END-OF-LIFE CARE & ADDICTION

A Family Systems Approach
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I would like to dedicate this book to my own family, whose emotional process has made me who I am today.

—B. D.

I would like to dedicate this book to my husband, Bob; and my family who have always encouraged and supported me, and from whom I first learned what it means to be part of a family system.

—S. Y. B.

We also dedicate this book to those who work with families facing end-of-life and addiction.

—B. D. & S. Y. B.
This book began with a simple observation we repeatedly encountered in our work with hospice teams: Providing care to patients and their families was different somehow when those patients and/or families had histories of addiction. We noticed that certain discernable patterns were repeated, to the extent that when a family entered hospice care, someone on the team thought the new family was similar to another family we had served not long before. “This Jones family? They are an awful lot like the Smiths,” would characterize the typical case presentation. And we would worry that we were not treating each family as its own discrete entity—but sure enough, soon the Joneses would indeed begin looking to us very much like the Smiths.

In our effort to understand what we were experiencing, certain discoveries emerged. For one thing, the medical model, common in hospice care, did not help us discover the uniqueness of each family. In part this is because the medical model is reductive: It only told us who the patient was according to the conclusions of his or her disease process. The medical model led us to have certain expectations of the persons who came onto our hospice services—mostly that they would die in a way appropriate to the course of the disease taking their life. There was, we supposed, a comfort in this—not for the person or the family, but for us, the members of the hospice team. Somehow being among so much death and dying was made more comfortable if, in some way, the processes we witnessed were predictable.

Unfortunately, that predictability led to disinterest. The end of some people's lives became “ho hum” for us because of the routine. However, when a disease took an unexpected turn, suddenly there were moments of interest again. We were interested because the way that particular person was dying was “different,” and that difference caught our attention.
By the same token, one might think that the patients and/or families with histories of addiction would have sparked the interest of the hospice team. But the team’s habit of categorizing them in terms of other, allegedly similar families diminished this interest. Instead, the team sought the comfort of familiarity and predictability. More surprisingly, a sense of blame or judgment often entered into our discussions about these families. We began to wonder why this was the case.

This wonder led us to the research and writing of this book. We began to organize our ideas, and to present them at clinical team conferences of the National Hospice and Palliative Care Organization. There, our ideas were well received. Workshop participants repeatedly told us that they needed to know more about providing end-of-life care to persons and families with histories of addiction. It is in no small part because of their encouragement that we are offering our ideas here.

One theme of this book is: “It takes two.” First, we believe that it takes two eyes or points of view to see the patient and the family accurately. Our bodies are “stereoscopic”: It takes two eyes to give us depth perception. In the same way, we say that it takes a stereoscopic vision to provide comprehensive end-of-life care.

On the one hand, we recognize that hospice care is a form and extension of medical care. It is for this reason that the medical model is used to direct patient care, and it is on the basis of a hospice’s competence with the medical model that they are certified and accredited. Thus the medical model has its uncompromising importance in the delivery of end-of-life care. We affirm this.

On the other hand, the medical model itself is only one way to view the patient—and it almost never takes into account the family. We believe that end-of-life care is best practiced when both the patient and the family are taken into consideration. We advocate that the way to do this is to become knowledgeable about families and how they function. In this volume we offer family systems theory as one possible way to develop this understanding, but our point is more general. Taking families into account expands one’s vision of the patient beyond whatever physical condition has brought him/her to the hospice service, and this provides a better, deeper, more human vision. This aim leads to the hospice maxim that the family is the “unit” or focus of care. It is our belief that this book will provide a better way for hospice teams to fulfill this goal.
We also explore a duality in the way information is presented here. In writing this book, we had much information to impart, but also had a story to tell. In fact, we had a number of stories, and we could not tell them all! So we decided to conflate our stories into one, and to complement our nonfictional information with the fictional account of one family—George, Wilma, John, and Amy Cinnamon. The Cinnamon family is absolutely fictional, but based on our observations of families treated in hospice. Likewise, we created a fictional hospice, which we call “Heart of Gold,” staffed with fictional professionals. These characters are intended to play representative and illustrative roles (and are not intended to represent any persons living or dead) in our explanation of end-of-life care rather than reflect any specific individuals.

The theme of “it takes two” also relates to the ears we bring to end-of-life care, especially when it comes to listening to addicts and their families. We have the clinical ear that listens to our patients and families, and understands what they are saying. The other ear is the “ear” of the heart. This ear not only hears what they are saying and understands what they mean, but it also listens with compassion.

