PART III

CLINICAL PRACTICE ISSUES IN END-OF-LIFE CARE
INTRODUCTION: CLINICAL PRACTICE

In the previous sections, we have emphasized the importance of the clinical social worker’s having respect for, and an appreciation of, the patient who is dying, and of the family and community who accompany the patient on the journey. We have made clear the need for theories that explain the biopsychosocial domains of dying and of bereavement. We have underscored the importance of theory about interdisciplinary work, ethical issues, and psychological and spiritual practices.

In this section, on clinical practice, we continue to realize a goal that is consistent throughout this book: one that fosters a respectful death, whether working with a dying child, an adult, or a person who has lived a long life. The social worker may meet with the patient and family once, at a point of diagnosis or in the event of a traumatic death, or may work with the family and patient over the long term of the illness and through bereavement. Dying may take place at home, on the streets, in a hospice, hospital, prison, nursing home, or bone-marrow transplant unit. Dying people and their families may seek support from social workers for creative solutions to illnesses, losses, and bereavement: in groups, in family work, or in family camps that help them deal with loss. Dying people and their families have a range of human concerns—psychological, financial, spiritual, cultural, and ethical—and the clinical social worker in end-of-life care must try to help the family and client meet their needs, with dignity and with some degree of choice.

In this section on practice, however, we have chosen not to attempt to discuss every illness nor every end-of-life setting, because this would require another book and because many of the principles of excellent clinical care with the dying and the bereaved generalize to a range of settings, populations, and illnesses. Hence, our division of these very rich and compelling clinical practice chapters is finally somewhat arbitrary, given the overlapping roles of the social worker and the needs of patients and families in every setting and with every disease and stage of the life cycle.

In this section we offer many exemplars of excellent clinical practice in a range of settings and with a range of populations. What, ultimately, do we mean by excellence in clinical practice? What requisite social-work skills enable patients and families to have respectful deaths?

Foremost, the clinician needs to be able to create authentic relationships with patients and families in which he or she is prepared to be present with both her heart
Clinical social-work practice needs to be flexible, because the social worker carries multiple roles: case management, counseling, advocacy, and as a liaison between the patient, family, team, and community. Social work practitioners need to learn anew from every patient and family: who they are, how they came to be that way, their history with death, dying, and bereavement and with medical care, and their inclusion or marginalization in larger social systems. Excellent clinical care requires attending to the meanings of loss for each individual and family. Quality clinical care requires knowing oneself—one’s fears about death, loss, and mortality—in order to “be present” for others who are dying or bereaved. While death is a universal event, it is also universally feared, avoided, or dreaded, and so much of what constitutes excellence in clinical practice is the capacity to stay connected, to be willing to enter into a family or patient’s journey while also maintaining perspective, hope, and humor. Excellent clinical practice is client-centered and promotes a patient’s and family’s choices about the right ways to die. Death, dying, and bereavement are often isolating and often lonely processes, made more so when the disease is stigmatizing or the setting is punitive. The social worker has an obligation to stay in the work: to stay connected to patients and families and to help them maintain connections to their communities of caring. Excellent clinical social work care helps patients and families to advocate for themselves, to make choices, and to make decisions that are consistent with how the dying person has lived.

Hence quality clinical social-work care attends to a range of biological, psychological, and social issues that patients, families, and children regularly face. Psychologically, people who are dying may experience a loss of self-esteem, anxiety, depression, guilt, loneliness, hopelessness, conflicts over dependency and independence, and fears of suffering, abandonment, or being a burden. Quality social-work care creates safe and supportive environments to elicit these fears, to hear them, and to respect their expression. Quality clinical social-work practice requires recognizing a patient’s and family’s cultural values, religious practices, need for privacy, financial, and psychological resources, and connections to friends and the community. Quality clinical practice attends to practical issues: who will care for dependents and provide transportation or household care? Quality clinical social-work care helps those who are dying deal with the end of their lives through legacy building, life closure, rites, rituals, celebrations, funerals, and services. Clinical social workers also help families to survive their grief, loss, and mourning. Clinical social workers attend to the physical aspects of death and dying: the management of pain and the management of a range of symptoms. In every case, the social worker responds to who the patient and family are: their values, beliefs, developmental stages, strengths, levels of literacy, competence, disabilities, gender, race and ethnicity, and sexual orientation (Ferris et al. 2002).

