FOREWORD

THOMAS R. EGNEW

BENJAMIN FRANKLIN long ago observed that in this world nothing is certain but death and taxes. Though taxes may be a source of stress, this hardly matches the distress surrounding death and the processes of dying in contemporary American society. The sorrow of death is as old as humanity, and it cannot be evaded. Although our medicine can support life at its biological edges, it will never overpower the planned obsolescence that is part of our genetic programming (Nuland 1994). We are born with the seeds of our death, and, in light of the potential of medicine to manipulate its timing, the decisions we make around the reality of death are important and far-reaching for ourselves, for those we love, and for our nation.

For ourselves, we want respect for our values, preferences, and attitudes regarding how we prefer to live until our death. We would like those providing care for us and our families and coordinating the services involved in our dying to be caring, professional people. We would likely want some sense of control, some voice in the process of dying, and an opportunity to bring closure to what is important to us. For our families, we would hope that they were well supported during our dying and that our estates were not depleted paying for care that extends our lives without any meaningful quality. And for our nation, facing an onslaught of end-of-life care for an aging baby-boomer generation, we need a care system that can competently and compassionately provide these services without bankrupting the country.

The death of a family member invariably involves suffering, the resolution of which requires multidisciplinary interventions (Seaburn et al. 1996). Systems supporting quality end-of-life care have evolved as multidisciplinary entities, including social workers as essential members of palliative care teams. Yet, the requisite skills and knowledge in palliative care are unevenly taught and poorly integrated with theoretical concepts and research in schools of social work. Christ and Sormanti (1999) note that social work preparation for work in end-of-life care is woefully inadequate. Some schools of social work offer an elective course on death and dying, and only recently has any continuing social work education in end-of-life care been offered. At the organizational level, the National Association of Social Workers has issued a policy statement on end-of-life care (NASW 1994), stressing client self-determination. However, this policy offers no practical steps for social workers to assist in resolving myriad end-of-life care ethical issues (Csikai and Bass 2000) and may be confusing regarding the ethical priorities of the social worker (Wesley 1996). Social workers are therefore inadequately prepared to provide care to dying persons and their families at the BSW, MSW, and postgraduate levels.

None of these policies and only a few of these educational programs address what is described in this volume as a respectful death, let alone the social worker's role in palliative care. What prescribed set of attitudes, skills, and knowledge do social workers need to support dying persons and their families professionally and competently? What roles—and there are many—do they play in supporting such a death? What working conditions influence how these roles are enacted? In other words, for social workers participating in end-of-life care, what are the implications of supporting a respectful death?

This book addresses the theoretical knowledge necessary for working with the dying and their families. Social workers need to know how to adapt social work skills to the end-of-life environment. They need the knowledge and skills to be effective interdisciplinary team members and a mastery of the values and attitudes needed to fulfill their roles. And, perhaps most important, they must have a passion for the personal connection that relieves suffering. Proficiency in these areas can help assure that social workers functioning in end-of-life care settings are adequately prepared to discharge their duties competently and professionally.

THEORETICAL KNOWLEDGE

Death is one of the most powerful of human experiences. As such, it has been a source of fascination to philosophers and theologians, artists and scientists throughout the ages. The ways in which physical, social, psychological, ethical, and spiritual issues interact in death and dying demand that those working in end-of-life care have a broad understanding of the issues related to death and dying (see chapters 5, 6, 7, 9, 10, and 13). The knowledge required by professionals on the palliative care team is shaped by the roles played in the support of the dying and their families. For example, physicians direct and administer medical treatments whose theory and practice are beyond the scope of the social worker. Conversely, social workers provide material support and referral and counseling services that are beyond the purview of the physician.

The role of the palliative-care social worker is shaped by the nonmedical goals set by the palliative care team, the systems requirements to meet these goals, and the expectations of all involved (Monroe 1993). Nonmedical goals involve the expression of emotional pain and the exploration of spiritual pain. "Dying people," Monroe observes, "want to explore: 'Why, why me, why now, for what purpose'" (1993:565). The answer to these questions is crucial to learning the patient's and family's story and thereby understanding the unique values, meanings, and perspectives that must be reflected in the care that supports what they consider a respectful death. Exploration of these questions requires considerable insight into the human condition and theoretical knowledge of a variety of related topics.

