Education: A Complex and Empowering Social Work Intervention at the End of Life

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Education is a frequently used social work intervention. Yet it seems to be an underappreciated and a deceptively complex intervention that social workers may not be adequately prepared to use. Reliable, accessible information is essential as it helps prevent unnecessary crises, facilitates coping, and promotes self-determination. This article conceptualizes education as a fundamental social work intervention and discusses the role social workers play in providing information that is both empowering and culturally sensitive. In particular, this article focuses on social workers working with patients and families facing life-threatening situations, including those in hospice and other end-of-life care settings. After reviewing the relevant literature and theory and exploring the inherent complexities of educational interventions, the authors recommend strategies for more effectively helping patients and families access the information they need.

KEY WORDS: *death and dying; education; end of life; empowerment; health literacy; informational support*

As in most practice environments, social workers in health care settings often assume the responsibility of providing information to patients and family members. This is particularly important when patients and their families are coping with the prospects of a life-threatening diagnosis (Adler, 1989; Deja, 2006). The role of educator seems a suitable one for practitioners because the effective exchange of reliable information promotes client empowerment and self-determination (for example, Bern-Klug, 2004; Lee, 1996). Unfortunately, social workers and other health care providers frequently undervalue education (Christ & Sormanti, 1999; Rabow, Hauser, & Adams, 2004), overlooking its complexity and viewing it as a simple, nontherapeutic, and, perhaps, mundane task (Makoul, 2003). Skill and compassion are needed to convey salient health-related information when patients and families are trying to understand what it means to face a life-threatening illness (Csikai & Bass, 2000; Rabow et al., 2004; Rose, 1999). Furthermore, research suggests that many social workers feel underprepared to provide patient and family education on end-of-life issues (Christ & Sormanti, 1999; Csikai & Bass, 2000; Kovacs & Bronstein, 1999).

As Kubler-Ross (1969) wrote in *On Death and Dying*, "The question is not should we tell. . . ? but rather 'How do I share this with my patient?'" (p. 28). A deeper appreciation of how information is exchanged between practitioners and clients is important because, at some point in their practice, most health care social workers will encounter end-of-life issues (Csikai & Bass, 2000). Whether they work in a dialysis clinic, rehabilitation center, extended care facility, hospice, or hospital, social workers will likely come across patients who are coping with life-threatening health conditions. These illnesses may be recently diagnosed—marking the beginning of the end of life—or may be in the later stages. Social workers should be knowledgeable not only about what informational content is needed, but also about the inherent complexities and barriers involved in the education process. Otherwise, a well-meaning practitioner might unknowingly undermine patient self-determination and empowerment or might neglect key contextual factors that influence how information is processed and understood.

The purpose of this article is to conceptualize education as a fundamental, yet complex, social work intervention when working with individuals who are confronting end-of-life issues and to discuss the role social workers can play in helping patients and families access the information they need in a way that is both empowering and culturally sensitive. To do this, we summarize the related literature; illustrate that education is a well-established, theory-based social work intervention; identify the potential benefits of education; highlight the major sources of complexity related to the effective use of education; and discuss ways for social workers to help negotiate these complexities. Our focus centers on the nature of the educational dialogue that needs to take place at the end of life. We address general principles that may be applicable across a variety of practice settings, regardless of where patients are in their experience with an acute, chronic, or terminal condition. In addition, we provide implications for social work practice and education.

EDUCATION AT THE END OF LIFE: A ROLE FOR SOCIAL WORK

Although providing educational support at the end of life is recognized as an interdisciplinary team responsibility (Sheldon, 1998), social workers are often entrusted with this role (NASW, 2003). According to the National Hospice and Palliative Care Organization (Hay & Johnson, 2001), education is considered a core clinical intervention for social workers who work with terminally diagnosed individuals and their families. Similarly, Miller and Walsh (1991) identified patient and family education as a primary role of social workers in end-of-life care settings. This role often dovetails with the educational support provided by nurses, physicians, and other interdisciplinary team members. By reiterating and clarifying important content, evaluating the effect of such communication, and filling information "gaps," social workers, in concert with others, can help families access the information they need in an understandable way (Deja, 2006). By educating individuals and their families about relevant end-of-life issues, social workers serve as "context interpreters" (Bern-Klug, Gessert, & Forbes, 2001). Health care social workers help families put pertinent information into context and deal with feelings evoked by the information. In addition, "most people who are dying—or at increased risk of dying—benefit from a 'big picture' perspective of the end-of-life journey they are making, including discussions about the possible paths to dying and death" (Bern-Klug et al., 2001, p. 44).