Every patient and family has wishes and preferences about dying with dignity and these must be elicited anew. Every patient and family carries a range of affects—anger, sadness, hopelessness, or hope—and these must be borne within the larger contexts of the family’s history with loss and bereavement. Many deaths are out of sequence, traumatic, or simply tragic, and the social worker must be able to share a patient and family’s suffering because she is able to bear her own. A clinical social worker needs
most of all to be able to work with an open heart because she has faced loss, mortality, and the unknown herself.

We begin this section on clinical practice with three particularly powerful and evocative chapters; the first addresses the trajectory of illness, the second looks at working with individuals who are dying, and the third focuses on working with children who are dying. Each of these three chapters approaches end-of-life care from an experience-near perspective. Allen Levine and Wendy Karger show how, from an initial diagnosis onward, the newly diagnosed person and family embark upon a journey not of their own making, not within their control, and certainly not of their own choice. This chapter asks the reader to look mortality in the eye, drawing the practitioner to examine the ways in which an initial diagnosis changes a person’s relationship to herself and to others as well as to the medical community. A diagnosis may be followed by a series of normative losses: of role, of function, of body change, of disfigurement, of autonomy. A diagnosis and an ensuing illness may lead to a range of intense feelings, a changed self-concept, a loss of faith, or of hope. The reader smells, tastes, and feels the fear and foreignness that accompany the trajectory of illness toward death, an event each of us encounters only once alone.

The chapter by Felice Zilberfein and Elizabeth Hurwitz on the dying individual further sets the context for dying with respect and dignity. In every stage of the life cycle, and in every setting, the social work practitioner needs to create a caring, responsive holding environment aimed toward reducing a client and family’s suffering. Zilberfein and Hurwitz refer to this clinical stance as working with “an open heart,” and, like a “respectful death,” it is a stance that we advocate for all practitioners who work with those at the end of their lives. These authors make clear that an open heart is not an empty heart. An open heart bears witness to a range of feelings—fear, sadness, anger, hope, surrender—without having to “fix” or change them. An open heart listens, but can be silent. A practitioner whose heart is open knows a great deal about a range of developmental issues, disease processes, affects, needs of the family, and resources in the community, but also is able simply to be present. This is only possible when the practitioner knows herself well.

Perhaps nowhere is the practitioner challenged to be more present, more authentic, than in working with dying children, and their families. Nancy Cincotta, in her chapter on working with dying children and their families, takes the reader into the last part of the lives of dying children who must come to terms with their life-threatening illnesses and make meaning of them. For the practitioner, working with dying children can be daunting, and even unbearable. But Cincotta identifies the profound rewards that are possible when practitioners can remain emotionally and physically present to the dying child and her family. The social worker’s capacity to represent the child’s best interests during a shortened lifetime may profoundly influence the child and family’s ability to die with the highest possible quality of life. While new parents can usually learn about parenting from a book or a course, Cincotta reminds us that there is nothing that prepares parents for their children’s life-threatening illnesses or deaths. Using the words and wisdom of dying children and their parents and siblings, Cincotta grounds her clinical assessment and practice in “the data” of children’s and their
family’s lives, underscoring the unique culture in which dying children must live.

Having lived a long life is very different from dying when one’s life has hardly begun, and Sue Thompson and Neil Thompson, in their chapter on working with older people at the end of life, argue that good palliative care, regardless of age, has universal principles: care for the individual and family that restores dignity and self-determination. The elderly are also often a stigmatized and isolated group, their common humanity ignored. They are often lumped together, as if their concerns, needs, and wishes are all the same.

