



PALLIATIVE CARE WITH OLDER ADULTS

SECTION 2: SOCIAL WORK ROLE IN PALLIATIVE CARE

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Social Work's Unique Contribution to Palliative Care

- ◆ Social work has great potential to improve care for older people with life-threatening illnesses or those who are dying or bereaved.

As previously noted Social Workers are the largest group of mental health professionals working with this population in both hospice and palliative care. They encounter individuals with advanced illness in a broad range of health care and social organizations and agencies. Social Work values, knowledge, and skills are inherently consistent with the principles of palliative care: client self-determination, the biopsychosocial/spiritual perspective, family and social systems, cultural competence, and promotion of social justice are a natural fit in the palliative care context. With their psychosocial training, social workers have comprehensive skills, not only as practitioners, but as educators, researchers, and policy makers as well. Social workers are fundamentally trained to practice from a “person in his or her environment” perspective, and this theoretical view is invaluable to the medical care team.

Expertise in Medical and Social Systems

- ◆ The social worker possesses expert knowledge about navigating the medical and social systems that frequently present barriers to the client. Social workers are experts in communication with families, and also between the client and family and the healthcare team, since they draw upon the family's experience in a unique way and guide the team in their interactions with them.

Social work in practice naturally invites collaboration with the family, the interprofessional care team, and the community. Social work's view includes an appreciation of cultural and spiritual dimensions of the family's life.

As experts at helping individuals and families maximize coping in crisis and at addressing the psychosocial domains of symptoms and suffering, as well as the experience of grief and loss, social workers are able to provide intensive counseling for those confronted by life-limiting illness and the myriad complex problems imposed by

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illness (Taylor-Brown, Altilio, Blacker, Christ, & Walsh-Burke, 2001). The profession's focus on "starting where the client is" encourages exploration of the client's needs, strengths, and resources that inform the ongoing work of living with advanced illness or end-of-life issues.

Commitment to Social Justice and Alleviation of Health Disparities

- ◆ Social work's long commitment to social justice positions it for a leadership role in analyzing, advocating, and implementing policy changes that can mitigate the multiple factors leading to disparities in health care.

The social work role as patient advocate is also critical to palliative care. Linking patients to resources and helping patients negotiate the goals of care are an essential therapeutic focus. Often social workers are part of ethics committees or consult teams (Csikai & Sales, 1998; Taylor-Brown et al., 2001). Upholding the principles of self-determination and autonomy, justice, and access for all within the care delivery system are important elements of social work advocacy. Social workers have played a critical role in many areas of health care policy creation and reform, and in insuring access to quality care for the dying.

Social work researchers have the potential to further expand the focus on palliative and end-of-life care to include areas such as ethnic, cultural, and economic disparities; substance abuse; incarceration; interventions at different stages in the life course; crisis interventions; and interventions in community and organizational contexts. Social work expertise in implementing changes in policy through advocacy and leadership should be used to bring about important improvements in care for people who have an advanced chronic illness or are dying or bereaved (Kramer, Christ, Bern-Klug, & Francoeur, 2005).

Education of Patient and Family

- ◆ Providing information about resources, advance care planning, caregiving tasks and supports, and normative grief responses is common to social work practice in end-of-life care (Blum, Clark, & Marcusen, 2001; Hedlund & Clark, 2001).

Social workers commonly intervene when there are languages, literacy, or cognitive deficits that present barriers to patients' understanding of complex information.

In summary, as stated in the "National Agenda for Social Work Research in Palliative and End-of-Life Care" (Kramer et al., 2005), social workers have an important role to play, "given their work in varied and divergent practice settings across the life-span, their role in addressing mental health needs, grief, and psychosocial aspects of well-being, and their commitment to promoting culturally competent, effective, and

humane care, particularly for the most vulnerable and oppressed members of society” (p. 418).

Assessment of Needs and Preferences for Palliative Care in the US Population

Surveys of the U.S. population concerning patients’ and families’ needs and preferences for care during advanced illness have supported the expansion of palliative care and continue to inform professionals about the values of the general population, but also have stimulated research on variations among cultural groupings. For example studies of marginalized groups who believe they have been poorly treated by the health care system for other medical issues found that they may refuse to sign advanced directives giving the physician permission to withhold treatment. Social work has often been in the forefront of research into the different views of marginalized subgroups (Bullock, 2006; del Rio, 2006). This knowledge base is used in the individual and family assessment by inquiring about patients and family’s values and preferences and previous experiences with health care.

Assessment of U.S. Population Needs and Preferences

Early Surveys

Although hospice has been accepted by professionals and advocates of better end-of-life care, it was reaching only a small proportion of those dying in the U.S. because of the restrictions on prognosis and curative treatments. Two landmark national studies and an Institute of Medicine (IOM) report (cited below) gave particular momentum to a movement to change the culture of death and expand the palliative care philosophy and approach to include hospitals and the full range of health services.

- ◆ The “Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments” (SUPPORT STUDY) conducted from 1989-1991 explored the actual experience of 4301 U.S. hospitalized patients who were expected to survive 6 months or less. They found that patients received a lot of aggressive treatment, their wishes were not known, they did not have “do not resuscitate” orders until very late in the course of their illness, and they experienced pain and spent time in the intensive care unit (Knaus & Lynn, 2000).
- ◆ The second study, conducted by the American Health Decisions research team in 1997 and funded by the Robert Wood Johnson Foundation, surveyed Americans’ views, hopes, and beliefs about the process of dying in America. The researchers found Americans feared reaching the end of their lives hooked up to machines. They did not believe that the current health care

system supported their concept of dying. They felt it was important to plan for death and dying but were uncomfortable with the topic and resisted taking action.

Current Practice with Patients and Families

- ◆ A review of existing practices and current research, summarized in the 1997 IOM report *Approaching death: Improving care at the end of life* (Field & Cassel, 1997) identified four major concerns of the elderly:
 - Needless suffering by many patients at the end of life when they do not receive supportive care or when they receive unnecessary or in-effective invasive treatments.
 - Legal, organizational, and economic factors that impede the delivery of care.
 - Inadequate education of health care professionals on end-of-life care.
 - Lack of research to support evidence-based care during advanced illness.

- ◆ Seven recommendations were made by this IOM report to improve care:
 - Improve public dialogue and professional education.
 - Re-establish doctor-patient relationships.
 - Develop improved advance directives/care planning.
 - Overcome barriers to pain management.
 - Provide information to support informed decision- making.
 - Expand hospice-type services.
 - Respect cultural and religious differences.

Recent Studies

Two recent surveys by two different research groups had similar findings as the earlier surveys.

- ◆ In the first, 340 seriously ill patients reported the following five responses when asked what they wanted during a terminal illness process (Singer, Martin, & Kelner, 1999; Steinhauer et al., 2000).
 - Pain and symptom control.
 - Avoid inappropriate prolongation of the dying process.

- Achieve a sense of control.
- Relieve burdens on family.
- Strengthen relationships with loved ones.
- ◆ In a separate study of 475 family caregivers of elderly patients who had died 1 to 2 years prior to the survey, respondents listed the following 10 items as what their desires had been (Tolle, 1999).
 - Loved one's wishes honored.
 - Inclusion in decision processes.
 - Support/assistance at home.
 - Practical help (transportation, medicines, equipment).
 - Personal care needs (bathing, feeding, toileting).
 - Honest information.
 - 24/7 access.
 - To be listened to.
 - Privacy.
 - To be remembered and contacted after the death.

