PART II

THEORETICAL ASPECTS OF DEATH AND DYING
INTRODUCTION: THEORY

THE OBSERVATION that social workers have not been trained or prepared to work with people who are at the end of their lives or with the bereaved has been made several times already in this book. The chapters in this section were chosen to provide the theoretical perspectives that we consider crucial to informing social work practice more effectively. They assume that the reader is building upon basic social work knowledge. However, as we look at social workers’ personal experiences in dealing with death and how this influenced their practices, we feel justified in asking if we can ever be fully “trained or prepared” to engage with others in our role as professional helpers? If we thought this before, we are now more certain, after reading the narratives in the first part of the book as well as the chapters in the other sections of this book, that this work cannot rely only on our cognitive or intellectual abilities alone. But to be an effective helper in the context of the work that we do, we cannot rely exclusively on our own experience and feelings, either. There is a body of knowledge, much of which builds on what we have already learned in our training as social workers, that is essential to being effective in work with people at the end of their lives. In a sense we need to work from both sides of our brains: the cognitive and the affective.

In this section we bring together a number of chapters that focus on various domains of theory, by no means inclusive, that will add to our knowledge base and have immediate relevance for social worker practice in end-of-life care. We think of these chapters as providing both conceptual and theoretical frameworks that are the underpinnings of good practice in end-of-life care. These are the ideas that can and do direct, inform, and justify what we do. They help us move beyond the individual case to see common patterns in our practice and help us select from a variety of perspectives about where to put the emphasis in our relationships with those we are serving.

Yet in many ways we cannot move beyond the individual case. Dying is a very personal and individual matter. Dying is something every person does alone. But people die in many settings—at home, in hospitals, in prisons, in nursing homes, under traumatic circumstances. By default, others are involved with the dying process, and many religious traditions are clear that people should not die without others at their side. Social workers need to know about the contexts in which death occurs and the influence of these contexts. Each context has values, attitudes, beliefs, and tradi-
tions that need to be understood and the differences between them recognized. These values and attitudes influence how society constructs particular views of the human experience, including how the individual is valued and finds meaning. How the individual constructs his or her death emanates from these values and attitudes. These attitudes and values also influence the kind of resources available in any given community as well, and the kind of care the person receives that is consistent with the ethical and moral approaches to care and the institutional settings this society supports. To this we add the behavioral, cognitive, and relational factors that affect how the individual dying person and family came to their way of approaching dying and mourning.

We frame some of our understanding in the question: “What is their story?” How people put together their stories involves, as well, the cultural, socioeconomic, and spiritual milieus that have informed their lives. This multifaceted perspective reflects multiple theories, informs how these needs are defined and how these needs are met, and contributes to our making sense of what is happening to the dying person and her family. Thus the chapters in this section provide various contexts or lenses for understanding how any given individual comes to view living and dying: psychologically, relationally, spiritually, and ethically.

In this modern and postmodern world, there is a new appreciation for the range of acceptable human behaviors, making each person’s story richer and taking in a broader view of their lived experiences. We see the value of examining their behaviors from many points of view to which we add, for example, ethnic, cultural, interpersonal, developmental, and intrapsychic lenses. We recognize that dying may differ based on sexual orientation, social class, and gender as well.

Very little about dying is universal except that all of us will die. We need to recognize that much of how we look at dying is socially constructed, changing over time. In this book, we focus throughout on what is involved in creating environments that respect the needs of the dying and their families. The values and attitudes that promote a respectful death must be reflected in our individual practices and in the institutional settings in which we work. Death, in the end, is inevitable, an experience over which we have no control and less understanding. In some ways theories, as described in this section of the book, about what we do at this time, provide us with ways to feel grounded when faced with this mysterious and unknown terrain.

What do we mean by theory? From a modern, positivist approach, theories provide hypothetical explanations for observable phenomena. For a theory to be accepted as true it would need to be studied and tested. As we look at human experience, at the very fact of life and of death—how they stay constant and how they have changed over time—we develop many theories for explaining what we observe that cannot be tested. We turn to philosophy, to religion, to history, to the arts, to psychology, to life experience to provide us with ways of understanding living and dying.

