist may end (Stedeford, 1979). Familial conflicts regarding end-of-life decisions are likely to occur. Psychologists can play a positive role by clarifying the situation, facilitating discussion, providing support, and helping family members deal with feelings of guilt or regret over their decisions (American Psychological Association, 2001).

Neither George's wife nor his daughters chose to participate in the weekly family support group provided by the hospital. George's family members also chose not to participate in family counseling despite the fact that they were often the focus of the individual therapy conducted with George. During therapy, George discussed his concern for his wife's welfare and his expectations that his daughters would care for his wife in his absence. Ways of communicating expectations to his daughters were explored. However, the fact that his family members preferred not to be involved in therapy hampered the ability to change the family dynamics. Another important factor that hampered therapy was lack of knowledge about George's family history.

Oftentimes, end-of-life decisions require involvement of the family. According to Rothchild (1998), several variables are likely to affect the family's decision-making process:

1. The patient's role in the family: George's role in his wife's life was so crucial that the wife decided to reconnect George to the ventilator machine following a deterioration in his medical condition, despite his initial request not to be reconnected to the ventilator machine.
2. The developmental stage of the family and the patient: The daughters' preference that George would go through terminal weaning was at least partially influenced by the fact that he was an elderly man.
3. The degree of cohesion of the family: The crisis of a dying family member can bring up old loyalties and power struggles. Scharlach and Fuller-Thomson (1994) interviewed 83 adults following the death of one of their parents. The majority of respondents reported that families were extremely helpful during the grieving process. However, several respondents reported that conflicts and childhood power struggles were reactivated during this process. Discrepancies between George's wishes, the wishes of his wife, and the wishes of his daughters were evident. George initially wished not to be placed back on the ventilator if his condition worsened. However, once his condition had worsened, his wife, who had power of attorney, decided that he should be placed back on the ventilator. Once George's wife died, his children wished that he would go through terminal weaning, despite previous evaluations suggesting that he would agree to move to a nursing home connected to the ventilator machine. This scenario reflects the lack of cohesion in the family and the difficulties of the family members to reach mutual decisions.
4. The structural characteristics of the family: A close system may share little information with the staff and may strive to protect the patient against the world. In the case of George, his family members chose not to consult with the psychology team at the hospital as well as not to share information with one another. After the death of the wife, the

daughters decided not to tell George about the event, despite suggestions of the psychology team to the contrary.

5. Denial and guilt or "the daughter from California syndrome": This concept refers to a daughter who comes all the way from California and struggles to keep her mother alive even though she has never been involved in her mother's care before. Similarly, once George's wife had died, a daughter from Arizona, who was estranged from George for many years, came to the hospital for the first time and argued that George should be taken off the ventilator.

RELIGIOSITY

A second aspect of George's treatment plan emphasized religiosity. The importance of religious issues in the general population is well documented. Of people older than 65, 52% attend worship services and 75% indicate that religion is very important to them (Princeton Religious Research Services, 1985). Koenig, George, and Peterson (1998) studied 87 people older than 60 who came to a medical clinic for treatment. Intrinsic religiosity predicted shorter time for remission of depression. In addition, one third of the participants spontaneously and without prompting indicated that religious aspects (i.e., "God," "the Lord," "my faith," "prayer," "Jesus," and so forth) helped them deal with the stress associated with their physical illness.

According to the American Psychological Association (2001), use of religion may supplement but not replace traditional psychotherapeutic strategies. The patient should be provided with permission to discuss and practice spiritual beliefs (Coward & Reed, 1996). In addition, spiritual involvement of clergy should be encouraged (Moss, McGaghie, & Rubinstein, 1978). For George, religiosity provided a sense of hope and self-esteem and helped him accept his death. He was encouraged to talk about his spiritual experiences and the involvement of clergy was also encouraged.

PREPARATION

A third aspect of the treatment focused on preparation for death. When working with terminally ill patients, fears about loss of autonomy and dignity and separation from the world should be addressed. The clinician should be aware of the fact that the suffering of a dying person may be physical, emotional, social, and spiritual (American Psychological Association, 2001). Loss of independence was extremely distressing for George, mainly because of his high level of independence prior to hospitalization. George discussed responsibility for his wife's welfare and his perception of his upcoming death as untimely. George's feelings of loss of control were expressed as anger directed toward staff, his daughters, and himself. Therapy attempted to help him gain more control over his care by introducing simple activities that he was able to carry out, such as taking care of his financial business. Therapy also attempted to help George understand the origins of his anger. George was highly functioning at the time of admission and had had various ongoing plans and activities that had to be cancelled due to the hospitalization.