Biopsychosocial Assessment of Individual Patients and Families

The biopsychosocial assessment of older patients in the advanced stages of life-threatening illness begins with the recognition that patients and families are confronting two challenges in a more acute way than they have previously in living with these chronic conditions: a) reorganization and adjustment to change and b) grief and loss. Factors influencing how families cope are incorporated into a social work assessment and include the seven domains discussed below. This framework is a modification of domains identified in Blacker and Rainess Jordan's chapter on working with families in the book *Living with Dying: A Handbook for End-of-Life Health Care Practitioners* (Blacker & Rainess Jordan, 2006).

I. Past and Current Medical Situation

- ◆ Older adults may have experienced years of coping with multiple illnesses and chronic conditions, and they require time and assistance in comprehending their often complex medical situation.

Many older adults with chronic illnesses have gained skills from their challenges and many demonstrate considerable resilience and ability to reconcile themselves to physical decline. Others, however, are overwhelmed by the stress of life threat and

ambivalent about the goals of palliative care, i.e., whether they would rather be pursuing curative or restorative treatment goals. Current physical or psychological symptoms (e.g., pain, fatigue, depression, anxiety, and delirium) must be assessed carefully because they frequently occur in patients with multiple chronic conditions. The social work assessment explores how patients understand their symptoms and illness and how they plan to manage this phase (Zabora & Loscalzo, 1996; Blacker & Rainess Jordan, 2006).

Key questions for the clinician to consider:

- ◆ What is significant to this patient's medical history?
- ◆ What is their experience with and level of trust in the health care system?
- ◆ What is the current stage/extent of illness and what should be expected next?
- ◆ What are current goals of treatment?
- ◆ What are the patient's current physical or psychological symptoms (e.g., pain, fatigue, depression, delirium)? Are they being addressed?
- ◆ What is the patient/family's understanding and interpretation of this information?
- ◆ What are barriers to communication and understanding?

2. Symptom Assessment

The presence of symptoms of pain, fatigue, etc. must be assessed from a multidimensional perspective. The social worker considers the nature and quality of these symptoms and also their impact on the patient's quality of life. Tools for assessing symptoms include, for example, a pain scale or pain diary. More extensive guidelines for assessing the psychosocial aspects of pain and symptom management can be found in (Altilio, Otis-Green, Hedlund, & Cohen Fineberg, 2006; Jerant, Azari, Nesbitt, & Meyers, 2004; Liao & Ferrell, 2000)The Edmonton Symptom Assessment Scale and the Memorial Symptom Assessment Scale are two measures of symptoms and distress that give evidence of providing a brief, but valid, systematic approach to monitoring symptoms, their intensity, and their impact on functioning over time. A selected list of high quality measures of pain and symptom management, functional status, psychosocial care, caregiver assessment, and quality of life currently used in practice and/or research can be accessed at the National Palliative Care Research Center Web site under measurement and evaluation tools (http://www.npcrc.org/resources/resources_list.htm?cat_id=1246).

3. Impact of Stage in the Life Cycle

Many older individuals become resilient as they learn and practice strategies for coping with personal losses and physical declines over time. However, they may also have fewer social, economic, and personal resources to cope with advancing illness and physical decline. The network of informal supports to help care for them may have been seriously diminished by death, illness, and geographic distance. The spouse or partner of the terminally ill older adult may themselves be frail. Therefore, a history of past experiences of illness, disability, and death, as well as of coping and strengths, is helpful not only to the social worker and other members of the team, but also to the older client's own understanding of their feelings and reactions (Boockvar & Meier, 2006; Hooyman & Kramer, 2006; Hooyman & Kiyak, 2008).

Key questions for the worker to ask in order to consider the family's developmental stage include:

- ◆ How will the illness and treatment demands affect the family's developmental stage?
- ◆ What losses are typically associated with this life stage, and how will this crisis affect the family?(Hansson & Stroebe, 2007; Hooyman & Kramer, 2006),
- ◆ To what degree does the patient/family experience the illness as a burden? (Blacker & Rainess Jordan, 2006) (Dumont, Fillion, Gagnon, & Bernier, 2008; Dumont et al., 2006; Raveis, 2007; Raveis, Karus, & Pretter, 2004; Wilson, Curran, & McPherson, 2005)

4. Family's Past Experiences and Coping with Illness

This can be assessed by exploring seven areas. These areas represent factors that have been found over a broad range of social and psychological studies to be significant in people's ability to cope with medical illnesses.

- ◆ Resources accessed in the past that were helpful or not.
- ◆ Misconceptions that may occur due to past experiences(Bullock, 2006; del Rio, 2006; Johnson, Kuchibhatla, & Tulskey, 2008)
- ◆ The presence of past/current mental health problems (Kadan-Lottick, Vanderwerker, Block, Zhang, & Prigerson, 2005; Robertson, 2008; Vanderwerker, Laff, Kadan-Lottick, McColl, & Prigerson, 2005; Wright et al., 2008)
- ◆ History of alcohol/drug use(Farkas, 2004; Passik, Kirsh, Donaghy, & Portenoy, 2006)
- ◆ Previous use of formal and informal supports (Schroepfer, 2008; Schulz & Beach, 1999; Schulz, Tompkins, Wood, & Decker, 1987)

- ◆ Identified strategies for coping, accessing help, information (D'Zurilla & Nezu, 2006)
- ◆ Ability to communicate with the health care team and navigate the system. (Blacker & Rainess Jordan, 2006)

Key questions to address in this specific domain of the assessment include:

- ◆ Does this patient or family member have any past or current mental health problems or symptoms?
- ◆ Does this patient or family member have a history of alcohol/drug use?
- ◆ Does the patient/family member present with anxiety or depression?
- ◆ What supports have held the patient and family members in the past when faced with difficult situations?
- ◆ How have this patient and family defined a strategy for coping and accessed help?
- ◆ How do this patient and family define hope? (Clayton et al., 2008)
- ◆ How well are this patient and family able to communicate with the health care team and navigate the system? (Blacker & Rainess Jordan, 2006)

5. Spirituality/Faith

Because for many people their spiritual beliefs contribute to both the individual and the families' coping with advanced illness, this is an important area to assess and incorporate into treatment planning. A commonly used assessment tool for spirituality is the FICA defined in the following way (Pulchalski, 2002):

F—Faith or beliefs	What is your faith?
I—Importance	Is it important in your life?
C—Community	Are you a part of a spiritual community?
A—Address	How should this be addressed in your health care?

Key questions for the social worker to consider include in the assessment include:

- ◆ What meaning has this patient/family given to this illness?
- ◆ How do they define who/what is in control of or influencing this situation?
- ◆ How do spiritual beliefs contribute to the individual's and family's coping?
- ◆ How has this illness affected the patient's and family's spiritual well-being? (Pulchalski, 2002)

6. Socioeconomic Factors/Resources

What are the resources the family has to enable them to manage the care and economic demands of advanced illness? Common problems include financial strain, low literacy level, lack of insurance, lack of transportation, inadequate caregiver situation (for example the frailty of the caregiver), and inappropriate environment for safety in the home. These needs, often addressed by the social worker as discharge planner or case manager, are frequently the most critical to the patient and family's well being. They are rarely studied systematically in relation to psychosocial outcomes, but are provided because they are widely perceived to be a humanitarian benefit. Among the sparse research that has sought to determine the effects on health or health care of providing logistical or material resources, one study documented that when individuals with cancer lacked transportation, treatment was foregone (Guidry, Aday, Zhang, & Winn, 1997). And studies of people with a variety of chronic diseases have found that environmental barriers such as cost and logistical obstacles interfere with the ability to manage their condition (Bayliss et al., 2003; Vincze, Barner, & Lopez, 2004). Finally better patient and family satisfaction and better quality of care were associated with practical help for advanced illness patients in a review of review articles in palliative care (Mularski et al., 2007).