As we listened to patients and families with a history of addiction, we came to understand that what set them apart was the degree of shame they felt. The more we listened, the more we were convinced that providing compassionate end-of-life care meant responding in appropriately caring ways to this shame.

We learned that the Chinese character for “shame” (ch’ih) depicts a heart next to an ear (Whitehead & Whitehead, 1995, p. 90). We believe that it is through listening with the “ear” of the heart, hearing about and accepting another in the shame of their vulnerability with both humility and grace, that end-of-life care is best accomplished.

Further, “it takes two” applies very much to the collaboration that went into the writing of this text. One of us is a social worker, the other a spiritual caregiver. It has taken two professions to make this book, as well as two minds, and two hearts. We have experienced the benefits of dialogue. But we are not merely two people talking—we are two joined in the singular experience of life that is conversation.

Our conversations have been lively at times. We have different traditions, styles, and professional approaches, with overlapping theories, models, and approaches to people in their wholeness. Our commitment to holistic hospice care, to honoring the work of both recovery and dying, and to families whose stories live on beyond death, is what
kept our conversation going. Here, we aim to share the fruit of that conversation, and to speak with one voice.

In offering this book, we are inviting others to join our conversation, too. Our obvious hope is not only to address those interested in end-of-life care and those concerned with addiction treatment and recovery, but also to bring people from those two fields of interest into conversation with each other. We believe that there is much we can learn from each other.

The most important thing of all we can learn from each other concerns the nature of family life. This book is for those who want to come to better understandings of their families—whether because there has been or is about to be a death in the family, or whether there is a history of addiction in the family, or simply because our families are worthy of our interest. What makes our families both interesting and our own is our family’s story. We hope that what we offer here sparks sharing of families’ stories and from that the discovery of how unique we are as well as how alike.

The final way in which this book “takes two” has to do with what is happening at this very moment. For it does take two—writer and reader—to make all of our stories come to life. We are grateful for your attention and hope that this volume offers you new ways to approach end-of-life care, addiction, and your families.

REFERENCE

We would like to acknowledge those who have helped us along the way:

- The Betty Ford Center for the hospitality and pedagogy of its Professional In Residence program;
- The National Hospice and Palliative Care Organization for giving us the opportunity to present workshops at NHPCO conferences, where we initially shared many of the ideas that found their way into this book; the conversations were both helpful and encouraging;
- The courageous families we have had the privilege of knowing and serving:
  - families who have faced extraordinary challenges at the end-of-life, and in their grief;
  - families who have lived with addiction; and
  - families who have demonstrated enormous strength in recovery—living beyond grief, loss, and addiction; and
- The recovery community for its example and support.
Death and Addiction: A Family Affair

George settled glumly into the passenger seat of the car, gathering the clear plastic tubing that ran from his portable oxygen tank to his nasal canula. His wife, Wilma, took her place behind the wheel, but made no attempt to drive. Neither spoke at first. They had just come from the oncologist’s office, where the doctor had said, “George, I have run out of options for treating your lung cancer.” George had asked, “Do you mean there’s nothing more you can do for me?” The doctor had nodded her head, and said some other things, but he couldn’t remember what they were.

Wilma did. She looked over at George and said, “I guess we better go home and call hospice, like the doctor suggested.” She waited for George to respond. After what seemed like an eternity, George said, “I really could use a cigarette right now.”

THE ROLE OF HOSPICE IN END-OF-LIFE CARE

The lives of George, Wilma, and their family have just taken a dramatic turn. George’s oncologist had made a routine assessment by asking herself: Would I be surprised if this patient died in the next 6 months? Most likely, she admitted that she would not be surprised. This question
and its accompanying answer are what most often lead to a referral to hospice services.

What was a routine medical assessment for his oncologist, was an existential turning point for George. His life is now headed in a new direction, clearly toward its end. He and his entire family are going to be affected by this change in medical status.

Specifically, George's medical team will no longer try to cure George of his disease. Instead, they will concentrate on caring for him now that his prognosis is officially terminal. Once Wilma initiates hospice care for George, this shift will be underscored. Caring for people at the end of life is what hospice does best.

At the moment, George and Wilma are stunned and bewildered by this turn of events (even if, subconsciously, they had been anticipating it). Only gradually will the true meaning of this moment become apparent to them, and to the other members of their family. Hospice will help them discern that meaning and make the necessary life adjustments.