Social workers also have a professional obligation to minimize communication barriers within the health care system because ensuring that patients and families are adequately informed is a prerequisite for client empowerment and self-determination. In other words, to facilitate autonomous decision making, patients and families must understand their options, have access to the necessary information, and not feel pressured or coerced. The exchange of information is essential for establishing informed consent for medical care, fostering adaptive coping strategies, and preventing unnecessary crises. Thus, rather than an ancillary task, patient and family education should be a priority for practitioners.

Patient and family education should always begin with a good biopsychosocial–spiritual assessment. It is important to recognize what type of information is needed and desired as well as the timing and manner in which the family wants to receive it. Of course, a comprehensive, individualized assessment involves more than a simple checklist of risk factors. Rather, it strives to uncover the patient and family's experience and unique story (Baker, 2004; Richards, 2000). Permitting time for people to share their narratives about the illness serves multiple purposes. It often provides health educators with essential and meaningful information, while allowing the storytellers to have control over their own narratives (Makoul, 2003; Richards, 2000). Practitioners can elicit feedback about whether individuals are ready for health-related information and the preferred format. Moreover, social workers can explore how individuals understand the information they have received and can help identify hopes, goals, expectations, and fears. Facilitating an assessment dialogue can and should allow individuals the opportunity to explain the circumstances of the illness and its meaning within the family context (Sheldon, 1998; Taylor-Brown, Blacker, Walsh-Burke, Christ, & Altilio, 2001).

During the assessment, social workers should also discern what type of education is needed and desired as the information needs of caregivers often differ from the needs of patients (Clayton, Butow, & Tattersall, 2005). The preferred timing, amount, and content of information vary greatly among family members and other informal caregivers (Fallowfield, 2004; Rose, 1999). Aoun and colleagues (2005) reported that caregivers desire information on topics such as how to provide hands-on patient care, how to relieve patient distress, expected emotional reactions of both patient and caregiver, and ways to access medical services and equipment. They may also want a deeper understanding about the meaning and circumstances surrounding the illness (Bern-Klug et al., 2001; Rose, 1999). Some patients and families may prefer that these care-related issues be discussed primarily with the caregivers to avoid creating undue anxiety for the patient. However, in other families, it may relieve anxiety for the patient to be involved in these discussions (Clayton, Butow, & Tattersall, 2005).

A THEORY-BASED INTERVENTION

The role of educator is recognized in health social work as an integral part of illness prevention and health promotion (Dhooper, 1997). Education is a fundamental, theory-supported social work intervention and a vital strategy when working with individuals and families at the end of life (Hay & Johnson, 2001). A few theories that frequently guide social work practice and conceptualize education as a valued intervention are described in the next sections and ego psychology, cognitive, behavioral, empowerment, and crisis theory.

Ego Psychology

This theory focuses on the role the ego plays in negotiating between internal needs and the demands of social living (J. Walsh, 2006). Much of the focus is on peoples' coping strategies for dealing with situations that induce anxiety. This theoretical approach proposes five techniques that are ego supportive and two that are ego modifying; education is one of the five ego-supportive techniques (Goldstein, 1995). In many health care settings, this might involve content about the dying process, caregiving roles, hospice, or other palliative care services. More specifically, people may want information about their diagnosis, prognosis, medication and treatments, advance directives, and the disease process in general. Education about family and group dynamics helps individuals consider the effects of their behavior and life situation on others, such as their family, friends, and health care team members. The more concrete and perhaps obvious role for the educator is to inform families about available resources and services and how to negotiate health care and other external systems. Within ego psychology, education facilitates options for change and assists with problem solving by increasing a person's "fund of knowledge" and his or her level of insight (J. Walsh, 2006). Thus, educative techniques can be a critical source of support to patients and families living with a life-threatening illness.