To open one’s heart fully to another’s suffering, the clinician must also be able to assess a range of factors that affect the dying or bereaved individual and the family. The social work clinician must be able to assess a family’s strengths and vulnerabilities as well as those of their community, using a bio-psycho-social-spiritual perspective. As we have maintained throughout, dying is not in and of itself pathological. Yet many factors are brought to bear in any death that may strengthen or may undermine the last chapter of a life. There may be psychological difficulties such as anxiety or depression that may need treatment. Dementias or other cognitive impairments need to be assessed when a patient’s competence is at stake. There may be a history of major mental illness that if assessed and treated may add quality to the end of a life. Kathy Walsh-Burke’s chapter on psychiatric assessment discusses the psychological variables of the bio-psycho-social-spiritual equation. How to differentiate anxiety, depression, and adjustment reactions when death threatens can be very challenging.

Persons who are dying may also suffer unduly and unnecessarily based on their physical pain. Pain is always subjective, and always carries a range of meanings for the patient and the family. Pain may, for some, represent redemption; for others, it may represent punishment. A person’s levels of pain, and its associated meanings, must always be elicited, understood, and addressed. Terry Altilio’s chapter on pain and symptom management makes clear the social worker’s role in accurately identifying the sources and nature of physical, spiritual, and psychological pain, which may be different based on culture, gender, and race. The social worker plays an essential role in advocating for pain and symptom relief with the palliative care or hospice team, the family, and the community, as well as in providing pain management using cognitive techniques, relaxation, and guided imagery.

Susan Blacker’s chapter on palliative care considers all of the factors in the bio-psycho-social-spiritual equation and discusses what social workers do to reduce suffering, work with the patient and family to ensure that their wishes and needs are represented, and serve as a liaison to the team. Palliative care addresses all of the physical, psychological, practical, and spiritual needs of patients and families; it helps them to prepare for a self-determined life closure, cope with loss and grief during illness and bereavement, and promote meaningful opportunities for personal and spiritual growth and self-actualization. Any patient or family living with a life-threatening disease, with any prognosis, regardless of age and at any time, is appropriate for receiving palliative care (Ferris et al. 2002).

Barbara Dane expands upon the role of the social worker in integrating spirituality and religion in palliative care and on the ways in which the practitioner elicits the
patient and family’s spiritual practices and beliefs, while being aware of the practitioners’ own spiritual countertransference.

The social work practitioner, whether as a member of a palliative care team or not, has an equally important role in advocating for the client and family based on a thorough assessment of the family’s culture and history of oppression, especially within healthcare systems. For example, depending on whether the family comes from an individualist or collectivist culture, “truth telling” or “patient autonomy” have completely different meanings. Some groups may seek the most aggressive treatments, based on a history of exclusion from healthcare, while other groups may seek no treatment at all. Some groups may be denied access to pain medication based on their race, ethnicity, or the community in which they live, and other groups may view Western medicine with doubt and suspicion and choose to use complementary and native healers exclusively. Here Norma del Rio’s chapter on culturally sensitive theory and practice in end-of-life care helps the practitioner to recognize cultural differences and the ways in which race, culture, and oppression interact, and to intervene at the micro, mezzo, and macro levels in providing culturally competent care.

Nowhere is this more germane than in working with underserved individuals and families at the end of life. Shirley Otis-Green and Chris Rutland examine the particular challenges of working with those who are addicted or mentally ill, who may also be homeless. They address the cognitively impaired and the disenfranchised patients and families who have limited resources and a lack of access to prescription drugs. They look at those whose culture, language, and social status is stigmatizing and isolating. For those most marginalized and stigmatized, it is incumbent upon social workers to recognize their concerns, advocate for their support, and uphold the core values of our profession in working with them at the end of their lives.

The clinician must also elicit and try to understand who constitutes the family, whether it is a group of friends, a same-sex partner, a multigenerational family, or a community. The clinician needs to know about the client’s and family’s past history with illness and whether medical care been viewed as helpful, or whether the patient and family has encountered racism, homophobia, or cultural discrimination within the healthcare system. Bruce Thompson and Yvette Colón address the unique needs of patients with AIDS, who die from a highly stigmatized disease. While some of the tasks are similar to any person who is dying, there are also different needs that clients and families face as they deal with the burden of the illness such as having been closeted, estranged, or oppressed on the basis of the disease.