George and Wilma have become accustomed to the routines of medical treatment, as do most families in this situation. Their lives have been structured around doctor visits, hospital stays, and reactions to therapies. As fatiguing as it may have been, the rigors of seeking a cure gave George and Wilma, along with others in their family, something to do and talk about. Now, rather suddenly, much of that activity will stop, and what ensues is an unsettling stillness.

Their emotional and spiritual lives will also radically change. Up until now, George and Wilma have been hoping for (if not expecting) a cure and a return to their “normal” lives. Now that a cure will no longer be pursued, they are uncertain about what to expect and will need to begin adjusting their hopes.

Their lives are now fraught with unknowns, which can cause different fears and worries for everyone in the family. Fortunately, hospice professionals are familiar with a time in life that is unfamiliar to most. They are skilled at normalizing the end of life by providing information about what to expect.

Once George and Wilma invite a hospice team into their lives, they will initiate relationships that will last not only until George dies, but well into his survivors’ mourning. When the Heart of Gold hospice team arrives, they will supplement the family’s activities of care and support each member as he/she adjusts to this new, temporary way of living.
Accepting hospice care is not always easy. Initially, like many hospice users, George and Wilma may not be entirely clear about what a hospice team can do, nor what they want them to do. Moreover, because most hospice care occurs in the home, calling hospice means quite literally opening one’s door to strangers. Families are expected to be welcoming and accommodating to hospice staff. Yet many feel that their privacy has been breached and their home invaded by hospice care.

Hospice professionals understand this. They understand that, in a symbolic way, an “invasion” has already occurred. For many families, hospice care represents not only the intrusion of death, but also its discomfoting consequences. The arrival of the team and the materials they bring with them (new medications, medical equipment, a hospital bed) symbolize the disordering of people’s lives brought about by a terminal prognosis, even as the team seeks to bring with it a sense that order can be restored.

The temporary relationships created by hospice care are extraordinary for all involved. As a result of hospice’s interventions, the relationships among George and Wilma’s family will be forever changed. Hospice care is an interactive experience of tremendous intimacy that often has life-altering consequences for the patient, the family, and even the hospice team. Hospice teams aim to accomplish this experience by focusing on the whole family. In hospice, there is a belief that “the family is the patient.”

In our years of working with hospice teams, we have developed a deep appreciation for hospice. Given the complexities of end-of-life care, hospices do admirably well with the vast majority of the patients they serve, especially given the relatively brief time of that service. To function as well as they do, relationships and alliances need to develop quickly among the families, the patients, and the hospice team members. Hospice provides a crucible for caregiving relationships to begin, function meaningfully, and then end appropriately. Although most hospice teams do this exceedingly well, we believe that there is room for improvement.

Specifically, the shift in focus from the patient as an individual seeking a cure, to a family seeking care, is difficult to accomplish. There are reasons why many hospice teams tend to focus on individuals within the family system, instead of the system itself. One of the goals of this book is to shift the focus of attention to the whole system from that of its individual parts. If the family is truly to be the “unit of care,” a
grasp of “family systems” would therefore be essential not only to the care of George and Wilma, but also to all who enter hospice care.

To understand how and why hospices have difficulties regarding the family as the patient, we will begin this chapter by offering a brief history of hospice. We will then describe how hospice operates at the confluence of three fields: business, medicine, and psychosocial care. Psychosocial care in particular struggles to reconcile the competing interests of these fields (Healy, 2005; Taylor, 1998; Williams, 2003), as holistic approaches are more concerned with context and inherent values that may not be fully reflected in the other dominant and often competing fields (Healy, 2005).

Next, we discuss the application of family systems theory to hospice care, and how that approach can be particularly useful in families with histories of addiction. Understanding family systems is an essential tool for those engaged in end-of-life care, and even more so for families that have experienced addiction. We believe that a parallel process exists between hospice care and substance-abuse treatment. Similar to hospice services, substance-abuse treatment programs are medically based and medically guided businesses. In our opinion, however, recovery is not merely a matter of the efficacy of either business or medicine, but more a matter of the psychological and/or spiritual growth of the addict and the addict’s family. Thus these concerns are common to both end-of-life care and addiction treatment.

Finally, we will discuss how a family systems approach may not only be useful in the care of hospice patients and their families, but also for understanding the functioning of the hospice team itself.