Cognitive and Behavioral Theories

Practitioners using these theories address problematic thought processes and behaviors that lead to depression, anxiety, phobias, obsessive thoughts and behaviors, or any other symptoms that complicate lives and relationships. Education is a central part of cognitive and behavioral work, teaching patients and family members about their erroneous beliefs, automatic thoughts, maladaptive schemata, and, most important, the process for change (Beck, 1995). In the framework of behavioral theory, educational interventions focus on five domains of behavior: social, environmental, emotional, cognitive, and physical cues (J. Walsh, 2006). People are taught about the relationship between cues, behaviors, and consequences. For example, a social worker may help a caregiver tactfully confront cognitive distortions, such as "if she would just eat, everything would be fine." Both understanding that appetite diminishes when the body is shutting down and helping the caregiver find alternative ways to "nourish" his or her loved one involves the gentle confrontation of past ways of thinking.

Empowerment Theory

We refer in our title and throughout the article to the importance of empowerment. This "theory" is probably better characterized as a social work practice approach rather than as a formal practice theory. Regardless, it remains a core social work value (Lee, 1996). Empowerment may be especially relevant when working with seriously ill people. As people who are dying become weaker and begin to retreat from life, our interactions with them need to maximize their involvement in decision making. Perhaps unintentionally, the pace and intensity of our health care system often overwhelms and disempowers even the most well-prepared patients. Consequently, educating patients and their caregivers about rights, resources, the health care system, and what is happening to them, enhances the potential for empowering, holistic, and ethical care (T. Walsh & Lord, 2004). Small and Rhodes (2000) suggested that adequate access to information can help counteract some of the disempowering aspects of serious illness. Using this perspective, social workers can incorporate a "bottom-up" model that fosters client strengths, encourages a sense of control, and fosters an equal exchange of information (Ingersoll-Dayton, Schroepfer, Pryce, & Waaral, 2003).

In the context of end of life, crisis theory may actually be most relevant when it becomes clear that the person is not going to get better or at what may be the beginning of the end of life.

Crisis Theory

Social workers call upon crisis theory frequently in their work with people coping with life challenges (J. Walsh, 2006). A crisis is complex and personal, yet some aspects are universal. The Chinese have no single character for our equivalent of the word "crisis." To address the complexity of this concept they combine the characters for "danger" and "opportunity" (James & Gilliland, 2001). We maintain that education can help a person maximize the opportunities (for example, for emotional and spiritual growth, time with loved ones, and participation in decision making), while minimizing the dangerous aspects of the situation (for example, social isolation, withdrawal, or "unfinished business"). In crisis, a stressor may be biological, such as a major illness; interpersonal, such as a sudden loss or threat to a relationship; or environmental, often related to natural disasters or human-made disasters that could include loss of employment, home, and other norms. Life-threatening and terminal illnesses present some or all of these stressors. In the context of end of life, crisis theory may actually be most relevant when it becomes clear that the person is not going to get better or at what may be the beginning of the end of life. Providing information about the illness, its effect on family caregivers, and resources to help support the patient and family physically, emotionally, and financially can mollify potential crises, while allowing for growth, meaning making, and the strengthening of relationships.

THE BENEFITS OF EDUCATION

Educational interventions by social workers and other health professionals are known to benefit clients in a number of ways. Although appropriate topics for an educational discussion will vary from situation to situation, people tend to want details about their illness and care options to help them feel more in control. Patients often desire health-related information after receiving a life-threatening or terminal diagnosis (Proot et al., 2004). Facilitating an open dialogue about peoples' educational wants and needs can benefit them by fostering coping strategies, promoting self-determination, thwarting preventable crises, and reducing health care costs.

Coping

Much of the research exploring the benefits of educational support to families is based on the premise that information facilitates the coping abilities of patients and caregivers (for example, Pickett, Barg, & Lynch, 2001). A lack of clear communication and limited access to information are known barriers to family support (Aoun et al., 2005). In addition, providing information on the projected disease course may lessen fears, increasing a sense of predictability (Aoun et al., 2005). On the other hand, Parry (1990) suggested that communication of sensitive information has the potential, in some cases, to attenuate patient and family guilt, shame, or other feelings of inadequacy.