How does the social worker advocate for those who have been traditionally disenfranchised by the nature of their disease, their ability, their sexual orientation, their social class, their cognitive, or physical limitations, with dignity and respect? Gary Stein and Lucille Esralew turn the lens again to consider the needs of the disabled and the cognitively impaired at the end of their lives: for autonomous decision making, for education, for the right to withdraw treatments. Social workers who work with the disabled need to be able to assess individual’s abilities, offer a range of modalities (counseling, behavioral, and psychopharmacological), and be prepared to help and to advocate for patients making healthcare decisions that allow them choice, dignity, and access to hospice and palliative care.
Once an individual’s, family’s, and larger community’s needs and resources have been assessed (and this is always an ongoing process), a range of help may be provided that includes group work, family work, consultation, and education, as well as mobilizing natural supports within the larger community. Social workers need flexibility in taking on roles that have always been part of the social work tradition, but are too often lost as we focus too narrowly on the individual. In clinical work with the dying and with the bereaved, social workers act as facilitators, innovators of new practice, team members, educators, advocates, and teachers.

One powerful intervention that a social worker can make is in leading or referring a patient or family member to a group. Here patients, parents, grandparents, children, caregivers, and siblings are able to express, in supportive and safe contexts, a range of feelings and experiences that afford them a sense of sameness, ways to solve problems, a sense of belonging, and a place for feeling less alone. Groups offer a place where hopelessness may be expressed and strengths may be identified. Amanda Sutton and Daniel Liechty’s chapter on group work in end-of-life care and Yvette Colón’s chapter on technology-based groups demonstrate the power of eliciting people’s stories and their unique ways of coping. Sutton and Liechty’s chapter pays particular attention to the role of the leader, the stages of group formation, the importance of confidentiality, as ways of providing holding and support in face to face groups on dying or bereavement. Colón’s chapter discusses the ways in which in telephonic and online support groups may enhance self-disclosure, provide outreach, offer support, and provide a range of information to those caregivers and patients who might otherwise not be able to access help. Susan Blacker and Alice Jordan conclude this subsection with an important discussion of the role of family work and family conferencing in end-of-life care.

Phyllis Silverman’s chapter moves the practitioner to the terrain of bereavement. Her chapter on Helping reminds us that there are a range of helpers for the bereaved, including clergy, funeral directors, and health professionals. Social workers need to collaborate and as appropriate, to make referrals. They need to be what Silverman calls “ombudsmen” or “ritual specialists.” Every individual or family has, regardless of their age or position in the family, their own energy and imagination. Often the bereaved find creative solutions and ways of being in the world that they would never have imagined for themselves prior to the death, and social workers need to help them to find their own solutions. Silverman emphasizes the natural helping networks that can destigmatize the bereaved.

The social worker also needs to help the patient and family to express their own wishes through the use of advance directives or healthcare proxies. Every social worker encounters conflicts between the wishes of the patient that may differ from those of the family, or from the service. The social worker is often in the position of helping the patient, the family, and the team come to terms with competing values and aims. Sometimes this means helping each simply to understand each other’s behaviors and points of view. Often this requires participation in ethical decision making. Susan Gerbino and Shelley Henderson discuss the complex ethical dilemmas that are often a part of social work practice.
In every setting there are challenges that may be specific to that setting. Patients in prisons encounter isolation, the loss of dignity, and a decided lack of support. Here living is devalued, and so is dying. In fact, in prisons, death with dignity is an oxymoron. Sheila Enders, in her chapter on dying in prisons, takes the reader to one of the most dehumanizing settings in which dying occurs: where prisoners may be shackled to their beds or be seen as deserving of only punishment, not care. The social worker working in a nursing home also may encounter clients in dehumanizing conditions and must be able to elicit the joy and the hope that are a part of a long life lived. Nursing homes are also places in which clinical, legal, ethical, and spiritual issues converge in the provision of a respectful death. Mercedes Bern-Klug addresses the biopsychosocial issues of this often neglected population.