**A BRIEF HISTORY OF HOSPICE**

Although to date a definitive history of the hospice movement has not been written, what follows can suffice as a brief summary.

Hospice, as it is now practiced, has its roots in medieval times, when some monasteries set aside rooms for dying monks, and focused especially on their spiritual care. More recently, the contemporary hospice movement had its source in the pioneering work of Dame Cicely Saunders, a nurse and medical social worker who founded St. Christopher’s Hospice in England in the 1960s. Saunders’s effort to treat the dying with dignity by recognizing the limitations of medical interventions has had a lasting impact on end-of-life care throughout the world.
In the United States, recognition of her work roughly coincided with that of two other pioneers in changing dominant attitudes toward end of life. The impact of Elisabeth Kübler-Ross’s *On Death and Dying* is well known. First published in 1969, Kübler-Ross’s breakthrough was the affirmation of the humanity of the dying. She listened to people as they spoke about their feelings and experiences. She formulated what she called the “five stages” of dying: anger, denial, bargaining, depression, and acceptance. Kübler-Ross’s research essentially founded an entire new field of study: thanatology, the study of death and dying, especially the psychological and sociological aspects of death.

Also among the notable early contributors to this field was Dr. Avery Weisman, a researcher at Massachusetts General Hospital, who spearheaded Project Omega. Project Omega studied the way cancer patients responded to their illness and its ramifications. Weisman’s work led to what has come to be called psycho-oncology.

As the field of thanatology expanded, predominant cultural attitudes toward death and dying slowly started to change. What had begun as essentially a psychosocial–spiritual movement evolved further, as doctors and medical professionals became interested in thanatology. This gradually led to the establishment of hospices in the United States, many of which followed the model of St. Christopher’s in England. Medical practices toward the terminally ill were examined and eventually altered, leading to the field of palliative care, a medical specialty that alleviates or manages pain. Even though the focus of palliative care extends beyond those who are dying to all who are in pain, it has in common with hospice the goal of palliation, which is the alleviation of suffering.

In 1982, the Medicare Hospice Benefit was enacted by Congress. This landmark legislation did two things: it established the four “core” hospice professional disciplines as medical, nursing, psychosocial, and spiritual care. It also provided criteria for reimbursement of hospice services, thus allowing hospices to become viable businesses.

**HOSPICE AS A BLEND OF BUSINESS, MEDICINE, PSYCHOSOCIAL, AND SPIRITUAL SERVICES**

Today, hospice, as it is practiced in the United States, blends the worlds of business, medicine, and spirituality. First, hospices are businesses. According to the National Hospice and Palliative Care Organization
(NHPCO, 2007), 92.6% of all hospice agencies were certified by the Centers for Medicaid and Medicare Services (CMS) to file for reimbursement under the Medicare Hospice Benefit, and 83.7% of hospice patients were covered by it. NHPCO estimates that in 2006, approximately 49% of hospices had not-for-profit status, whereas 46% were for-profit, and the remaining 5% were government-run programs such as those provided by the U.S. Department of Veterans Affairs. As an industry, hospice has grown to more than 4,500 programs since the first one was opened in 1974.

Most recent growth has been in small, freestanding programs. The median daily census in 2006 was 45.6 patients and only 16.2% of providers routinely [cared] for more than 100 patients per day (NHPCO, 2007). Industry growth is projected to be more likely in the for-profit sector than in nonprofits. Research indicates hospice’s fiscal efficiency: “hospice services save money for Medicare” (NHPCO, 2007, p.5).

Most Medicare-certified hospices receive a per diem amount for each person receiving service, a rate of reimbursement determined annually by Medicare. Service must be provided for all patients and their families within that per diem multiplied by the average daily census over the course of the year. Some hospice patients’ care costs more than others. A savings with one patient can be applied to the care of another, and differences are often offset by charitable donations.

Contracts are negotiated with providers outside the hospice, for example, with other businesses that provide durable medical equipment (DME) or oxygen or with pharmacies for commonly used medications. Sometimes, hospice teams discuss what changes might be made to the standard service “package” so as to remain competitive with other hospices in the area. Some medications are more expensive than others. For example, some hospices provide for ancillary needs (such as incontinence diapers and food supplements). Thus, although all hospices hold to certain standards, the range and quality of hospice services varies across hospices, just as it does in other businesses.