Practical as well as emotional needs are often heightened at the point of transitions in care, especially during advanced illness. These occur when symptoms progress, treatment is ineffective, the goals of care change, and often the care setting is insufficient to meet the patients needs necessitating additional services or change of site. Interventions that provide information, care coordination, and follow up as well as practical help have been found to improve care and patient and family satisfaction (Coleman, 2003b).

Key question to investigate in this domain include:

- ◆ What resources (formal and informal supports) does this family have to enable them to manage the demands of the illness?
- ◆ How is the patient/family managing the financial demands resulting from this situation?
- ◆ Does the patient want to remain at home and die at home?
- ◆ Is there a caregiver, or group of caregivers, who will be available to the patient until he dies?
- ◆ If the patient wants to die at home, do family members feel they can bear to live there after the death?

- ◆ If the patient is remaining at home, what needs to be initiated to help make this happen safely? What durable medical equipment needs to be obtained to maximize safety and comfort?
- ◆ What referrals for hospice and community support need to be initiated?
- ◆ If not, what kind of contingency plans need to be made (e.g., placement in a nursing facility or inpatient hospice, move in with children, hire private duty help)?
(Blacker & Rainess Jordan, 2006)

7. Cultural Values and Beliefs

Identification of how cultural beliefs contribute to the individual's and/or family's understanding and coping patterns requires assessment. The family's culture, values, and beliefs underlie the patient and family's perception of the health care system, their understanding of the meaning of the diagnosis and treatment, the roles of different genders and of different family members concerning caregiving responsibilities, the supports and resources available to them, and the particular death rituals required for the last stages of the illness and post-death period (Bullock, 2006; del Rio, 2006; Kagawa-Singer & Blackhall, 2001). Understanding the patient and family culture helps social workers (and the full medical team) to develop effective communication with them, to reduce conflicts and misunderstandings, and to determine how family members are best included in care planning and sharing bad news.

Key questions to consider in the areas of patient's and family's cultural background include:

- ◆ What is the identifiable "culture" (e.g., formal cultural or religious group beliefs, sexual orientation) of this family?
- ◆ How do this patient's and/or family's cultural values and beliefs contribute to their understanding, coping style, and psychosocial needs?
- ◆ How is terminal illness dealt with in the patient's culture? What values affect family caregiving, the use of medical technology, decision-making regarding treatment, use of advance directives, truth-telling, and concerns about place of death?
- ◆ Are there conflicts between the patient's culture and values and those of their family?
- ◆ How do the cultural differences between the care team and the patient/family affect this situation?
(Blacker & Rainess Jordan, 2006,)

Social Work Interventions in Palliative Care: the Evidence Base

The evolving nature and current state of the evidence base in hospice and palliative care can perhaps best be summarized by four recent reviews beginning with a 2004 AHRQ report on systematic reviews, intervention and observational studies in palliative care (Lorenz et al., 2004; Mularski et al., 2007). This was followed in 2007 by an updated review of outcome measures in end-of-life care (Mularski et al., 2007). In 2008 a systematic review of all randomized controlled trials in which specialized palliative care was the intervention and for which outcomes included quality of life was published in JAMA (Zimmermann, Riechelmann, Krzyzanowska, Rodin, & Tannock, 2008). Finally in 2008, a publication of a large multisite study of cost savings of palliative care programs in hospitals presented their findings of cost effectiveness of this intervention (Morrison et al., 2008).

The 2004 AHRQ review selected 10 systematic reviews, 12 intervention studies and 17 observational studies to identify individual outcome measures most strongly associated with patient and/or family satisfaction with end-of-life care. They found the preponderance of intervention and observational literature support the effectiveness of palliative care for improving patient and caregiver satisfaction. However they indicated an emerging problem with the measurement of outcomes. Those that were developed specifically for palliative care settings and processes were more likely to show positive effects. They suggested inconsistencies in findings of research may relate to the use of more global and nonspecific measures or those developed for other populations. (Lorenz et al., 2004)

The 2004 AHRQ report also reviewed 12 systematic reviews or meta-analyses, 18 intervention studies and 14 observational studies that met their rigorous criteria to identify factors associated with better or worse outcomes. They found evidence of the association of satisfaction and better quality of care with pain management, communication interventions, practical support, and enhanced caregiving. Interventions that improved patient or family satisfaction included those aimed to ameliorate cancer pain, relieve depression, non-pharmacologic interventions for behavioral problems in dementia and those used to foster continuity in cancer and chronic heart failure care.

These articles reflect the challenge of developing both psychosocial and medical research in an area in which both are important and relevant to desired outcomes. For example, a second 2008 review of the effectiveness of interventions in palliative care reviewed 33 systematic reviews and 89 high quality interventions (Lorenz et al., 2008). They found strong evidence of the effectiveness of medical interventions to treat pain and other physical symptoms, and some evidence of the effectiveness of treating depression with psychotherapy. However they regretted that they could not review specific interventions such as patient and family centered approaches, spiritual support

and bereavement due to the nomenclature challenges, for example, the lack of consistent words used to describe such interventions, and the breadth of the literature. They found strong evidence of support for multi-component interventions to improve continuity, moderate evidence to support advance care planning led by skilled facilitators who engage key decision makers and moderate evidence to support interventions to alleviate caregiver burden. This documents some of the challenges in a new, interdisciplinary, and evolving research area.

Most measures in palliative care practice and research focus on quality of life, quality of care and symptoms (Lorenz et al., 2004). A more recent review of measures in end-of-life care (Mularski et al., 2007) reported gaps in the development of measures for continuity of care, advance care planning, spirituality, and caregiver well-being. These reviewers supported and updated the Toolkit of Instruments to Measure End of Life Care available at <http://www.chcr.brown.edu/pcoc/BIBLIOGRAPHIES.HTM>. This toolkit evaluates measurement tools used through 2000. In this resource review we additionally recommend the use of the National Palliative Care Research Center's (<http://www.npcrc.org/>) resources on measurement in end-of-life care research. Both reviews of the literature on measurement highlighted the fact that different studies almost always use different measures in the more developed domains. The use of a large number of measures of uncertain quality makes it difficult to compare findings or to synthesize insights across research or quality improvement studies. Therefore more rigorous testing of the highest quality measures is a recommended research direction.

The 2008 review of 22 randomized controlled trials (selected by rigorous criteria) published in JAMA found the most consistent evidence for the effectiveness of palliative care programs in improvement of family satisfaction with care (7 of 10 studies favored the intervention). However, only 4 of 13 studies assessing quality of life and 1 of 14 assessing symptoms showed a significant benefit of the intervention. Again reviewers identified the problem that these studies did not use quality of life measures specific for terminally ill patients and the exact components of their palliative care intervention varied considerably. The most provocative finding for palliative care colleagues was that only one of seven studies showed significant cost savings. Methodological limitations were identified in all trials, including contamination of the control group, and substantial problems with recruitment, attrition, and adherence. The authors concluded that the evidence for benefit from specialized palliative care is sparse and limited by methodological shortcomings. They recommended carefully planned trials, using a standardized palliative care intervention and measures constructed specifically for this population.

This study was shortly followed by a report of a multisite, randomized controlled trial designed to specifically study the cost savings of palliative care by matching 2278 palliative care patients to 18 427 usual care patients from 8 different hospital sites, treated during the same 2 year period of time. They were able to report significant cost

reductions and therefore concluded that palliative care consultation does result in considerable cost savings including intensive care and laboratory costs associated with usual care patients.