Therapy encouraged George to talk about his losses and to express the wide variety of feelings associated with his terminal illness and upcoming death.

Discussion of end-of-life decisions took place only very late in therapy, and George's primary therapist was not involved in the discussion because of her role as a practicum student. The role of mental health professionals in evaluating decisional capacity and in determining end-of-life decisions has increased in recent years. The patient self-determination act advocates provision of written material to patients and their families as to their rights to make medical decisions and advance directives. The directives become effective if and when the patient is unable to make coherent decisions. Advance directives are used to communicate to family and health care professionals what life-sustaining procedures to use under which medical circumstances in case the patient loses the capacity to decide. Advance directives include the following two parts: (a) the living will, which contains directions to guide medical decisions if decisional capacity is lost, and (b) durable power of attorney, which assigns decision-making capacity to a specific surrogate in the event of future incompetence (Weinstock, Leong, & Silva, 1994).

According to Quill (2000), discussion of end-of-life decisions should include the following topics: (a) goals, which address the hopes and the fears of the patient; (b) values, which address the question of what makes life worth living; (c) advance directives, which address the question of who would best represent the patient's views; (d) discussion of do-not-resuscitate orders; (e) control of pain and other symptoms; and (f) any unfinished business that has to be addressed before the patient can let go. According to Quill (2000), discussion of end-of-life issues has to occur in certain occasions. These occasions include: situations in which the patient is facing imminent death; the patient talks about wanting to die; the patient and the family inquire about hospice; the patient recently was hospitalized for a severe progressive condition; the patient suffers out of proportion to prognosis; when discussing treatment options with low probability of success; when discussing the hopes and fears of the patient; and finally, when answering no to the question, Would I be surprised if this patient dies within 6 to 12 months?

In the case of George, end-of-life discussion was initiated when it became clear that George would not be able to wean from the ventilator machine. He faced the options of going through terminal weaning or of going to a nursing home connected to a ventilator machine. The clinical psychologist who evaluated George was under the impression that he was able to comprehend the implications of his decisions and that he would prefer to stay connected to a ventilator machine. In contrast, George's daughters had initiated a third discussion in the presence of a case manager and concluded that he would prefer to go through terminal weaning.

ASSESSMENT OF PROGRESS

As indicated elsewhere in the text, thorough formal measures are less likely to be employed with terminally ill populations. Instead, informal observations were employed

to evaluate George's progress in therapy. Indicators of the positive aspects of therapy were expressed by George's verbal communication. He indicated that therapy sessions were "refreshing" and stimulating and served as his main comfort at times. Another indicator of George's involvement in therapy was the method of communication used during therapy. Initially, he was connected to the ventilator machine and was able to communicate only by silent speech. George was also severely hard of hearing and therefore written communication on the side of the therapist was required. After George's condition had improved, he was able to use the passive mere valve (PMV), which allowed him to produce sounds. His family had also brought him a pocket talker, which improved his hearing. George's insistence on using these two devices during therapy indicated high levels of involvement in therapy. The content of communication during therapy had also changed. From discussion of sleep and appetite patterns or political events, George started to discuss more personal issues, such as his expectations from family members, his fear of dying, and his spiritual experiences. The length of sessions had also changed dramatically, indicating his positive experience in therapy. Initial sessions lasted for less than 20 minutes, whereas later sessions lasted for more than an hour.

The therapy provided to George had several flaws. First, although therapy was highly focused on preparation for end of life, discussion of advance directives did not occur early enough in therapy and did not occur with George's primary therapist. Second, lack of involvement of family members hampered therapy, especially because George's primary concerns were associated with his family members. Third, failure to conduct a thorough assessment made therapy more complex because important information such as George's family history was not available. Fourth, termination of therapy occurred when George was not able to comprehend its meaning due to abrupt mental status changes associated with a decline in his medical condition.

8 COMPLICATING FACTORS

DIAGNOSIS

Certain symptoms of depression are considered as part of "normal aging" (Gottfries, 1997). In the 1970s and 1980s, depression in old age was perceived as normal (Bruce, 2000; Shaffer, 2000). Only in 1991 did the National Institute of Health propose that late-onset depression could be diagnosed and differentiated from normal aging. Somatization in the elderly is very prevalent (Grau & Padgett, 1988) because somatic symptoms are often more acceptable to older patients than psychological complaints. Somatization results in inappropriate health service utilization and misdiagnosis. Koenig and Kuchibhatla (1998) studied the use of health services in medically ill elderly. After controlling for demographic variables, the Hamilton depression score significantly predicted hospital stay, total inpatient days, and number of outpatient visits in the previous 3 months. Depressed medically ill elderly patients used more hospital and outpa-

tient medical services than nondepressed patients, but they did not utilize more mental health services than the nondepressed group.