Costs per patient are monitored as long as patients are on service. Very short terms of stay are costly for hospices because initiating an admission is labor intensive. As patients remain on service, their costs may decline as their medical conditions are stabilized, or they may increase, if their medical conditions deteriorate. Costly patients who remain on service a long time deplete a hospice’s assets. Less costly
patients add to a hospice’s bottom line and allow a hospice to manage and allocate its expenses better so as to meet the needs of other patients.

Second, hospices are medical care delivery systems. NHPCO estimates that 1.3 million patients received services from hospice in 2006, and that 36% of all deaths in the United States that year occurred under the care of a hospice program (NHPCO, 2007). The overall aim of contemporary hospice care is to provide the means for patients to die in the place they call “home.” In 2006, nearly three quarters of all hospice patients died in a private residence, nursing home, or other residential facility, as opposed to an acute care setting (NHPCO, 2007). In contrast, in the general population about 50% of people die in acute hospitals. Almost 20% of all hospices operate a dedicated inpatient unit or facility; typically this inpatient care is provided by larger agencies with an average daily census greater than 200 patients (NHPCO, 2007). Less than 10% of hospice patients died in a hospital setting that was not managed by the hospice organization (NHPCO, 2007).

In the 1970s, when the hospice movement began in the United States, the majority of admissions were cancer patients. In the 1980s, a significant number of hospice admissions were patients with HIV/AIDS. Today, the hospice admissions profile has again changed. Only about one half of 1% of hospice patients are admitted with diagnoses of HIV/AIDS. And as deaths from cancer in the United States have declined to about 25% of all deaths, their proportion of the hospice census has declined as well. In 2006, about 44% of hospice patients were admitted with a cancer diagnosis. Significant among the noncancer diagnoses numbers were heart disease (12.2%); dementias, including Alzheimer’s disease (10.0%); and lung disease (7.7%) (NHPCO, 2007).

Although hospice does offer service to younger persons (and has even established a field of pediatric hospice) over 80% of all hospice patients in 2006 were 65 and older, and about one third were over the age of 85 (NHPCO, 2007). This volume will focus specifically on hospice and end-of-life care for older adult patients and their families.

An analysis of Medicare beneficiaries over 65 who died in 2002 showed that females tended to use hospice more than males; Caucasians, more than people of color; and about 29% of older Americans made use of hospice for end-of-life care. More than other determining factors, hospice use was higher for “diseases that impose a high burden on caregivers, or diseases that predictably lead to death” (NHPCO, 2007, p. 7). The emotional and spiritual support that hospice offers to caregivers,
along with their knowledge about the time frames of the courses of disease progression, are factors that attract families to hospice services.

Finally, hospice has a strong psychosocial and spiritual dimension, as demonstrated by the visionary work of Saunders, Kübler-Ross, Weisman, and others. As mentioned earlier, the Medicare Hospice Benefit affirms this dimension by including the provision of social work and spiritual care in hospice services.

NHPCO estimates that about three quarters of hospice employees provide patient care and/or bereavement support. According to NHPCO figures, nurses are the largest percentage of employees and physicians the smallest, with social workers falling in between. Chaplains and spiritual caregivers are regarded as essential by the Medicare Hospice Benefit, but this aspect of hospice care is not institutionalized in a uniform way. (For example, there are no NHPCO figures available for actual standard caseloads of chaplains, as there are for nurses, social workers, and home health aides. There are, however, “Guidelines for Spiritual Care in Hospice,” which reflect Medicare Benefit guidelines for chaplaincy caseloads.) Across the spectrum of hospices, the relative emphasis on spiritual care, as well as on psychosocial services, varies greatly (Williams, Wright, Cobb, & Shields, 2004).

Still, NHPCO figures show that the bereavement services hospice provides average about two family members per death, and that “most agencies (93.9%) also offer community-wide bereavement programs” (NHPCO, 2007, p. 5). In addition, hospices benefit from the service of over 400,000 volunteers, who provide an estimated 5.1% of all clinical staff hours. The majority (58.9%) of volunteers assist in providing direct patient care, and the remainder provide general support (e.g., in fundraising or serving on hospice boards). Many, if not most, of these volunteers come to hospice to serve because they themselves and/or their families were served by hospice. Thus the number of hospice volunteers illustrates the efficacy of hospice in providing end-of-life care and its availability to provide continuing emotional and spiritual support to those who grieve.