Palliative-care social workers must understand theories of death, dying, and bereavement to explore and interpret the experience of the dying and their families thoughtfully. They must be cognizant of ethical theory to appreciate the balance between self-determination and the family common good when discussing care options (Wesley 1996; see chapter 9, this volume). They must understand the personal and familial impact of pain, disability, and chronic illness across the life span and be able to integrate physiological data pertinent to a particular case (Sieppert 1996; Egan and Kadushin 1999; see chapters 6 and 13, this volume).

Social workers must also appreciate how particular settings—residential settings such as nursing homes or prisons—profoundly affect ways of dying (see chapters 31 and 32). They must understand national policies, funding, and other systems variables that affect the care effort (Yagoda 2002). Social workers are generally knowledgeable about advance directives (Baker 2000; see chapters 37 and 38, this volume), but they must be careful that their own values regarding the care they would prefer do not unconsciously influence the choices of the dying person and family.

Palliative-care social workers must understand psychodynamic, developmental, and relational theories and be knowledgeable about spirituality. This knowledge helps the social worker to shape a death experience that respects the values of the dying patient and family amid the complex personal, social, and systems contexts in which dying occurs (see chapters 6, 7, 8, 12, and 13).

Practically, dying persons and their families want help with the process of dying, the support of which requires an interdisciplinary team that shares common goals and expectations of care. Social workers must therefore understand team dynamics to help coordinate the team's efforts to meet the needs of all involved—patient, family and caring system—while supporting a death that reflects the patient's and family's values (see chapter 8). By employing an ecological perspective focusing on persons, their environments, and the interactions therein, social workers contribute valuable perspectives to help insure "safe passage" for dying patients (Rusnack, Schaefer, and Moxley 1988; see chapters 7, 28, and 29, this volume).

An appreciation of the person demands that the focus of care originate from the perspective of the dying patient who is best understood in the contexts of not only family but also community and time. Within these contexts, numerous forces determine those interventions that best support that patient's and family's conceptions of a respectful death. Social workers, trained in relational skills and a systems focus, are well suited to be productive members of the palliative care team and to help assure that the client and family have experiences of death that respect their desires. Given the complexity and emotionality of death and dying, the breadth of theoretical information informing palliative-care social work is formidable. This volume addresses many of the theoretical topics that are essential for orienting social workers to end-of-life care and has summarized much of the pertinent knowledge social workers need in palliative-care settings.

SKILLS

Palliative-care social workers commonly provide counseling, case management, and advocacy services (Christ and Sormanti 1999). These traditional social work activities, in the palliative-care setting, are highly influenced by the expectations and attitudes of patients and families, colleagues, and society. Flexibility is necessary to fit services to the needs of a particular patient and family facing an end-of-life situation. Promoting self-determination and acting as a liaison between healthcare providers and the patient and family are essential palliative-care social-work activities (Csikai and Bass 2000). In a respectful death, self-determination is best realized when the dying person and the family have authorship of their story of their time left together and when the care dispensed supports the values and desires they define (see chapters 1, 2, 3, and 13).

The principal palliative-care social-work task "concerns the social and psychological health of the patient and family before and after death" (Monroe 1993:566) and requires skills in both assessment and intervention. An ecological assessment involves the patient as an individual, the family as a unit, and the social and physical resources available to support the care effort. Accordingly, this book emphasizes advanced skills in patient-centered interviewing (Steward et al. 1995; Laine and Davidoff 1996) that focus on the patient's experience. Such an approach helps assure that the care plan developed centers on the story of the dying person and family. Only after hearing the story that embodies the values and preferences of the dying person and the family may the interventions that reflect their wishes be determined and the actions that support them initiated. Social workers must therefore know how to develop therapeutic alliances with dying persons and their families to facilitate incorporating discussion of advance directives with assessment (Rosen and O'Neill 1998; Baker 2000; see chapters 37 and 38, this volume) and provide personal support. The sensitive, in-depth end-of-life discussions accompanying a respectful death require that the social worker be an extremely skilled interviewer who is very comfortable with the emotional aspects of death and dying (see chapters 14, 15, 16, 17, 24, and 44).