The large number of recent studies and reviews of studies shows the importance of this intervention as the population ages and the numbers of individuals with advanced disease expands. Clearly quality of care, patient and family satisfaction with care and the costs of care are important outcomes. It also demonstrates the challenges of an evolving research area that is interdisciplinary and requires, even more than most other health areas, the simultaneous use of both psychosocial and medical interventions. If palliative care is viewed as a care coordination model it faces the same challenges as other such approaches: the need to work toward a more clearly described and standardized intervention and development of the highest quality measures that can be used across studies.

Specific psychosocial components of palliative care programs that relate to patient needs and have developed some evidence base in palliative care are described here.

- ◆ Psychoeducation for patient and family (Houts, Witmer, Egeth, Loscalzo, & Zabora, 2001)
- ◆ Life completion discussions that focus on above assessed, psychosocial, spiritual, and emotional concerns (Steinhauser et al., 2008).
 - Life Review processes (Butler, 1980; Chochinov et al., 2005).
 - Self-disclosure and exploration of completion in relationships (Fratorolli, 2006; Greenberg, Wortman, & Stone, 1996; Pennebaker & O'Heeron, 1984).
 - Legacy building through transmission of knowledge and wisdom.
- ◆ Family conferencing (Curtis et al., 2001; Curtis et al., 2005; Hudson, Quinn, O'Hanlon, & Aranda, 2008; Yennurajalingam et al., 2008).
- ◆ Cognitive behavioral interventions to assist with pain and symptom management (Altilio et al., 2006; Loscalzo & Jacobsen, 1990).
- ◆ Transition/ care coordination interventions (Coleman, 2004).
- ◆ Medical crisis counseling (Loscalzo & K. BrintzenhofeSzoc, 1998).

Social Work Conceptual Frameworks for Intervention

Social work interventions in advanced illness use at least two conceptual frameworks: 1) identifying the tasks of terminal illness and interventions that can help patients and families fulfill those tasks; 2) identifying the psychosocial health needs of patients and families, and the psychosocial health services to address them. Intervention approaches with older adults often rely on an evidence base generally

developed with younger patient populations, and most interventions with older adults are drawn largely from the consensus of the practice literature. Future research is required to expand the evidence base for interventions with older adults in the advanced stages of illness.

Tasks of Terminal Illness

The tasks for patients with terminal illness can be viewed as comprising four areas. Interventions using this model focus on helping patients fulfill these tasks (Moynihan, Christ, & Gallo-Silver, 1988).

Maintaining Acceptable Quality of Life during Advanced Stages

Since the advanced stages of many diseases now span months, sometimes years, patients and families often need to focus on ways to maintain an acceptable quality of life while the patient is dying. This requires considerable effort to manage symptoms and pain, but also to find ways to remain emotionally connected to family and friends. Patients often need to detoxify or become less anxious about death's inevitability by having opportunities to discuss their fears and concerns. These discussions with formal or informal support providers enables them to maintain a hopeful, but realistic attitude about their condition (Schroepfer, 2006). The long months of waiting can be boring, and patients seek ways to meaningfully fill their time. They often long for communication with others about their fears, but also need support for developing distracting and normative activities that keep them connected to ongoing life. Patients may require help with decisions about continued treatments for their diseases as they weigh the benefits of additional months of life offered by medical advances, but with the possibility of reduced quality of life and additional suffering for themselves and their families.

Coping with Deteriorating Physical Condition

As the disease progresses, more of the patient's attention is focused on managing symptoms, pain, and related psychological distress. They require support for mourning losses in function as they occur, but also for recognizing and maximizing remaining strengths and capacities.

Confronting Existential, Spiritual, and Religious Issues

As the disease progresses patient's also confront thoughts about the meaning of their lives, their suffering, and their impending death. Cultural, religious, and spiritual views impact their thinking. Patients struggle with fears of existential aloneness. The search for a positive sense of meaning in one's life, death, and suffering has received greater attention in recent years, since it has been found to impact the patient's quality of life as much as physical symptoms. The ability to see oneself in a context greater and more enduring than the self moves many patients from suffering to a sense of well-

being, and therefore, a focus on seeking meaning is being incorporated into interventions (Mount, Boston, & Cohen, 2007).

Planning for the Remaining Family and Friends

No matter how old the patient is, there may be family or friends left behind. Planning for their care and well being and having final conversations that address final goodbyes, loving connections, forgiveness, and reconciliation can provide important solace for both patients and families.

The tasks for families of individuals in advanced illness stages include the following:

- 1) Remaining involved with the family member, sometimes over many months and years of illness and challenges in functioning.
- 2) Arranging for effective medical and custodial care of the family member.
- 3) Adapting to role changes as the patient's condition alters over time.
- 4) Bearing the effects of grief over the patient's losses in functioning.
- 5) Coming to terms with the reality of the impending loss.
- 6) Saying goodbye.

Psychosocial Health Needs and Health Services for Older Patients with Advanced Disease

The model that identifies psychosocial health needs of older patients with advanced disease and the psychosocial health services that address these is outlined in Table 5. For some interventions, such as psycho-education, cognitive-behavioral interventions, and family conferencing, an evidence base for treatment exists, but it is mostly with younger populations. Other interventions rely on the consensus found in the practice literature.

Table 1: Psychosocial Health Needs and Services that Address Them

Psychosocial Health Needs of Patient/ Caregiver	Services Required in Palliative Care in Aging
Information about illness, treatments, health, and services	<ul style="list-style-type: none"> ▪ Continuous provision of information (e.g., on illness, treatments, goals of care, psychosocial services) and helping patients/families understand and use information.
Help in coping with emotions accompanying illness and treatment	<ul style="list-style-type: none"> ▪ <i>Normalize the many emotions experienced during advanced illness.</i> ▪ <i>Provide opportunities for clarification and discussion of life review and the meaning of one's life and legacy, and having needed conversations with loved ones.</i> ▪ <i>Identify and expand formal and/or informal support network.</i> ▪ Counseling/psychotherapy to individuals or groups. ▪ Pharmacological management of psychological symptoms.
Help in managing illness	<ul style="list-style-type: none"> ▪ <i>Anticipate and educate about symptoms, transitions in care, advanced planning, and decision-making.</i> ▪ <i>Crisis intervention around unexpected disease changes, treatment reactions, or emotional responses.</i> ▪ <i>Case management to organize coordinated and continuous care.</i>
Assistance learning behaviors to minimize impact of disease	<ul style="list-style-type: none"> ▪ <i>Behavioral/health promotion for pain, discomfort, and emotional distress.</i> ▪ <i>Provide continuous assessment and interventions with symptoms, pain, discomfort, emotional distress, and positive health behaviors such as diet and exercise.</i> ▪ Assist with communication with physician. ▪ <i>Supportive interventions such as relaxation, massage, music therapy, art, etc.</i>
Material and logistical resources	<ul style="list-style-type: none"> ▪ Provision of resources, improvement of home environment, transportation, home care.
Help in managing disruptions in work, activities, family life, and social networks	<ul style="list-style-type: none"> ▪ <i>Family/caregiver education, counseling regarding role, task assignment, emotional support.</i> ▪ <i>Continuous education, counseling, and support for caregiver/family regarding symptoms, illness trajectory.</i> ▪ <i>Monitor adequacy of caregiving arrangements for patient safety and well-being, anticipating care transitions.</i> ▪ Provide assistance with activities of daily living (ADLs), and instrumental activities/chores (IADLs). ▪ <i>Counseling re advance directives, health care proxy, and other relevant legal issues.</i> ▪ <i>Social network development, conflict resolution, and mediation of differences.</i>
Financial advice and/or assistance	<ul style="list-style-type: none"> ▪ Financial planning/counseling, management of activities such as bill paying. ▪ Insurance counseling/advocacy, risk benefit analysis of treatments. ▪ Eligibility assessment for other benefits (SSI and SSDI). ▪ Supplemental financial grants.
Bereavement support	<ul style="list-style-type: none"> ▪ Provide follow up contact with family/caregiver and bereavement resources.