Related to coping is preparedness (Rabow et al., 2004), a multidimensional construct incorporating medical, psychosocial, spiritual, and practical dimensions of one's unique situation. Steinhauser and colleagues (2001) surveyed and interviewed health care providers, patients, and family members to better understand the role and dimensions of preparation at the end of life. Components related to preparation include naming someone to make decisions, understanding what to expect about one's physical condition, putting financial matters in order, knowing one's doctor is comfortable talking about death and dying, feeling the family and the patient are prepared for the death, and having funeral arrangements planned. Providing information is an integral part of each of these components of preparedness. Informational support is another way of framing this educational experience. A form of social support, informational support (that is, informing a person about ways to manage a problem and cope with the related stress in a manner that enhances one's perception of control) is highly correlated with emotional support (Krohne & Slangen, 2005). Studies of cancer patients have highlighted the desire for individualized informational support using Internet-based resources (Shapiro, Coyne, & Kruus, 2004) and the importance of both tangible (for example, books, pamphlets, Web sites, or self-help groups) and interactive informational support in patient–physician interaction (Maly, Leake, & Silliman, 2004).

Self-Determination

Promoting client self-determination is an essential part of contemporary social work practice. Social work scholars have advanced the argument that to preserve client self-determination at the end of life, dying patients (or their designated proxies) must have access to reliable information so they can make sound, well-educated decisions about their care. As Beauchamp and Childress (1994) suggested, individual choice is meaningless without good information. Respecting a patient's decisions is especially important when working with terminally ill individuals, because maintaining a sense of control is consistently reported as one of the primary concerns voiced by dying patients (Proot et al., 2004).

From an empowerment perspective, patients should be viewed as active agents rather than empty vessels waiting to be filled with expert knowledge (Lee, 1996). When seen as knowledgeable participants, patients are better able to assess their own educational needs and preferences. Ideally, providing concrete information about available services, equipment, professional roles, practical limitations, and realistic expectations would help maximize independence and control. This may be more difficult than it sounds, however. Even in the best of situations, people have difficulty taking in all of the details related to diagnosis and prognosis. This process is often compounded by the emotional overlay of hearing information one does not want to hear or may not understand (Stoneberg & von Gunten, 2006). In addition, as Powazki and Walsh (1999) reminded us, many terminally ill people, especially those in the advanced stages of their illness, may lack the emotional or cognitive capacity to make an informed choice. When this occurs, social workers should identify and consult advance directives and the patient's surrogate decision maker regarding what is known about the patient's wishes.

Crisis Prevention

In addition to promoting self-determination, education can help some patients and families avoid unnecessary distress. The delivery of sensitive information can increase a family's sense of control, minimizing the likelihood of a perceived crisis (Grbich, Parker, & Maddocks, 2000; Tringali, 1986). If patients and family members have some indication about what to anticipate given their diagnosis, prognosis, and care options, practitioners may help them prepare for possible contingencies.

Reduced Costs

Preparatory education not only helps minimize patient and family crises, but also can reduce health care costs by minimizing preventable "false alarms." This might help explain why the presence of a social worker during hospice intake visits appears to reduce overall health care costs (Reese & Raymer, 2004). In addition, when social workers were present during the initial admission visits, patients had a higher quality of life, staff retention and satisfaction were higher, the number of hospitalizations dropped, and families required fewer on-call visits (Reese & Raymer, 2004). These correlates may be the result, in part, of good educational interventions that have the potential to reduce anxiety, provide family support, and prevent foreseeable crises.

THE COMPLEX PROCESS OF PROVIDING EDUCATION

Although the benefits of providing education to patients and their families are generally recognized, the inherent complexities of doing this effectively are less clear. When considering the educational desires and needs of patients and families, social workers face multiple challenges in areas such as those explored in the following paragraphs: cultural variation, cognitive status, health literacy, patient and family expectations, emotional responses, practitioner bias, and the unknown.

Cultural Variations

Personal views about illness, caregiving, dying, and death are shaped by, among other things, one's cultural background. An individual's unique social and cultural experience often determines rules or norms about when, where, and with whom it is appropriate to discuss end-of-life issues. Depending on a person's cultural orientation, conversations about advance directives, diagnosis, and prognosis may be considered unapproachable (Jennings, Ryndes, D'Onofrio, & Baily, 2003). Others might believe that patients should be protected from this information. Some cultures believe discussing such issues could bring about negative outcomes. For example, some Chinese cultures hold fatalistic beliefs that openly talking about a patient's illness or death will bring about unfortunate events (Braun, Tanji, & Heck, 2001). This underscores the importance of a culturally informed and sensitive assessment early on.