The social worker must also be highly skilled in the assessment of psychiatric distress and be alert for the same. Dying patients commonly experience anxiety, depression, and cognitive disorders (Jacobsen and Breitbart 1996; see chapter 18, this volume), which can compromise their abilities to complete any unfinished emotional business that may be a part of their particular story. Appropriate diagnosis and treatment can alleviate many troublesome symptoms, freeing energy for possible closure activities. Most terminally ill persons suffer troubling thoughts and concerns about death (Cherny, Coyle, and Foley 1994). There are unfortunately no generally accepted methods for assessing the existential distress of dying patients (Jacobsen and Breitbart 1995), but chief among these are fears of intractable pain and abandonment (Cassell 1976; see chapter 19, this volume). Determining the fears and hopes of dying persons and assessing their psychiatric status are essential to helping patient and family to have a respectful death experience.

The patient's family must be assessed as well. The strengths and liabilities of the family system, general family functioning, and the existence of any vulnerable individuals within the family should be ascertained, which requires skills in family group interviewing. The family is most often the basic source of support for the dying patient (see chapter 28). The physical and emotional burdens of being a caregiver are major sources of suffering for family members (Jacobsen and Breitbart 1996; Ramirez, Addington-Hall, and Richards 1998), and social workers possess skills to provide emotional support while advocating for material assistance (Luff and Blanch 1998; Oliver and Gallagher 1998; see chapters 25, 28, and 32, this volume).

After the desires and wishes of the patient and family have been determined, the physical and social resources available to support their perceptions of a respectful death must be assessed. Does the family have adequate financial resources, and is housing adequate? Are resources available to address unmet physical needs such as ramps in the home or meal services? What types of formal and informal systems for support of the patient and family are on hand? What ethnic, cultural, and religious influences affect the patient and family and shape the illness/death trajectory (see chapters 21, 22, 23, 25, and 34)? The palliative-care social worker must be both knowledgeable about community resources and skilled at effecting referrals and arranging care. At times this involves creating programs that provide services not currently offered but necessary to meet the unique needs of the dying person and the family (Rusnack, Schaefer, and Moxley 1988; see chapter 33, this volume). Skilled assessment of the social and community resources available to support the patient and family encourages a care plan that reflects their wishes and values (see chapter 12).

Palliative-care social work interventions include the provision of information, the facilitation of communication, and bereavement services (Monroe 1993). The social worker must be a highly skilled communicator, capable of imparting sensitive information in both a vocabulary and venue that promote an accurate understanding for the dying person and the family (Buckman 1992). The sharing of feelings and information is crucial for the dying person and the family to resolve the problems that death brings (Monroe 1993). The social worker must therefore be a highly skilled facilitator of communication among family members to help create the harmony that helps them to come together in their desires for the time remaining between them (Csikai and Bass 2000; see chapters 17 and 24, this volume). Interventions require skills in many arenas, but a "key task" is listening and talking (Monroe 1993:570), for through listening and talking are the relationships forged and the values and preferences determined that define a death considered respectful by a particular client and family (see chapters 34, 35, and 36).

Palliative-care social workers must also be skilled in understanding developmental issues for the dying child, adolescent, or adult. They need knowledge about traumatic and unanticipated deaths and the unique issues that families face in light of them. They need to understand a range of disease entities and the meaning to the patient and family of each disease and treatment. The social worker also needs to know that death is inevitable, and that when we talk of death occurring "out there" and to someone else, we must always be aware that we are also talking about ourselves (see chapters 15, 16, 17, 31, and 32).