*Italics represent services specific to advanced illnesses and older adults.

Range Of Social Work Interventions for Advanced Illness

Psychoeducation

Psychoeducation includes teaching patients with advanced disease and families about the illness and treatment process and how they can cope with their disease, the health care system, and at the same time prepare psychologically for the terminal illness. The evidence base suggests that a broad range of teaching assists can be helpful in educating patients, but often need to be tailored to individual preferences and capacities (Elliott, Ross-Degnan, Adams, Gelb Safran, & Soumerai, 2007; Gastona & Mitchell, 2005; Houts, Witmer, Egeth, Loscalzo, & Zabora, 2001; McPherson, Higginson, & Hearn, 2001; Walling et al., 2008). The following topics have been incorporated in these patient and family psycho-education approaches in palliative care:

- ◆ Psychosocial impact of advanced illness.
- ◆ Navigating health care and social systems.
- ◆ Communicating with their health care team.
- ◆ Communicating with each other as a family.
- ◆ Completing advance directives.
- ◆ Coping with/managing symptoms and distress.
- ◆ Managing practical needs.
- ◆ Recognizing and managing the effects of grief.

Decision-making during Advanced Illness

In the treatment setting, the need for discussion about goals of care and decision-making often occur during certain crisis or transition points in the illness. Clearly attention to well implemented transitions in care is vital to effective care coordination and patient and family well-being (Coleman, 2003a, 2003b; Mayfield, 2004; Parry, Kramer, & Coleman, 2006; Schroepfer, 2006; Walling et al., 2008). Typical transitions include:

- 1) Transitions from aggressive/curative treatment to palliation only.
- 2) Establishing DNR/DNI status.
- 3) Planning for where the death will occur or change of setting for the patient: hospital, home, hospice, long-term care.
- 4) Determining what resources can be accessed.

Facilitating decisions takes place in the context of concerns of health care professionals and family members, both of whom worry about “taking away hope”

(Albinsson & Strang, 2003; McCarthy, Addington-Hall, & Lay, 1997; Raleigh & Boehm, 1994; Schroepfer, 2007).

Crisis Intervention

Crises in medical care are typically situational. Commonly the crisis is related to emotional exhaustion in both patients and family caregivers. The goal of crisis intervention is to enable clients to quickly regain a sense of equilibrium, maintain hope, and focus on meaningful and effective activity. Social workers are uniquely skilled to manage the challenging family dynamics that can occur and to draw on multiple systems of support to help the family and patient solve the problems at hand (Loscalzo & BrintzenhofeSzoc, 1998; Schroepfer, 2007).

- ◆ Guidelines for social workers during medical crises include the following:
 - Accepting your limitations helps patients accept theirs, and helps you make appropriate referrals.
 - Promise only what you personally can insure will happen.
 - Do not prematurely stop the expression of intense emotional feelings.
 - Avoid saying "I know how you feel."
 - Telling a client that everything will be alright may not make anyone feel better.
 - Demanding a positive attitude can be an unrealistic burden.

Cognitive-behavioral Interventions

Cognitive-behavioral interventions are based on the postulate that mental and physical symptoms are in part a function of underlying thoughts, feelings, and/or behaviors that are of a maladaptive nature. The goal of these interventions is to restructure the individuals thinking and feeling to be more adaptive to the situation. For example to identify realistic goals they can achieve even with their current functional limitations.

Cognitive-behavioral interventions:

- ◆ are among the most widely offered psychosocial services in comprehensive cancer centers,
- ◆ have an evidence base that shows they are effective in reducing emotional distress and controlling physical symptoms,
- ◆ can be administered in a brief period of time,
- ◆ can be easily tailored to the individual,

- ◆ are readily accepted by patients since the emphasis is on providing increased sense of personal control and self-efficacy.

A package of cognitive-behavioral interventions may include several of the following techniques. The evidence base suggests that they are effective in improving mood, quality of life, and reducing pain and symptom distress; however, further research is needed to clarify whether one approach is more effective than another during advanced illness. Two examples follow:

- ◆ Life review is an intervention with a growing evidence base in working with older adults and advanced illness. It includes components of reminiscence, reconciliation, forgiveness, and resolution of past conflicts. It offers individuals a chance to “edit” their life story by re-telling and in the process reintegrating events in the broader perspective of a full life course. In recent years using this intervention with older adults has shown improved psychological well-being and life satisfaction, and improved levels of depression (Bohlmeijer, Smit, & Cuijpers, 2003; Butler, 1980; Chochinov et al., 2005).
- ◆ Progressive muscle relaxation, cognitive restructuring, coping self-statements, distraction, systematic desensitization, hypnosis, guided imagery, and problem-solving therapy are often effective when used in combination to help patients manage pain, and other physical and emotional symptoms of advanced illness (Altilio et al., 2006; D’Zurilla & Nezu, 2006; Loscalzo & Jacobsen, 1990).

Family Conferencing

A team intervention strategy, a family conference intervention is consistent with the interdisciplinary focus of palliative care practice and acknowledges the unit of care as the patient and their family and support network. Benefits cited by professionals from studies of this intervention include the following (Hudson et al., 2008; Yennurajalingam et al., 2008).

- ◆ The conference presents an opportunity to both gather and disseminate information efficiently.
- ◆ It is a means to minister to the needs of the patient and family.
- ◆ It is an important tool for consensus-building when a decision needs to be made.
- ◆ It decreases the possibility of miscommunication.

- ◆ It reduces lengths of stay in the ICU and increases patient and family satisfaction with their care while there. (Curtis et al., 2005; McDonagh et al., 2004)

A recent review of the limited practice and research literature on family conferencing found that social workers are the major conveners reported for this interdisciplinary intervention. They recommended much more research to develop definitions, clarify goals and objectives and specify therapeutic processes and desired outcomes (Hudson et al., 2008).

Practical Dimensions of Care for Patients and Families

While practical interventions, which are so central to the social work role, are rarely researched, there is such long standing and wide acceptance of these as humane services that there has been little question as to whether they “work.” One study has shown that the absence of information, finances, transportation, and adequate living arrangements do have a negative impact on treatment adherence (Institute of Medicine, 2007). As mentioned above, a 2007 synthesis of findings of end-of-life care outcomes found evidence of the association of satisfaction and better quality of care with practical support, and enhanced caregiving as well as other medical interventions. (Mularski et al., 2007).

Knowledge and communication

What to do for pain and other symptoms, how to make decisions, who to call, what to do after death?

- ◆ Physical Environment and personal care. What to provide for immediate comfort and control, how to manage personal care, how to permit privacy or companionship when wanted, how to provide physical access and safety, how to provide education about managing personal care.
- ◆ Family and others close to the patient. What to do for primary companion and caregiver, what to do for dependents, who to be the on-call in emergencies.
- ◆ Financial and other practical issues. How to handle short-term finances, what to do about longer-term finances, how to manage the household.

Social Work Specialization and Generalist Training in Palliative Care

Social work’s specific contributions in education, research, administration, and policy development have more recently become an integral part of the interdisciplinary discussion of appropriate practice parameters in this expanding field. The Social Work

Leadership Development Awards from the Open Society Institute's Project on Death in America and CSWE's Hartford-funded Gero Ed Center programs have facilitated the creation of Social Work leadership in program development, research, and education. Still the expanding population of patients with advanced illness requires all health social workers be trained in palliative care. The Social Work Hospice and Palliative Care Network (www.swhpn.org) continues to advance, with the support of stakeholder organizations, the goals that have been established to move the field forward. Over 40 social work leaders were funded from 1999 through 2004 to create new models of service delivery and professional training, and to advance research within their discipline and across disciplinary boundaries (Walsh-Burke & Csikai, 2005).