Bereavement work is a core function of social work, and so we have included two other chapters that address creative settings for bereavement work. Chris Itin, Susan McFeaters, and Susan Taylor-Brown, in their chapter on a family unity camp for families who have AIDS, combine individual, family, and group work skills that foster both activity and reflection as part of living with dying. Their chapter also identifies the very creative roles that social workers play as program developers. Lisa Aronson’s chapter on international disasters brings in another set of clinical skills for traumatized people in international settings. Cross-cultural competencies, consultation, and bereavement skills are discussed therein.

The last two chapters in this section take the reader to the bone-marrow transplant unit, where a life-threatening disease is treated by an equally life-threatening cure, and to the oncology unit, which in many ways serves as a template for excellence in palliative care. We end with these chapters because they capture the complexity, the conflicting roles and responsibilities, the practice methods, and the consultative and teaching roles that every social worker who works with the dying needs to play. We end with these chapters, too, because, like so many chapters in this section, they convey a sense of awe and wonder about the practitioner’s own reactions to issues of death, dying, and bereavement as they interact with the clients and families whom they serve. John Linder poignantly describes the tasks of the social worker working with patients with cancer and seamlessly identifies the challenges for the patient and family within the palliative-care setting. Iris Cohen-Fineberg beautifully enumerates the particular issues that bone marrow transplant patients face: isolation, aggressive and debilitating treatments, the loss of dignity and control, and the use of treatment that treats the disease but not the person in her environment with the disease.

Both authors, and indeed all of the authors in this section, have interwoven into their practice the concerns of the disenfranchised and underserved. All of the authors have stressed the importance of assessment: of developmental, spiritual, cultural, psychological, and physical issues and their convergence. Many of the authors make use of a range of creative modalities that include individual, group work, family work, pain and symptom management, spiritual work, play, and expressive therapies consultation and ethical decision making.

Because we are mortal and will all face death, end-of-life care is always subjective and intersubjective. The social worker is shaped by his or her own experiences with
loss, as well as frustrations, beliefs, values, and ethics in relation to this work. The worker is challenged to discover or to rediscover parts of himself or herself in working with the dying. Because patient, family, and caregiver are human, they are always influencing one another. The clinician who strives to be objective or the “expert” is not likely to be open to learning about living and dying from the patient or the family anew. There are very few objective “truths” in this work, as we try to practice with the dying and bereaved. There are fewer absolutes, and “prescriptions” for dying need to be left out of the discourse altogether.

But the social worker does have skills: the capacity for empathy, for listening, for bearing witness, for reflecting upon what the client and family may be saying, for support and for insight, for helping patients and families become aware of the ways in which they may be repeating past losses, not hearing one another, scapegoating family members, shutting down, or tuning out. The social worker has the skills to identify the patient’s and family’s strengths in coping with the current crisis, past losses, and past adversities.

Every clinician has reactions, feelings, and moments of “not knowing” in this work. These are inevitable and important. In the past, social work clinicians were trained to rid themselves of their reactions and feelings, of their “countertransference” to achieve clinical objectivity. Not only can we never be “objective” about the feelings and experiences that end-of-life care evokes, but our subjective states—confusion, sadness, anxiety, existential angst—also influence the work we do always. Authentic attunement involves the capacity for engaging multiple subjectivities: that of client and family as well as the worker as they interact with each other about physical, psychological, existential, and spiritual pain. The social worker can only do this when she listens anew to each patient and family’s stories about: how they construct the meaning of illness, hospitalization, or hospice care. In work with the dying, or the bereaved, the social worker needs to be aware of the institutional setting’s influence—how its practices, values, and attitudes may or may not promote a respectful response to the patient and family—and to consider how to effect change in the large system.

We hope that the reader will take away from this section the complexity, the conflicting and creative roles and responsibilities, the developmental and life-cycle issues, the innovative practice methods, and the consultation and teaching roles that every social worker engaged in work with the dying must do. Most of all, we hope that the reader will keep a sense of awe and of wonder about their own reactions to issues of death, dying, and bereavement and those of the clients and families whom they serve. In the next section, Irene Renzenbrink speaks of relentless self-care. In providing care for the dying and bereaved, however, we argue that that the social worker must be relentless in applying all that she knows to those facing the last chapters of their lives.

REFERENCES