Bereavement services are interventions provided to patients and families throughout the process of dying and after death. For these to be effective, social workers must develop a strong therapeutic alliance with dying persons and their families. Both patient and family must mourn the losses accompanying the progression of disease. Allowing the dying to discuss their concerns helps them become aware that their fears often involve the process of dying more than the actual death (Spiegel and Glafkides 1983), an insight that is comforting when the concerns about the dying process are addressed. Methods of effecting closure can be explored and developed so the dying person and family may have some control by setting goals and objectives for the time they share before death. The existential suffering of the dying regarding past regrets, present losses, and impending death must be addressed (Cherny, Coyle, and Foley 1994). After death, family members need support while adjusting to their loss. These services are instrumental in the safe passage of patient and family through the dying process and require palliative-care social workers to be highly skilled bereavement counselors (see chapters 12, 13, 26, 27, and 29).

As the authors in this book indicate, the complex nature of a respectful death requires a multidisciplinary care effort, and this necessitates specific skills for palliative-care social workers as well. In reality, all disciplines within the team provide psychosocial services (Monroe 1993; Rusnack, Schaefer, and Moxley 1990; Oliver and Gallagher 1998), and thus palliative care teams are considered interdisciplinary rather than multidisciplinary (see chapter 8). Collaboration among team members pools their expertise and yields a better understanding of both client needs and the resources available to support a respectful death (Abramson and Mizrahi 1996). To be effective palliative-care team members, social workers must be highly skilled collaborators who can communicate between disciplines and across systems (Christ and Sormanti 1999; see chapter 20, this volume) to advocate a care plan focused on the patient's and family's desires rather than the professional values of the care team.

Confidentiality must be respected, and considerable clinical judgment is needed to determine what information must be held confidential and what should be shared with other team members (Monroe 1993). The potential for role competition, confusion, and turf battles is considerable owing to the differences in the professional socialization of the various team members (Abramson and Mizrahi 1996; Mizrahi and Abramson 2000). Successful collaboration therefore not only requires an appreciation for the culture of the other professions (Seaburn et al. 1996) but also must ensure that the decisions that are enacted are not so medicalized that they no longer reflect the desires of the patient and family.

Shepherding the respectful death experience that this book promotes requires social workers to be highly skilled in a variety of professional activities. Utilizing traditional social work responsibilities such as counseling, case management and client advocacy, the social worker must be highly skilled in the assessment of and intervention in end-of-life scenarios. This requires exceptional interviewing skills to determine the values and preferences of dying persons and their families concerning the impending death, and extraordinary collaborative skills to assure that the interdisciplinary team supports the same. Failure to develop and maintain high skill levels risks compromising the abilities of the dying person and family to determine the values and preferences reflected in the care provided them.

ATTITUDES

Palliative-care social workers must also possess the values and attitudes that allow them to engage therapeutically with those experiencing loss, death, and suffering without rushing to fix problems or eventually burning out (Ramirez, Addington-Hall, and Richards 1998). Indeed, social workers experienced in end-of-life care must examine their own values regarding end-of-life issues (Csikai and Bass 2000; see chapters 15, 16, 23, and 36, this volume). Such insight is important to assure that the starting point for services is defined by the dying person and the family, and not by the professional role or cultural, religious, and spiritual beliefs of the social worker (Monroe 1993; see chapters 10, 21, 22, and 23, this volume).

It is crucial for the social worker to come to terms with any personal fears of dying and death and any previous losses, for we "cannot listen properly to the loss of others if our own losses, actual or feared, are unexplored and unresolved" (Monroe 1993:570). Palliative-care social workers must therefore make peace with their personal losses and become reconciled to their mortality to reduce any psychiatric morbidity concomitant to providing end-of-life care. On the other hand, having gained perspective, the stress of caring for the dying can be balanced by the personal satisfaction of assisting dying persons and their relatives to experience a peaceful death reflective of their hopes and dreams (Ramirez, Addington-Hall, and Richards 1998). But this always requires the "relentless self-care" that Irene Renzenbrink describes in chapter 44.