Many cultures make health decisions within a family or community context rather than on an individual basis. The notion that patients should be in control of their care options is a Western phenomenon and may not make sense to those unfamiliar with these culturally based assumptions (Jennings et al., 2003; Koenig, 1997). Because the NASW *Code of Ethics* (2000) charges practitioners with advancing client self-determination, this clash of cultural perspectives may create a difficult professional paradox. As Taylor-Brown and colleagues (2001) phrased it, "one dilemma that often confronts health care teams is reconciling autonomy and respect for self-determination with a family's cultural traditions" (p. 6). Dean (2001) referred to this as a "paradoxical combination of two ideas—being 'informed' and 'not knowing' simultaneously" (p. 628). Social workers should, instead, honor and explore the unique cultural expectations of each family and realize that, even within the same family, different expectations may exist. This reinforces the notion that family assessments and educational interventions should be individualized and conducted with respect, impartiality, and a deep interest in understanding each person and family. In short, health care workers should not presume they know what is best for a patient on the basis of their membership in a particular ethnic group or social class (Bern-Klug, 2004). In fact, we must acknowledge that we do not know, and then set out to learn from each patient and family.

Cognitive Status

Another complicating factor is that a patient's cognitive status often changes during the course of care. Whether because of normal disease progression, sedation, or emotional distress, an individual's competence and capacity may fluctuate or deteriorate over time. Caregivers may also have a diminished ability to absorb educational content, as a caregiver's capacity may be compromised by stress and fatigue. Because most empowerment efforts focus on individuals who are cognitively aware (Ingersoll-Dayton et al., 2003), the challenge is to figure out how to best facilitate empowerment when decision-making capacity is compromised. Also related to cognitive status, another consideration for practitioners is the developmental stage of those involved, especially when dealing with children and adolescents. Unfortunately, this important topic is beyond the scope of this article, but for a summary of contemporary approaches to helping children cope with a parent's life-limiting illness see Christ and Christ (2006).

Health Literacy

Recent research on public health literacy highlights concerns about the exchange of medical information between health professionals and care recipients. The federal public health initiative, Healthy People 2010 (2005) defines *health literacy* as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (p. 11). In essence, the health literacy movement is concerned with how well patients acquire, comprehend, and act on available health information. Nearly one-fifth of the American public is functionally illiterate (Kirsch, Jungeblut, Jenkins, & Kolstad, 1993). These findings were based on measures of general literacy, not health-related literacy specifically. Estimates of those with compromised health literacy are probably much higher because medical terminology is often jargon rich, Latin-based, and full of confusing acronyms. Unlike other easily observed barriers to patient education, health illiteracy is invisible. Therefore, social workers and other health professionals should evaluate each individual's unique literacy level, interest in accessing information, and cognitive–developmental status (Sheldon, 1998; Stoneberg & von Gunten, 2006). Although some people will continue to prefer that their health care professional handle the details, there is a strong consumer movement to engage lay people in their health care information and decisions (Healthy People 2010, 2005).

Patient and Family Expectations

Although the public is becoming increasingly better informed about end-of-life care, myths still abound. Bern-Klug (2004) advised social workers to encourage patients to discuss the assumptions and expectations they hold about their disease and available care options, honoring the family's cultural beliefs and traditions. Good information may dispel some unrealistic and potentially detrimental assumptions about the dying process (Bern-Klug et al., 2001). In this way, practitioners can help families develop realistic expectations. For instance, social workers can address some of the common myths about palliative care and align expectations within the bounds of what service providers can actually provide. One such myth is that admission into hospice care implies giving up hope. In these cases, social workers can work with families to reframe the meaning of "hope" from hope for a cure (which may be unrealistic) to hope for comfort and dignity in the remaining days of one's life.

Paradoxical expectations can also complicate educational interventions. Individuals may hold conflicting beliefs about their own information desires and needs. Some terminally ill patients hold discordant beliefs about the amount and type of information they want (Kutner, Steiner, Corbett, Jahnigen, & Barton, 1999). Patients often struggle between wanting to know as much as possible and wanting to hear only good news. If unaddressed, such conflicting desires can produce an upsetting double bind for patients and an awkward, complicated situation for practitioners trying to relay accurate information.