Below are listed key events in the development of hospice and palliative care within social work (Christ & Blacker, 2005).

- ◆ 1999: Need for education and training for SWs in EOL documented (Christ & Sormanti, 1999).
- ◆ 1999: Project on Death in America Social Work Leadership Awards Year 1 (first cohort), first joint meeting with PDIA Scholars (MDs and RNs).
- ◆ 2001: Publications by PDIA SW Leaders begin (SSWLHC Best Practices Paper); SW EOL Pall listserv established by T. Altilio.
- ◆ 2002: Smith College and NYU certificate programs in SW and EOL begin.
- ◆ 2002: First Social Work and EOL Summit held at Duke University.
- ◆ 2004: Standards of Practice for SW and EOL published by NASW.
- ◆ 2005: Second Social Work and EOL Summit held at NASW.
- ◆ 2005: *Journal of Social Work and EOL and Palliative Care* published by Haworth Press (Ellen Csikai, PDIA social work leader and Editor).
- ◆ 2006: SW Leaders attend first NASW Social Work Congress.
- ◆ 2007: Social Work Hospice and Palliative Care Network (SWHPM) becomes 501C3 not for profit organization.
- ◆ 2007: First PDIA social work leadership recognition award given at NHPCO.
- ◆ 2008: First Pre-conference Institute for Social Workers held at AAHPM.
- ◆ 2008: NASW and NHPCO develop social work certification.
- ◆ 2008: Second PDIA social work leadership recognition award given at AAHPM.

Conclusions

As this module documents, the palliative care needs of older adults are expanding exponentially and will become an important part of the social work role in advanced illness going forward. We conclude that at its base palliative care is a comprehensive care coordination intervention model with an emphasis on psychosocial services as its defining characteristic. In addition to advanced interdisciplinary care it involves meticulous pain and symptom management; careful attention to the social, psychological, and spiritual needs of patients and families; and an essential focus on improving care transitions, largely through improved methods of communication and coordination.

Social workers are clearly the major providers of mental health and psychosocial services to older adults with advanced illnesses, including critical services for their informal caregivers. The development of social work specialization in this area emerged from the Project on Death in America's leadership awards program and the CSWE Gero-Ed Center. Specialization continues to support the development and dissemination of research and training within the profession. However, because the population is expanding, all health social workers require knowledge and skills to intervene with older adults with advanced illness. This is further recognized by NASW's creation of a credential in this area.

Different reimbursement structures influence what services are available to older adults. At the same time new, potentially cost effective service delivery models are being evaluated.

As the field is a newly emerging one, so is the evidence base. The challenge to social work is not only to demonstrate expertise in biopsychosocial assessment and intervention in advanced illness with older adults, but also to take a leadership role in the development and research of these new integrated models of care as well as specific psychosocial interventions for patients and families.

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Curriculum Resources



Suggested Readings:

Textbooks

In recent years social workers have produced some excellent textbooks in health and health and aging including several specifically addressing palliative care and grief and loss. Many chapters in these books have been used throughout the health resource reviews. These handbooks and texts are a great resource for social work students and practitioners who are seeking to familiarize themselves with state-of-the-art social work practice and research in a broad range of important substantive areas in health and aging.

- Berzoff, J., & Silverman, P. (2004). *Living with dying: A handbook for end-of-life healthcare practitioners*. New York City, NY: University of Columbia Press.

Living with Dying: A Handbook for End-of-life Healthcare Practitioners is a remarkably comprehensive, authoritative, practical, well written, and well constructed handbook on social work and palliative care. It is edited by two social workers, and chapters are authored by a broad range of practitioners and academics in hospice and palliative care, many of whom were Project on Death in America (PDIA) social work leaders. It covers important historical and theoretical aspects of death and dying; a broad range of clinical practice issues (e.g., work with families and pain and symptom management); and special contextual and leadership topics such as advanced directives and assisted suicide, end-of-life care in prisons, and leadership in end-of-life care. It integrates theory, the evidence base, and important conceptual frameworks for practice. Case examples and diagrams are used well to illustrate practice concepts. It is a wonderful resource for practitioners, educators, and researchers seeking an understanding of important issues and variables for study. One chapter addresses working specifically with dying and bereaved older adults, but many chapters are applicable to work with aging adults, and there are multiple case examples of adults over 65 years of age.

- Csikai, E., & Chaitin, E. (2006). *Ethics in end-of-life decisions in social work practice*. New York: Haworth Press.

Ethics in End-of-life Decisions in Social Work Practice provides a comprehensive and practical approach to understanding end-of-life decisions. The authors connect long-standing philosophical theories to contemporary concerns in the field of bioethics. Topics covered are bioethical principles and key issues related to the end of life and ethical decisions in health care, including clinical decision-making processes and privacy and confidentiality. Also covered is how to assess capacity for decision-making and how to design treatment and intervention plans in coordination with health care teams. The authors include case studies to show the complex end-of-life decisions faced by patients, families, and health care workers. Approaches are offered for resolving debates about informed consent, privacy and confidentiality, and the refusal or denial of medical treatment. This book provides the practical knowledge that social workers need for effective practice with clients facing end-of-life decisions. It also

provides the knowledge social workers need to fully participate in interdisciplinary health care team discussions of these important issues. Students will find the information easy to read and to apply to their future practice.

- Hooyman, N. R., & Kramer, B. (2006). *Living through loss: Interventions across the life span*. New York: Columbia University Press.

This book highlights the wide range and types of losses encountered across the life span and profiles developmentally congruent and evidence-based interventions. In this way, it is a very useful resource for a grief class because it helps social work students understand the causes and conditions that give rise to grief and what they might do in practice to respond appropriately. The text explores the nature and centrality of the experience of loss encountered in practice very broadly and discusses death and nondeath-related losses (e.g., giving birth to a child with disabilities; living with chronic illness; going through a divorce; being assaulted, abused, or otherwise traumatized). Initial chapters provide a comprehensive review of the historical and contemporary theoretical perspective on grief and the grief process, and put forth a resiliency model for understanding personal, family, social, and cultural capacities that affect grief and other outcomes of loss at each developmental life phase. This is followed by chapters examining loss at five phases of the life span (childhood, adolescence, young adulthood, midlife, and later life) and corresponding chapters on developmentally appropriate interventions to address these losses at the individual, family, group, and community levels. The section on interventions with older adults is unusually informative on this population, providing a sense of the broad range of loss responses as people age and effective therapeutic interventions. Attention is given to the role of age, race, culture, sexual orientation, gender, and spirituality in a person's response to loss. Finally, gifts and challenges experienced by professionals who bear witness to the suffering of their clients are reviewed along with suggestions for self-awareness and self-care.

- Walsh-Burke, K. (2005). *Grief and loss: Theories and skills for helping professionals*. Boston, MA: Allyn & Bacon.

Grief and Loss: Theories and Skills for Helping Professionals provides case studies to illustrate theories and skills for strengthening the response of helping professionals to patients and clients experiencing grief and loss. Key concepts relevant to everyday practice are discussed, and student exercises suitable for in-class activities or independent assignments are included.

Articles/Chapters

- Kotkamp-Mothes, N., Slawinsky, D., Hindermann, S., & Strauss, B. (2005). Coping and psychological well being in families of elderly cancer patients. *Oncology Hematology*, 55, 213-229.