The palliative-care social worker must also be comfortable in the presence of suffering. Suffering comes from perceptions of a threat to the integrity of the self (Cassell 1982). Suffering is an inherently unpleasant emotional experience that is an enduring psychological state reflecting perceptions of helplessness (Chapman and Gavrin 1993). A common response is to rush to action in an attempt to be instrumentally helpful somehow. This is rarely productive, for its impetus lies in *our* emotional response to the situation, rather than being centered on the needs and desires of the dying person or the family. To be present to those who are suffering, it is important for the palliative-care social worker to cultivate what Dass and Gorman (1985:67) call a "Witness" that "gives us a little room" in which to be naturally compassionate while not detaching from the patient or family.

Allowing the dying and their families to share their suffering reduces it by addressing the isolation and abandonment that dying persons fear. But staying engaged also means sharing the experience rather than being a detached problem solver, as many chapters of this volume illustrate. Palliative-care social work cannot be done at arm's length, behind the protection of a professional role that focuses on the provision of services. Rather, it must be done through a personal connection. "Recovery from suffering," Cassell has noted, "often involves help, as though people who have lost parts of themselves can be sustained by the personhood of others until their own recovers" (1982:64). There is power in being present to suffering, and sharing the suffering of another is an honor that helps make a respectful death a reality.

The personal assessment and clarification of values that accompanies work in palliative care should be ongoing (Csikai and Bass 2000), inasmuch as numerous ethical dilemmas concerning self-determination, access barriers for services, advance directives, and issues of mental competence arise in home care settings (Egan and Kadushin 1999). Balancing patients' and families' rights to self-determination can be difficult, but is essential in the promotion of a death that respects their values and preferences. Mental competence erodes as dying persons become increasingly ill (Cassell, Leon, and Kaufman 2001), which poses ethical dilemmas in decision making. The personal nature of the decisions made in end-of-life care requires palliative-care social workers to be therapeutically present to those who are suffering without withdrawal, needless action, or burnout. Having clarified one's values and cultivated a capacity to witness suffering, the palliative-care social worker can be present to dying persons and their families and reap the rewards of assisting them in an experience of living until dying that reflects their values and preferences. In light of the pain and suffering that accompanies the death of a family member, the honor of assisting the dying person and the family to experience a respectful death is extremely fulfilling.

By now, the reader may have ascertained that palliative-care social work is both challenging and rewarding. The complex work of shepherding the dying and their families challenges the best of one's intellectual, relational, and emotional resources. It holds the reward of "seeing people make something good of a tough situation," as Dame Cicely Saunders, the founder of St. Christopher's Hospice, has observed (Egnew 1995:104). This book fills a void in the literature for social workers wishing to work in palliative care. Its chapters provide a rich framework for understanding the theoretical knowledge, attaining the requisite skills, and developing the appropriate attitudes to provide compassionate, professional palliative-care services. These pages can decidedly aid the reader to appreciate the contexts in which dying occurs. They warn the reader of the socioeconomic, cultural, and oppressive conditions that can undermine care to our most vulnerable populations—and we are all vulnerable to the helplessness that accompanies death. The stories told herein attest to the personal nature of this work, which is neither for the faint of heart nor for those who wish a social work practice that does not deeply touch them. As such, this volume is invaluable to social workers who wish to assume the mantle of palliative-care social work competently and professionally and is a substantial contribution to a field that holds the potential for tremendous personal and professional satisfaction.

REFERENCES

Abramson, J., and T. Mizrahi. 1996. When social workers and physicians collaborate: Positive and negative interdisciplinary experiences. *Social Work* 41(3): 270–281.

Baker, M. E. 2000. Knowledge and attitudes of health care social workers regarding advance directives. *Social Work in Health Care* 32(2): 61–74.

Buckman, R. 1992. *How to Break Bad News*. Baltimore: Johns Hopkins University Press.

Cassell, E. J. 1976. *The Healer's Art*. Cambridge, MA: MIT Press.

——. 1982. The nature of suffering and the goals of medicine. *New England Journal of Medicine* 306(11): 639–645.

Cassell, E. J., A. C. Leon, and S. G. Kaufman. 2001. Preliminary evidence of impaired thinking in sick patients. *Annals of Internal Medicine* 134(12): 1120–1123.