Family members may have different levels of preparedness regarding prognostic information, calling for an open-ended approach that helps individuals adjust in their own unique way. Patients and families can become empowered to regulate the timing and amount of information they receive. Therefore, if they need to maintain emotional distance or denial, they can do so. Prefacing an educational intervention in this manner allows people to brace themselves for potentially distressing news and provides an opportunity to hear each other's hopes, fears, and beliefs. In addition, families often need a chance to discuss when, where, how much, with whom, and what type of information should be exchanged.

Emotional Responses

Educational activities can evoke powerful and uneasy emotions in concerned patients and family members. When providing information about hospice, palliative care, or other end-of-life settings, social workers should acknowledge that this information is potentially distressing, and should be prepared for, and comfortable with, addressing a wide-range of emotional reactions (Taylor-Brown et al., 2001). Typical responses will vary depending on how the patient and others interpret the illness, but can include avoidance, depression, anger, fear, denial, anxiety, intellectualization, and guilt. Although extreme manifestations of these emotional reactions can be destructive, their presence is usually normal and emotionally constructive in the context of coping.

In one study of family caregivers of hospice patients, the more cognitive information caregivers received, the more likely they were to experience feelings of anger and anxiety (Willert, Beckwith, Holm, & Beckwith, 1995). The researchers surmised that the strong emotional responses were due, not to the amount of information given, but to the content. New information may threaten established coping strategies, challenge deeply held assumptions, or highlight conflicting beliefs. Families might simply feel overwhelmed by medical information, or certain "trigger phrases" might elicit strong anticipatory grief responses. For example, some caregivers might experience intense anxiety when discussing routine medical interventions, such as administering a dose of morphine or the delivery of a hospital bed to the home, especially if they view these as signs of the patient's imminent death. Or, applying for Social Security Disability might symbolize a marked and distressing loss of independence. Thus, social workers should be aware that providing educational support and concrete information about services may elicit strong emotional reactions. This is not to suggest, however, that information be withheld to protect patients and families, although there may be times when this is wise. Instead, social workers should prepare them by first inviting a discussion about potentially conflicting desires, the perceived meaning of medical interventions, unrealistic expectations, and the patient's and family's goals before discussing sensitive information.

Practitioner Bias

The way in which medical options are defined, interpreted, framed, and explained by health care professionals influences how patients and families make decisions. In other words, the manner in which health care knowledge is presented can influence treatment decisions and can jeopardize patient self-determination (Bern-Klug et al., 2001; Drought & Koenig, 2002). Well-meaning professionals may unknowingly describe health care options that reflect their own values, leaving patients (or their decision-making proxies) with a limited understanding of health care alternatives. In fact, social workers may inadvertently disempower patients by using suggestive or leading language to pressure patients or families into making agreeable (or compliant) decisions. For example, one might subtly communicate personal preferences nonverbally with a nod of the head when presenting certain treatment options, saying, "You wouldn't want to put your loved one through more treatment, would you?"

Social workers can qualify "facts" as information based on what typically happens and not necessarily what will happen in the patient's case.

The Unknown

A key social work role is to educate patients and their families regarding the expected disease course (Taylor-Brown et al., 2001). However, some of what families want to know, especially regarding the prognosis, is inexact and cannot be known with certainty. Practitioners must acknowledge this and feel comfortable saying "I don't know." Conversations may need to include extensive deliberations about "what is known" and "what is knowable" (Bern-Klug et al., 2001, p. 44), including questions about prognostic ambiguities or other uncertainties. Further complicating the issue is that family members often "don't know what they don't know" (Rabow et al., 2004, p. 483). Instead of simply dispensing information about possible disease outcomes, patients and families might benefit more from an invitation to discuss concerns about the patient's prognosis and feelings related to uncertainty. By addressing prognostic uncertainties, practitioners can discuss the limitations of the available information. Social workers can qualify "facts" as information based on what typically happens and not necessarily what will happen in the patient's case.

IMPLICATIONS FOR SOCIAL WORK EDUCATION AND PRACTICE

Patient and family education is a fundamental, yet complex, intervention in health care and one that is especially well suited for social workers. General preparation in systems theory, family and group dynamics, and the importance of an individualized assessment that is ongoing and multidimensional helps social workers start with the unique needs of each person. Training in policy, as well as in community-based practice and research, helps social workers understand the complexity of the health care system in which patients are living and dying. More specific training in the practice theories presented earlier would help to prepare social workers for some of the challenges inherent in this work. In their review of the knowledge, skills, and values for effective intervention with patients and families, Gwyther and colleagues (2005) identified providing information, support, and education as integral aspects of a social worker's role.