Vegetative symptoms of depression may be similar to medical symptoms. Four conceptual approaches to the diagnosis of depression in medically ill were suggested. The inclusive approach includes all symptoms and signs presented by the patient even when they are secondary to the physical illness. The exclusive approach disregards somatic symptoms such as anorexia and does not allow them to contribute to a diagnosis of major depression. The etiological approach determines whether the problematic behavior is secondary to physical illness or to mental disorder. The substitutive approach suggests substituting additional cognitive symptoms of depression such as brooding or pessimism for vegetative symptoms of uncertain or mixed etiology (Cohen-Cole & Stoudemire, 1987). The substitutive approach was employed in diagnosing George. More attention was placed on cognitive symptoms of depression, whereas the vegetative symptoms were disregarded because of their uncertain etiology.

LACK OF KNOWLEDGE

Working with medically ill populations requires proficiency in medical terminology. Without a thorough understanding of medical terminology and of the impact that certain medical conditions may have on cognitive and emotional functioning, psychotherapy is likely to be ineffective.

Lack of social knowledge is another factor that hampered George's therapy. Discussing with George his expectations of his daughters occurred under the therapist's impression that the daughters were the biological daughters of his wife as well. Only after George's death did it become known that he was married twice in the past and that his daughters might not have been the biological daughters of his wife.

THE SETTING

Professional boundaries are more fluid when working with dying people than in traditional psychotherapy cases (American Psychological Association, 2001). The therapist conducts the session in the patient's room, next to the patient's bedside. Medical staff and family members may interrupt the session at any time. Lack of professional boundaries can be manifested by the patient's requests for a blanket, a glass of water, or for a respiratory therapist in the middle of a session. For therapists who are used to the traditional model of psychotherapy, the hospital setting presents a major challenge.

Sessions are likely to be extremely short, determined by the patient's medical condition. In addition, medical patients in today's hospitals do not stay in the hospital for more than a few weeks. Treatment, therefore, has to be focused on the here and now and is likely to be problem-solving oriented rather than insight oriented.

END-OF-LIFE DISCUSSION

Another complicating factor is end-of-life discussion. The majority of physicians have never told a patient that he or she was about to die (Moss et al., 1978). When working with dying patients, the physician becomes more aware of his or her own impotence. Physicians are often reluctant to transmit bad news because they have a professional dedication to the preservation of life and lack psychosocial education about death and dying. The physician holds the notion of being able to cure and is therefore threatened by a dying patient (Kirchberg & Neimeyer, 1991; Lieff, 1982). The therapist and the physician are likely to face the dilemma of identifying the appropriate time to make the transition from rehabilitation therapy to end-of-life discussion and assistance in separation from the world. Lack of education about end-of-life issues is even more prevalent among psychologists. There is no mention of dying or death or end-of-life decisions in either the American Psychological Association accreditation guidelines for psychology programs or the American Psychological Association Code of Ethics (American Psychological Association, 2001).

A study of 151 physicians found that most feel the patient must be told of terminal illness. Older physicians were more negative about offering prognosis. On the other hand, experienced physicians in issues of death and dying tended to provide prognostic information (Rea, Greenspoon, & Spilka, 1975). In general, staff would be more likely to give a favorable picture within the framework of reality (Quill, 2000). In the general public, however, a survey of 1,555 healthy people found that most people would prefer to be informed about terminal illness (Blumenfeld, Levy, & Kaufman, 1979).

Discussion of end of life should take place with the physician because the physician has important information about the patient's medical condition. This discussion occurred very late in the case of George and did not involve his primary therapist, hampering the level of trust and intimacy.

Our society tries to respect the individual by offering the option of advance directives. However, the question of whether the current procedures employed promote the respect for the individual's wishes has to be asked. Many times, people would refrain from writing advance directives due to a "not yet" attitude and indecisiveness regarding matters that need to be decided (Vandecreek & Frankowski, 1996). The fact that a significant portion of the outpatient population misunderstands end-of-life options is also likely to be responsible for people's inclination to make advance directives (Silveria, DiPiero, Gerrity, & Feudtner, 2000). In addition, as conditions change, advance directives may not apply (Reilly, Teasdale, & McCullough, 1994). To complicate the picture, family members do not necessarily represent the wishes of their loved ones. Research has documented no significant correspondence regarding end-of-life decisions between adult children and their parents (Karel & Gatz, 1996).