It is also essential that in considering various theories, we learn to critique them as well: to recognize their limitations. Most of the time, when dealing with life and death, the only certainty we have is that death happens. In looking at these aspects of human experience, we need to accept uncertainty, ambiguity, and our inability to
understand and control all that is happening to our clients, and ultimately to ourselves. Our authors represent various schools of thought, some of whom may sound certain about absolutes in death, dying, and bereavement. It is important to be able to hold the uncertainty of any theory while trying to learn it at the same time. We have tried to present a variety of perspectives in the hope that the reader will test them out against her own practice and take from each what serves her or his clients best, recognizing and tolerating the uncertainty and ambiguity of what we do not know.

The chapters in this section represent the work of researchers and practitioners. Many of them are works in progress as the authors explore what they have learned from their practice and from research. They are works in progress because it is impossible to bring closure to the study of dying that has such unclear boundaries, and for which universal explanations are impossible. They are works in progress because good practitioners are always learning from those they serve and need to be open, in each encounter, to the unexpected. Carolyn Jacobs, for example, describes this very well. Her own journey as a practitioner concerned with the spiritual life of those she serves began as a result of an encounter with a client. These chapters are works in progress because views are always changing, and we are participating in making these changes by our own work in this book. In the process, we have become increasingly aware of aspects of the human experience that until recently were not attended to, such as the impact of gender, race, and sexual orientation on dying. Do we stigmatize people for their race, for their gender, even for the fact that they are dying? What are the forces that separate people and their common experiences from each other? How do we recognize each other’s differences and recognize our common humanity?

Good practice has to be responsive to the needs of those we serve. The paradigm for research presented here, that interfaces with and informs practice, is exemplified in Farber, Egnew, and Farber’s chapter on a respectful death and in the findings of Silverman’s research with the widowed and with bereaved children. A qualitative approach to research may be most relevant for this work (Silverman 2001). It does not test hypotheses, nor predict outcomes. It focuses on what people are experiencing at this time of their lives, accurately describing it and allowing the voices of clients or other people to energize and give direction to practice.

We also see the importance of thinking critically about the application of these ideas to practice. In a sense, every clinical interview is a small qualitative research project. Information is gathered about the client or family and a plan is made, based on an analysis of themes and a conceptualization of the problem is proposed. If the assessment and intervention(s) prove to ameliorate the problem or help people cope more effectively, then there is some reason to consider the hypothesis correct. If the intervention fails, then it is essential to develop new categories for understanding. We must always be ready to challenge and revise our theories based on our clients’ experiences. Often we say that if a theory does not apply, it is the client who is at fault. We blame the victim. Practitioners in this field need to be able to say if the theory does not apply, then it is not the client but the theory that is at fault.

This section contains eight chapters. It begins with Phyllis Silverman’s, describing how our views of dying, death, and bereavement have changed over the past millen-
nium and how these changes have led to the current practices, attitudes, values, and institutions that are evolving today.

Seeing dying as a medical failure has led to a focus on curative medicine. Most healthcare professionals have difficulty facing that some of their patients will not live to see the end of the year and are reluctant to consider palliative or comfort care. In so doing they most often ignore the individual and his story and his preferences in this matter. The chapter on a respectful death that follows Silverman's personalizes and humanizes the dying process. Stuart Farber, Tom Egnew, and Lu Farber describe how the concept of a respectful death evolved from their own research. We no longer talk about “patients” but “people” who are more than equal partners in deciding what care they need and can get. In reading this chapter we need to consider what is needed to implement the kind of respectful care advocated in this book. Most people do not want to die in the hospital or alone. In the past, hospitals were not prepared to provide palliative and comfort care. New settings were needed. What began as a grassroots effort, in part emulating the hospice program in Great Britain, has grown and become institutionalized as hospice and palliative care in the United States. Mary Raymer and Donna Reese, in their chapter on the history of social work in hospice, describe the growth of hospice as an innovative means of providing dying people with more humane care in their own homes or in institutional settings. Hospice is more of an approach to care than a service tied to one setting.