This article presents a thorough review of research findings and suggests directions for future studies on elderly cancer patients and the consequences of their disease for their partners and families. The authors are from Germany and extend their review to other countries. Studies are reviewed as they relate to five different areas of family functioning: 1) the family and the etiology of the disease, 2) the family as a source of support, 3) the family as a second order patient since they are often more psychologically stressed than the patient, 4) cancer as a challenge for the family, and 5) intervention approaches and models to reduce family stress.

The reader is encouraged to notice the consistency of findings in some areas such as:

- ◆ The importance of social support that can act as a buffer in diminishing the negative aspects of the disease for the patient.
- ◆ The influence of negative support and conflict in the support system.
- ◆ The different coping preferences of older adults (religiosity, cognitive strategies, and optimism) compared to younger adults (problem solving).
- ◆ The physical and psychological impairments of older adult caregivers.
- ◆ The complex dynamics of the disease process and the way it impacts the family.
- ◆ The evidence of effectiveness of educational and support interventions.

The authors advocate for more longitudinal research studies with homogenous populations to identify specific needs and burdens for different caregiving groups.

- Hauser, J., & Kramer, B. (2004). Family caregivers in palliative care. *Clinical Geriatric Medicine*, 20(4), 671-688.

This article is an excellent overview of the existing evidence base on family caregivers coping with a patient's advanced illness. Using a stress process model the authors review primary stressors (e.g., providing complex nursing care for which such caregivers were not trained) and secondary stressors of end stage caregiving such as family or role conflicts, work role conflict, and financial strains. These are all areas in which social workers can provide intervention and develop appropriate programmatic support. The authors identify important transitional points during which stresses are increased such as illness onset, nursing home admission, comprehension of terminality, and patient death. The stresses patients and families experience during these transitions create additional needs for professional education, guidance, and support.

The authors identify factors associated with negative outcomes as well as factors that seem to help families cope, such as the ability to see positive meaning in the experience, the use of religious coping, prayers, and rituals, as well as a broad range of community social support. Suggested interventions include the provision of information, explanation, and training in many different ways by multiple disciplines. They point to positive outcomes of programs for caregivers of dementia patients, such as support groups and individual and family counseling that could be used with other advanced conditions. Interventions for caregivers of cancer patients and patients with dementia have ranged from nursing care to respite services to group therapy, and problem-solving and individual education, but few have been evaluated in randomized trials.

The authors highlight the risks of bereavement for family caregivers. They cite evidence that the bereavement process is mediated by the provision of palliative care, including helpful information and communication to patients and families and bereavement services to family caregivers. The impact of bereavement appears to vary by factors occurring during a patient's illness. Specific suggestions for clinicians include 1) recognizing the stressors and rewards in caregiving, 2) knowing resources from support groups to respite services, and 3) helping during family bereavement. They also outline a basic approach for health care teams to engage caregivers as collaborators, providing support and education. The need for further research is suggested, research that incorporates innovative interventions with consistent application of validated outcome measures and strong study designs.

- Raveis, V. (2007). The challenges and issues confronting family caregivers to elderly cancer patients. In S. Carmel, C. Morse, & F. Torres-Gil (Eds.), *Lessons on aging from three nations, Volume II: The art of caring for older adults* (pp. 85-97). Amityville, NY: Baywood Publishing.

This article is a comprehensive and evidence-based review of the many stresses on older caregivers of cancer patients. In great detail and with helpful examples and illustrations the author discusses the complex psychosocial challenges these caregivers confront at diagnosis and treatment and during survivorship. It is this level of detail and illustration from an intervention with family caregivers that will deepen the student's understanding of their experience. She thoroughly reviews the high costs of cancer caregiving including "...restrictions on occupational, social, and leisure activities; a loss of privacy; financial burdens; conflicts with well family members; physical strain; and chronic fatigue" (p. 90) that often result in adverse psychological and physical conditions. She also thoroughly explores the impact of the life stage on the caregiver, including not just the spouse but also older daughters. The article joins the chorus of voices urging greater research and programmatic attention to understanding the multiple interconnected issues families encounter while caring for an elderly relative with cancer. The detailed descriptions of the factors affecting their experience suggest intervention approaches.

- Renzenbrink, I. (2006). Relentless self-care. In J. Berzoff & P. Silverman (Eds.), *Living with dying: A handbook for end-of-life healthcare practitioners* (see book section above).

"Relentless self-care" provides an excellent overview of the current conceptual frameworks used to describe the impact on the professional of work with emotionally intense situations in health care. Health care social workers confront grieving, high risk, vulnerable, and traumatized client groups on a daily basis. The practice literature and research support for these concepts and available research is well reviewed. They include burnout, compassion fatigue, vicarious traumatization, psychological trauma and healing, caregiver grief, grieving as a self-care strategy, intimate strangers, the wounded healer, the inner bereaved child, and the soul friend. Finally the author encourages social workers to "mind themselves" and practice "relentless self-care." She suggests that the social worker should use supervision, consider therapy, discover one's own values, maintain a healthy balance between home and work, use stress management techniques such as analyzing sources of stress, view some grieving for clients as normative, continue education about the substantive area, develop supportive teams, and become involved in community-development and social-action activities. This chapter provides the student the full range of ways of thinking about self care together with a solid bibliography to support future study.

- Schroeffer, Tracy A. (2008). Social Relationships and Their Role in the Consideration to Hasten Death, *The Gerontologist* 48:612-621.

This study used In-depth, face-to-face interviews with 96 terminally ill Elders to determine whether aspects of social relationships significantly predicted the patient's consideration to hasten their death. Using mixed methods research strategies they found that conflictual social support was a significant predictor of the consideration to hasten death. Qualitative analysis of the data clarified why family efforts to encourage the patient were ineffective. This research highlights the importance of quality social support in elders' consideration to hasten their death.

- Schroeffer, TA, (2006). [Mind frames towards dying and factors motivating their adoption by terminally ill elders](#). *Journals of Gerontology Social Sciences*, (61B)3, S129-S139.

This study used In-depth, face-to-face interviews with 96 terminally ill Elders to explore factors associated with ill elders not considering hastened death as well as those associated with consideration of this option. Six mind frames towards dying were identified: (a) neither ready nor accepting; (b) not ready but accepting; (c) ready and accepting; (d) ready, accepting, and wishing death would come; (e) considering a hastened death but having no specific plan and (f) those with a specific plan. Psychosocial factors were found to be more likely to predict the patients desire to hasten death than medical/physical

factors. This study supports a holistic approach to intervention with elder patients with advanced illness that assists them with their psychosocial and spiritual needs as well as their medical condition.



Case Study:

Palliative Care Social Work: Connecting with Family when You Need Them the Most

Mr. S, aged 62, was a frequent visitor to the local emergency room because of congestive heart failure. His trips to the ER were his only medical care. He often arrived in respiratory distress and was typically admitted for 7 to 10 days until stabilized.

Mr. S lived in a small apartment over a store. The building had no elevator, and the staircase was very narrow. Mr. S was one of three tenants in the building. Typically, he was transported home from the hospital by ambulance and was carried up stairs on a stretcher. He was usually deposited in his recliner, which he slept in, and did not leave the apartment again until his next visit to the ER. He managed to move around his small apartment by leaning on furniture, etc.

He received Meals on Wheels and often ordered additional meals from the local Chinese take-out restaurant in a storefront down the block. Occasionally, neighbors shopped for him and got him cigars, which he enjoyed smoking. The local liquor store delivered his inexpensive brand of beer on a weekly basis. He said he drank it to calm his nerves. The beer, cigars, and Chinese food made his condition worse. He did take his medicines after discharge from the hospital, but that lasted only as long as the visiting nurse came by. He used oxygen occasionally, although it was prescribed for continuous use. After each hospitalization, the nurse's visits typically became less frequent over time owing to restrictions in his medical insurance coverage. He had been a construction worker and had union-related medical insurance that was generous regarding hospital coverage but less so regarding outpatient care.