9 TERMINATING THE PROFESSIONAL RELATIONSHIP

When it became clear that George would not be an appropriate candidate for further therapy due to mental status changes, it was already too late to use so-called conventional termination methods. Instead, it was decided that the primary therapist would talk to George about the enriching experience of working with him. The therapist also told George that any choice he would make about his life would be the right one. George was unable to respond at that time, and it was not clear whether he was able to comprehend the therapist's communication. The attempt to terminate, however, had helped the therapist to do some closure of the therapeutic relationship.

10 FOLLOW UP

Following George's death, his daughters were offered condolences, but no further follow-up contact was initiated.

11 TREATMENT IMPLICATIONS OF THE CASE

The importance of communication with all sides involved in the patient's care is one of the major implications of the case. Caring for a medically ill patient and, in particular, discussion of end-of-life decisions has to occur in the context of consultation with the physician (Goldblum & Martin, 2000) and family members. The medical condition of the terminally ill patient has to be fully considered when developing a treatment plan as well as when conducting end-of-life discussion. The therapist should also strive to involve family members in the development of the overall treatment plan and in the decision-making process. Failure to do so is likely to result in difficulties of the patient and the family to reach end-of-life decisions.

An additional implication of the case is the fact that although insurance companies require clinicians to provide a DSM-IV diagnosis, the appropriate treatment plan may not always adhere to the official diagnosis. George's pathology was not a result of erroneous thought process but rather a result of tragic life events and a deteriorating medical condition. Attempting to reduce depressive symptomatology would have invalidated George's experience. Instead, it was essential to help George experience the wide range of emotions associated with the process of dying.

Finally, use of religiosity as a tool when working with dying patients should receive more recognition. Use of religiosity in treatment is likely to pose a problem for many psychologists because psychology has abandoned religion in the name of science. The "rest of the world," on the other hand, is more likely to appreciate and to use religion and spirituality as coping tools (Koenig, Larson, & Matthews, 1996). For George, as well as for

many other people, God was an important coping tool. Learning how to utilize this tool in therapy is essential.

12 RECOMMENDATIONS TO CLINICIANS AND STUDENTS

WORKING WITH ELDERLY PEOPLE

Therapy with an elderly person is complex as patients often have a mixture of multilevel problems. The therapist should acknowledge his or her expectations from elderly people and his or her beliefs about the ability of older people to change. If the therapist does not believe that older people are able to change, the effectiveness of therapy is likely to be hampered. In addition, at times the therapist may struggle to accept physical limitations associated with old age and medical condition whereas the elderly person has already learned to accept these limitations.

ASSESSING DECISIONAL CAPACITY

During assessment of decisional capacity and discussion of end-of-life decisions, the therapist must understand his or her own values, be willing to discuss the client's values, and to resolve possible value conflict (Goldblum & Martin, 2000). Competency is not an all-or-none ability. However, determining whether the patient has decisional capacity is an all-or-none decision and therefore places the therapist in a complex situation. The criterion for assessing competency is subjective, and psychiatrists often use the risk-benefit analysis of competence. This criterion determines that the least stringent tests of competency should be employed with patients consenting to low-risk and high-benefit treatments, whereas more stringent standards should be used for treatment refusals that carry serious consequences (Weinstock et al., 1994).

Requests to hasten death should be viewed with caution because they may be influenced by numerous factors. Not only should decision-making capacity be considered but also the physical, psychological, and spiritual suffering of the patient should be carefully evaluated when conducting end-of-life discussion (Block & Billings, 1995).

WORKING WITH TERMINALLY ILL PATIENTS

It is important that clinicians who work with terminally ill patients develop skills and resources for surviving this experience. According to Homer (1984), hospital staff tend to use a wide array of defense mechanisms when working with terminally ill patients. Use of defense mechanisms is likely to ease the emotional reaction of the staff toward terminally ill patients but may hamper the care provided to such patients. Therefore, other tools for dealing with the emotional reaction associated with caring for termi-

nally ill patients are recommended. Mahoney (1991) has acknowledged the emotional strain associated with providing care for others and has offered several options aimed toward increasing clinicians' ability to take care of themselves. Individual therapy, adoption of hobbies, taking care of psychospiritual needs, peer supervision, and development of a support system are all excellent resources that should be utilized by clinicians to improve their ability in providing care for the dying.

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