Chapman, C. R., and J. Gavrin. 1993. Suffering and its relationship to pain. *Journal of Palliative Care* 9:5–13.

Cherny, N. I., N. Coyle, and K. M. Foley. 1994. Suffering in the advanced cancer patient: A definition and taxonomy. *Journal of Palliative Care* 10:57–70.

Christ, G. H., and M. Sormanti. 1999. Advancing social work practice in end-of-life care. *Social Work in Health Care* 30(2): 81–99.

Csikai, E. L., and K. Bass. 2000. Health care social workers' views of ethical issues, practice, and policy in end-of-life care. *Social Work in Health Care* 31(2): 1–22.

Dass, R., and P. Gorman. 1985. *How Can I Help*. New York: Knopf.

Egan, M., and G. Kadushin. 1999. The social worker in the emerging field of home care: Professional activities and ethical concerns. *Health and Social Work* 24(1): 44–55.

Egnew, T. R. 1994. On becoming a healer: A grounded theory. Ph.D. dissertation, Seattle University.

Jacobsen, P. B., and W. Breitbart. 1996. Psychosocial aspects of palliative care. *Cancer Control* 3(3): 214–222.

Laine, C., and F. Davidoff. 1996. Patient-centered medicine. *Journal of the American Medical Association* 275:52–56.

Luff, G., and M. Blanch. 1998. Carers of patients receiving palliative care: Social workers bring specialist skills to care of carers. *British Medical Journal* 316(7140): 1316.

Mizrahi, T., and J. S. Abramson. 2000. Collaboration between social workers and physicians: Perspectives on a shared case. *Social Work in Health Care* 31(3): 1–24.

Monroe, B. 1993. Social work in palliative care. In *Oxford Textbook of Palliative Care*, ed. D. Doyle, G. W. C. Hanks, and N. MacDonald, 565–574. London: Oxford University Press.

National Association of Social Workers. 1994. Client self-determination in end-of-life decisions. In *Social Work Speaks: NASW Policy Statements*, 58–61. Washington, DC: NASW Press.

Nuland, S. B. 1994. *How We Die*. New York: Knopf.

Oliver, D., and D. Gallagher. 1998. Carers of patient receiving palliative care: Specialised psychosocial care may be needed for carers. *British Medical Journal* 316(7140): 1316–1317.

Ramirez, A., J. Addington-Hall, and M. Richards. 1998. ABC of palliative care: The carers. *British Medical Journal* 316(7126): 208–211.

Rosen, A., and J. O'Neill. 1998. Social work roles and opportunities in advanced directives and health care decision-making. www.socialworkers.org.

Rusnack, B., S. M. Schaefer, and D. Moxley. 1988. "Safe passage": Social work roles and functions in hospice care. *Social Work in Health Care* 13(3): 3–19.

——. 1990. Hospice: Social work's response to a new form of social caring. *Social Work in Health Care* 15(2): 95–119.

Seaburn, D. B., A. D. Lorenz, W. B. Gunn Jr., B. A. Gawinski, and L. B. Mauksch. 1996. *Models of Collaboration: A Guide for Mental Health Professionals Working with Health Care Practitioners*. New York: Basic Books.

Sieppert, J. D. 1996. Attitudes toward and knowledge of chronic pain: A survey of medical social workers. *Health and Social Work* 21(2): 122–130.

Spiegel, D., and M. S. Glafkides. 1983. Effects of group confrontation with death and dying. *International Journal of Group Psychotherapy* 33:433–447.

Steward, M., J. B. Brown, W. W. Weston, I. R. McWhinney, and T. R. Freeman. 1995. *Patient-Centered Medicine*. Thousand Oaks, CA: Sage.

Wesley, C. A. 1996. Social work and end-of-life decisions: Self-determination and the common good. *Health and Social Work* 21(2): 115–121.

Yagoda, L. 2002. End-of-life care for older clients: What social workers should know about the Medicare hospice benefit. www.socialworkers.org.

LIVING WITH DYING