Hospice care and most end-of-life care emphasize the importance of care by a team. No one has all of the requisite skills to provide both the required medical care as well the psychosocial and spiritual care of people at this point in their lives. Rather, a team of care providers seemed called for: a physician, a nurse, a physical therapist, a social worker, a clergyperson, a home health aide, a dietitian, a speech pathologist are all parts of the team. People who are ill in a hospital or at home often feel confused by the number of people wearing white coats who come to help and who are indistinguishable one from the other. Most people are neophytes in knowing how dying works and what professions, other than a physician and a nurse, are involved in their care. In their own homes, most people feel as if they have a bit more control over who comes and goes, whom they attach to, and who cares for them and about them. How is the team defined, then, for the dying person? How does the team define itself? How do they divide roles and responsibilities, help each other distinguish their areas of expertise, deal with the gray areas, resolve differences in expertise and what they do? Inge Corless and Patrice Nicholas, both nurses with extensive experience in end-of-life care, use a sociological lens to examine the issues that can interfere with team development, such as, for example, control and power. Social workers are generally not socialized to practice as part of a team, although in practice, especially in a medical setting, they often occupy a subordinate role. They need to consider how to collaborate, to share information, to learn from each other, and in the end to recognize that the patient or client not only is a member of the team but also should be the captain.

When we begin to focus on the needs of people who are dying, we open the door to another aspect of conflicting and competing viewpoints, this time between what
healthcare personnel may think is best for the client and what the client wants for himself. Ethical dilemmas permeate all end-of-life practice and by using ethical principles, differences may be reconciled between medicalized and patient-centered care. Patricia O’Donnell describes factors that contribute to the rise of ethical issues in the end-of-life care and how they are mediated by finding ways of dealing with conflicting principles and values.

What are the factors that move people at this time in their lives, that inform their attitudes and values? One key factor is how we make meaning out of what is happening to us. This takes us to the realm of spirituality and religion, areas of human experience that have not typically been part of social work discourse. Some people have faith systems that help them think about life and death and provide them with customs and rituals that give direction to this experience. Although not the same as a faith system, many people find this a time when their quest for meaning is important, and the social worker has to be prepared to join them on their quest. Carolyn Jacobs brings us on a spiritual journey directed by her colleague and clients. She provides a framework for adding questions about a client’s faith and spiritual beliefs into the interview. She begins to develop her thinking about how fluid the boundaries are between the social worker and her client and the importance of being present in the situation and of listening to what is being said rather than trying to force data into a theoretical framework.

Other factors that inform values and attitudes at the end-of-life include race, social class, gender, and ethnicity. Illene Noppe, using research data, opens a dialogue about the similarities in how women and death have been neglected in our society. She describes what it means to live in a gendered society. Her analysis forces us to examine how we treat one another and to acknowledge that our research designs, for all their espoused objectivity, often ignore or minimize these important differences.

The last two chapters of this section look at interpersonal and intrapsychic factors that influence how people think about themselves and how they act when they are bereaved. They both focus on how the bereaved are transformed by the loss and how they grow and change. Phyllis Silverman, building on her research, points to how the bereaved build new relationships with the deceased. She focuses on grief as a life-cycle issue that people live through and are changed by. Joan Berzoff’s chapter on psychodynamic theory offers a historical and theoretical view of bereavement, following Freud’s theories and those who wrote after him. Using concepts of identification, internalization, and introjection, she points to ways in which the bereaved take in aspects of the lost person that can be transformative, thus producing psychological growth.

Theories are valuable as they can be applied in practice, and we invite readers to apply, critique, and develop new theories based on both their practice and research. To do so is to begin to take leadership in end-of-life care.

REFERENCES