THE HOSPICE TEAM AND MEDICAL, BUSINESS, PSYCHOSOCIAL, AND SPIRITUAL SERVICES

After Wilma called Heart of Gold Hospice, an admissions team of Susan (a nurse) and Bill (a social worker) were sent to their home. Together, they
conducted the admission: Susan filled out the paperwork, reviewed George’s medications, and interviewed both George and Wilma about his medical condition. Bill began to get to know them as people. He asked George what he wanted most at the moment—and George said, “A cigarette.” Bill laughed, and said, “If I were going onto hospice, I’d start smoking again, too!” While he and Susan and George talked about how George’s smoking could be managed, Wilma was distracted by other thoughts. George’s smoking had long been a sore point. Now not only would he be smoking again, but they would have a noisy oxygen machine in their home! Wilma was not pleased with how things were going.

When they reported George’s admission at the team meeting, Susan began with her assessment of his medical needs, including adjustments in his medications. She presented her nursing plan of care for review by the medical director and the other nurses on the team. Bill followed with his social work assessment of George, and his recommended plan of care.

The interplay of business, medical, and psychosocial issues can be seen in our fictional account of the Heart of Gold team meeting. First, the business realities of providing care are addressed at George’s admission, and indeed they underlie every team discussion of every patient. Heart of Gold is a not-for-profit hospice, but it still needs to conduct itself in a fiscally responsible fashion.

Second, the language typically used to discuss persons and families on hospice service is primarily medical. For instance, Susan’s presentation of George sets the tone for all other discussions, even those that are psychosocial-spiritual in content. George is the “patient”; Wilma is “family.” As the patient, George receives the lion’s share of attention during the team meeting. The medical aspects of his care will be the primary focus of the discussion whenever his case is reviewed and, sometimes, if there is no change in his medical status, the team will direct its attention to the next patient without pausing to ask the question, “How is the family doing?” In other words, the medical focus of hospice end-of-life care is on the patient as an individual and on the disease process in that patient’s body.

It is our contention that, although business and medical issues are important to hospice care, and indeed necessary to their success as institutions, the discourse of the psychosocial and spiritual disciplines
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are most true to hospice’s original intent and purpose. Yet, because
the medical and business concerns often predominate in hospice prac-
tice, the psychosocial and spiritual disciplines are less likely to be heard.

For example, when George received a terminal prognosis, theoreti-
cally he stopped being a “patient” and could now be perceived again
as a “person” who happened to be living out the end of his life. Moreover, as a person, he need not be singled out from his family (as
he was, to a certain degree, when he was a patient) but could be
restored to his family, once again a member of a greater whole. Indeed,
this is how hospice would profess to regard him; for ideally in hospice,
“the family is the patient.” Unfortunately, neither the language of
business nor the language of medicine facilitate George (and his family)
being perceived in that way. Both treat George, in their own ways, as
an individual: a patient in a business sense is a unit of reimbursement;
a patient in a medical sense is a disease process or a diagnosis.

Too often, the voices of the business and medical perspectives
drown out the psychosocial and spiritual voices central to hospice
care. Yet, only the psychosocial and spiritual disciplines contain the
language necessary for describing George as a person, and in the context
of his family. Our question is: Why is it that this happens so seldom?
Why is it that the psychosocial and spiritual disciplines often fail to
articulate the perspective most original to hospice?

TOWARD A FAMILY SYSTEMS APPROACH TO END-OF-LIFE CARE

A psychosocial, spiritually focused hospice service would operate quite
differently than what we fictionally described earlier in the chapter. In
team meetings, for example, if George’s status as a patient were second-
ary to the family’s status as a group living through the imminent death
of one member and the grief of the survivors, then the sequence with
which these matters were discussed would be the opposite of what is
typically practiced now.

On the other hand, our sense from working with hospice teams is
that even when the psychosocial and spiritual matters are discussed,
they are not as complete as they could be. As most commonly practiced,
they, too, tend toward assessments based on individual psychology and
personal spirituality. Thus, they still often lack a framework that enables them to speak of the family as a whole.