Some research, however, suggests that social workers are not as well equipped to provide education on end-of-life issues as they could be (Christ & Sormanti, 1999; Csikai & Bass, 2000; Kovacs & Bronstein, 1999). To facilitate advocacy and to promote the effective assessment and dissemination of information to those living with life-threatening conditions, we recommend that social work practitioners and educators consider the following three things:

1. Theory: Recognize education as an essential, theory-driven component of professional practice. In particular, ego psychology, cognitive, behavioral, empowerment, and crisis theory conceptualize education as an important, if not essential, intervention.
2. Assessment and Intervention: Recognize the importance of an ongoing, individualized assessment that addresses the following inherent complexities related to working with each patient and family: cultural variation, cognitive status, health literacy (including developmental status), patient and family expectations, emotional reactions, practitioner bias, and comfort level with the "unknown." Perform these assessments in an open, patient-/family-centered dialogue, eliciting a holistic picture of each family's educational needs, culture, and context. From this, social workers should be able to identify what the family knows, needs, and wants to know. Specific practice implications may include the following:
    - Foster an equal information exchange—educational interventions should be dialogues rather than didactics.
    - Provide information in various formats (that is, verbally, written, and by demonstration). Avoid acronyms and medical terms, or, if using them, clarify whether these are understood.
    - Give patients and families a chance to tell their story.
    - When using cognitive techniques, tactfully confront cognitive distortions by educating patients and families about their erroneous beliefs and automatic thoughts. Help reframe their notions of hope, and align

their expectations within reason. Also, encourage families to challenge conventional conceptualizations of death and dying (for example, dying does not have to be depressing or painful).

- Remember that too much information may overwhelm family members, so give them permission to forget. However, also provide them with a "lifeline" so they know how to get the answers they need (for example, "You may not remember everything we talk about today, and that's ok. If you need to get in touch with us, just call 1-800-XXX-XXXX").
- Give families the information they need to avoid potential crises. For example, What should they do in case of emergency? How and when should they access community services and resources? What do they need to know about the disease or the dying process?
- Educate patients and families about family and group dynamics. For example, some family members might withdraw socially, others may overfunction and take control; some may be in denial and therefore get frustrated with family and staff who try to get them to "deal with it," whereas others might feel a sense of urgency to address every aspect; some may be angry and ask "Why?", whereas others are busy searching for information, answers, and second opinions. Understanding that these are common ways to respond to intense situations may be helpful to families.
- Educate patients and their caregivers about their rights (for example, those established in the Patient Self-Determination Act of 1990 and, more recently, in the Health Insurance Portability and Accountability Act [HIPAA]).
- Instill a sense of control. Remind patients and families that they are in charge; clarify their goals, foster strengths, and help identify opportunities for growth, meaning making, and enhancing social relationships.

3. Advocacy: Advocate on behalf of patients and their families. The more concrete and perhaps obvious role for the educator–advocate is to inform families about available resources and services and how to negotiate health care and other external systems. However, this may also include acting as a conduit to foster an effective exchange of information between the family and other health care staff or going beyond the clinical setting to help shape policy that addresses end-of-life and other health care needs.

In summary, we need to be educating social work students and practitioners about the value of education as an intervention. It may appear to be a simple process, but we maintain that it is deceptively complex. When done well, education acknowledges the uniqueness of each patient and has the potential to provide support, comfort, and empowerment to patients and families. **HSW**

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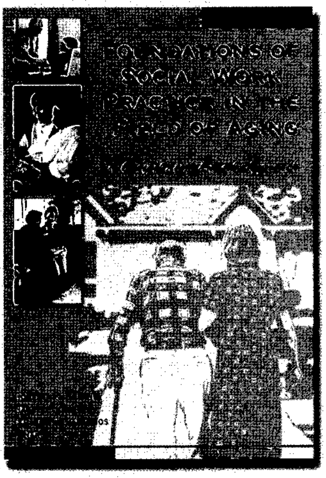

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