Although only 62, Mr. S looked much older. He had never married, but had a sister living in a nearby town who was 4 years younger and in poor health. She frequently argued with him about his situation and asked him to live with her, but this made him angry, and he often stopped talking to her for periods of time.

As Mr. S's visits to the ER became more frequent and his hospital stays grew longer, he was referred to the hospital's palliative care team. Because he had no regular physician, the palliative care team overseeing his treatment during each admission gave him some continuity of care, which he had never received before. Social workers on the hospital floor had helped him numerous times with arranging his discharges, but the social worker was different each time. Once the palliative care team was involved, however, he was assigned to the team's social worker, who saw him at each admission. Mr. S refused to have medical appointments as an outpatient, even when offered transportation because his medical insurance would only cover ambulance service if he was admitted to the hospital.

Upon first meeting the team's social worker, Mr. S told her a nurse usually visited a few times after he was discharged and that he did not need welfare. Essentially, he refused to be engaged until his next admission. Because his condition had deteriorated, the social worker explored his living situation and he

became very defensive, yelling that he would not go to a nursing home. This was clearly a great fear. Although living in a compromised and often dangerous situation, Mr. S felt safest in his own apartment. When the social worker asked permission to call his sister, he agreed, hoping that the social worker would convince her to leave him alone. The meeting with Mr. S's sister revealed that he had been a binge alcoholic most of his adult life. However, she was sympathetic because Mr. S had had a hard life. While he was often difficult and at times verbally abusive, she felt she "owed it to him" to try to help him. Their mother had been physically abusive, and Mr. S had always tried to protect his sister, even though that put him in more danger. Their mother abandoned them when Mr. S was 17, and they lived with their grandmother, who died when Mr. S was 19. Mr. S had raised her until she married an older man at age 18. She was now a widow and a breast cancer survivor and suffered with chronic pain from rheumatoid arthritis. Her daughter lived nearby and was a help to her.

The sister said she never spoke about the past, and in fact her own daughter did not know as much as she told the social worker. The social worker encouraged her to tell her daughter her story because it was a story of survival and resilience and something to be proud of. The family history gave the social worker insight into Mr. S's life choices and difficulties and helped her to understand why Mr. S did not connect well with others and was often combative. She wondered if Mr. S suffered from depression and "treated" it with alcohol. When she met with Mr. S and shared with him what his sister had shared, Mr. S indicated that it was ancient history and didn't matter any more. Nonetheless, he was appreciative of the social worker's empathy and praise for his efforts to protect and help his sister.

The social worker shared the family history with the health care team, and Mr. S was approached about a psychiatric consult the next time he was admitted. He yelled that he was not crazy when he was admitted but the hospital was driving him crazy. He demanded to be discharged although his condition was too unstable. The social worker explained that he was sicker than usual and reviewed what the doctors had told him about the severity of his symptoms compared to previous admissions. She told him the team was concerned that without his beer, he did not have anything to calm his nerves and brought up the subject of meeting with a psychiatrist again. He said that if he could not go home, he would need to see a psychiatrist because he was a prisoner in his room. Mr. S gave the psychiatrist a hard time but agreed to take a fast-acting mood stabilizer and to work with a physical therapist so that he could perhaps leave his bed.

The health care team concluded that Mr. S would be unable to go home and recommended a subacute nursing home placement but also agreed to a hospice referral as a backup plan. When the social worker asked the doctor to discuss the two plans with Mr. S before she addressed the plans with him, the doctor agreed but asked her to attend the bedside meeting as well. After giving Mr. S the information about his prognosis and possible plans, the doctor left the room. Mr. S shared with the social worker that he knew he was going to die but did not want to die in the hospital and would rather die in the street than go to a nursing home. The social worker pointed out that his medical insurance required the hospital to make applications to nursing homes, but hospice care also would be explored. When the hospice nurse screener said he could not receive hospice care at home because there was no care partner, he yelled at her. The hospice program knew about Mr. S because it was connected to the same visiting nurse service that had been trying to help him at home.

The social worker set up a family meeting with Mr. S, his sister, and her daughter to discuss the real possibility of transfer to a nursing home. Mr. S was very subdued and simply said he wanted to die before there was a nursing-home bed for him. His niece told him she was very thankful that he had protected and helped her mother when she was young and unable to protect or care for herself. The

niece wanted to repay Mr. S by offering to have him stay in her home and have the hospice program care for him there. Mr. S cried and agreed to the plan and thanked the social worker for giving him a family when he needed one the most. Mr. S was discharged with hospice to his niece's home and died 10 days later surrounded by his family.

Discussion Questions

- 1) Using Table 1, the psychosocial health needs and formal services required to address them, answer the following questions regarding this case:
 - a) Of the eight areas of need outlined in the table, what information do you have for each?
 - b) Which of the seven areas was most prominent in the assessment and development of a treatment plan for the short term and long term with this family?
 - c) Identify services used to meet each need.
 - d) What psychosocial theories were used for the intervention approach, e.g., ecosystems, strengths perspective, trauma theory, social network theory, cognitive theory?
- 2) With so many different potential problems, what prompted the palliative care social worker to get permission to contact Mr. S's sister?
- 3) Discuss the possible role of his mother's abuse to his current behavior.
- 4) What prompted the palliative care social worker to ensure that everyone involved knew about Mr. S's early care of his sister?
- 5) When a situation involves multiple problems, as was the case with Mr. S, why did the palliative care social worker emphasize his early care of his sister? Discuss the role of emphasizing the client's strengths, rather than his problems (drinking, not using oxygen, refusing alternative care options).
- 6) Discuss the role of a team approach in the care of a client, such as Mr. S. What are the pros and cons of having a physician discuss the actual prognosis with such a client in the social worker's presence and of having her discuss and develop realistic options with the social worker? What are the pros and cons of meeting with the family before meeting with the psychiatrist and the hospice nurse?
- 7) How does this case illustrate gaps in the current system of care? How might social work take leadership in developing a care system that would address these gaps in the current service structure?



Web Resources:

Social Work Hospice and Palliative Care Network

www.swhpn.org

This is the website for the newly formed 501c3 organization for social workers in hospice and palliative care. Its aim is to advance this specialty within social work practice, education, research, and policy. It provides up to date resources, conference announcements, a newsletter and other eblasts of current events, advice from experts on particular topic areas, and a members only virtual practice community for discussion and networking. Members also have free access to the Journal of

Social Work in end-of-life and palliative care. This network seeks to advance the role of the social worker in caring for the seriously ill, providing relief from pain, improving quality of life, supporting family and friends, assisting with difficult decision-making, and working with trauma, grief and loss.

- National Palliative Care Research Center

www.npcrc.org

This is a new website that provides research resources and reviews current studies in palliative care. It also provides opportunities for continued training and mentoring in research. This center supports a broad range of grants for research in hospice and palliative care.

- National Association of Social Workers

www.socialworkers.org/

This national social work organization has developed standards for the generalist social work practitioner, an online training program and is in the process of working together with NHPCO to develop a credential for social workers who specialize in hospice and palliative care practice.

- Growth House

<http://www.growthhouse.org/>

Growth House, Inc is an award-winning site that provides a broad range of resources for life-threatening illness and end of life care. Their primary mission is to improve the quality of compassionate care for people who are dying through public education and global professional collaboration. Their [search engine](#) gives you access to over 4,000 pages of reviewed educational materials from over forty major health care organizations. They aspire to be a portal to the best materials from partner organizations, including the full text of several books.