It is for these reasons that we are proposing family systems theory as a model for hospice end-of-life care, for all members of the hospice team. As originally conceived by Murray Bowen, family systems theory is a theory of human behavior that views the family as an emotional unit and uses systems thinking to describe the complex interactions (Kerr & Bowen, 1988) within that unit. To give just one example of how this shift in theoretical perspective can change a team’s treatment of a family, we offer this: From a family systems perspective, a death in a family is less an individual experience than an event experienced by everyone in the family. Instead of focusing just on the individual and the changes in his or her body, mind, and spirit as he or she dies, a family systems approach recognizes how each member of the family responds to this imminent loss. This approach recognizes the emotional processes of the family prior to the diagnosis, and assesses the impact of this transition on all of the persons enduring it.

FAMILY SYSTEMS THEORY AND FAMILIES WITH HISTORIES OF ADDICTION

This approach is especially needed, we believe, when offering care to families with histories of addiction. Whether the patient who comes to the hospice service is (or was) an addict, or whether there is another identified addict in the family, the addict tends to be somewhat isolated from the rest of the family. In our experience, this mimics the typical approach of substance-abuse treatment; addiction is spoken of as a disease of the family, but for the most part is treated as if it were the disease of the individual. The same is often true of hospice care.

We believe that end-of-life care and addiction treatment, seemingly two disparate fields, have much in common. Both would benefit from understanding that the family is the patient; the family is the unit of care. Both address aspects of human experience (dying, substance abuse) that carry with them a certain stigma.

When these two aspects of the human experience overlap—when the family with a history of addiction finds one of its members is dying—aspects of each are revealed that would become helpful to both, if they could learn from each other. We believe that a family systems
approach to the end-of-life care for families with histories of addiction would significantly enhance both end-of-life care and addiction treatment.

In end-of-life care, for example, a family systems approach would allow the hospice team to speak of the family as a whole, and understand how addiction affects everyone in the family, not just the identified addict. This perspective is especially important because the hospice team’s primary goal is not necessarily the “treatment” of the addicted individual but the guidance of the family through a major transition.

To return to our fictional example of George and Wilma, addiction has played a role in their lives that may not be readily apparent at first to the hospice team. As we (and the Heart of Gold hospice team) will eventually see, George has a history of alcoholism that has affected his family’s dynamics for a long time; the implications of his addiction will continue to have an effect on how he and the family behave while he is on hospice. Originally, George’s drinking brought him and Wilma together. Even though chemotherapy, radiation, and other treatments prompted him to curtail and later stop drinking (“I just don’t have the stomach for it,” George would say), the family patterns did not change. Thus Wilma’s alcohol use might also be a concern for the hospice team. Our premise is that a family systems approach would help end-of-life professionals both identify and address aspects of addiction in a family’s emotional process.

Why is it important to address histories of addiction in families under hospice care? Although no specific research has been done to identify the numbers of addicts and their families who have been served by hospice in any given year, it is more than likely that those numbers will increase. It is estimated that currently 1.7 million American adults over the age of 50 are substance dependent. This number is expected to increase to 4.4 million by 2020 (Farkas, 2008). If it is a reasonable assumption that addicts come to hospice care at rates approximately similar to the rest of the population, then hospice services can anticipate a parallel increase in the numbers of addicts they serve. It is also likely that a greater number of persons in recovery will require hospice service.

Substance-abuse treatment providers are already being advised to anticipate this increased need. One researcher describes what is to come as a “‘demographic tsunami’ that requires additional attention to issues of substance abuse and commonly occurring medical disorders” (Bartels, 2006, cited by Farkas, 2008, p. 1) as our population ages.
At the same time, there is a concern that the substance-abuse treatment community will not recognize the magnitude of the issue. For one thing, most substance-abuse treatment centers tend to be aimed at younger persons. Concern has already arisen in social work circles for the adequate assessment of substance-abuse and dependency issues in gerontological populations (Axner, 2008). Unlike younger patients, older adult substance abusers are likely to display “lifetime patterns of drug use” and/or addictive behavior (Farkas, 2008). Second, substance abuse and chemical dependence in older populations tend to be “masked by other later life medical, social, and psychological problems” (Farkas, 2008, p. 1).

Additionally, prescription drug misuse and abuse may be mis- or underassessed, even more than alcohol abuse, illegal drugs, and other addictive behaviors. We have recently seen an increase in the availability and use of both “prescription and over-the-counter pharmaceuticals to treat illness and discomfort” (Farkas, 2008, p. 5). The likelihood that these medications will be misused or abused (intentionally or unintentionally) by older adults who come to hospice service is great.

The possibility of substance use or abuse has significant implications for all hospice professionals, which we will examine in more detail in later chapters.

**FAMILY SYSTEMS THEORY AND THE HOSPICE TEAM**

Finally, we believe that family systems theory benefits hospice teams not only in better understanding the people they serve, but also in better understanding themselves. Because hospice teams are their own systems, knowledge of family systems theory in particular, and an awareness of group dynamics in general, would help hospice teams improve their functioning.

Hospice teams are comprised of persons of diverse disciplines and backgrounds who are expected to function in such a way that the care they provide together is better than the care any of them could provide alone. They operate with an understanding that their specializations are complementary; that although their professional practices overlap to some degree, each is an expert in his or her own field.

Many hospice teams also commonly experience a sense of “family.” For example, “family” is often the metaphor team members use to
describe how they do (or should) relate to each other. A family systems perspective would help a hospice team better appreciate what being a “family” might mean. Once the team members have a sense of their own personal family’s lives, they can gain a better understanding of what happens when their work “family” interacts with the families they serve on hospice.

Moreover, to some degree, in their work many hospice professionals bring to bear their own personal family experiences. This is of particular importance when hospice teams care for families with histories of addiction because many hospice professionals are themselves likely to be from families with histories of addiction (Baldisseri, 2007; Corsino, Morrow, & Wallace, 1996; Katsavdakis, Gabbard, & Athey, 2004; Smith & Seymour, 1985). In our experience, this correspondence may lead to underidentification of the presence of addiction in families and, paradoxically, overreaction to some behaviors in those families. On the one hand, there may be such familiarity with the addictive family’s dynamics that hospice professionals do not notice anything out of the ordinary. On the other hand, it becomes all the more important for hospice professionals to have a comprehensive understanding of their own experience so that they can treat others objectively.

A third dimension of this dynamic returns to how hospice professionals relate to one another as a team. All of us learn initially how to interact within a system from our families. Those whose families have histories of addiction have a different experience of what it means to be family than those who lack that history. Accordingly, the quality of teamwork depends on the family histories of those who come together to form a team.

**CONTENTS OF THIS BOOK**

The remaining chapters will elaborate on many of the concepts raised here. In chapter 2, we address appropriate adjustments in treatment (especially in medication adjustment) when there are histories of addiction in the patients (or the family members) who come under hospice care. In chapter 3, we discuss some physiological, psychological, and spiritual aspects of addiction. These chapters are by no means meant to be exhaustive. They are intended to provide a basic background within which addictive persons and their families might be better under-
stood, especially by end-of-life professionals who may not be familiar with the dynamics of addiction and its treatment.

Chapters 4 to 7 of the book address key aspects of families, addiction, caregiving, grief, and loss. Certain typical emotional processes occur in all members of the family whenever one member receives a terminal prognosis. In chapter 4, we provide key characteristics of family emotional process that may help hospice better serve families at the end of life. We consider this same situation in families with histories of addiction in chapter 5. Because our premise is that families with histories of addiction react differently than families without such histories, we will explore how the emotional processes and dynamics differ. We will introduce the concept of addiction emotional process to describe this difference in family systems’ terms. Also, we will show how the genogram can be used to depict these emotional processes.

With the admission to hospice, a partnership of caregiving begins. Providing caregiving to a dying family member presents its own challenges to the ones providing the care and to the one receiving the care. Hospice promises to expand the circle of care, beyond family and friends, to include the hospice team. As we will see in chapter 6, a systems approach appreciates what it takes to achieve this partnership.

The prospect of a death in the family creates a kind of a “clearing” within the emotional processes of that family. It offers an opportunity for things to be said that perhaps have gone unsaid; for emotions to be felt that perhaps have been suppressed or denied; and for relationships to be changed or rearranged. Many families experience an almost ominous quality during this period; as the finality of the situation becomes more apparent, a sense that this is their “last chance” arises. In families with histories of addiction, this moment amplifies dynamics that have distressed them throughout their history. The wounds of a history of abuse, neglect, or abandonment (which as we will see, are prevalent in such families) bring their own pain to what is often an already painful time. In chapter 7, we look at grief and mourning from a family systems perspective and see how it applies, in particular, to families with histories of addiction. We will show how using a systems approach might improve hospice’s bereavement care with these families.

Next, we turn our attention to the hospice team. As stated earlier, many hospice teams also consider themselves a kind of “family.” We will describe applying a systems approach to the functioning of hospice teams in chapter 8. In chapter 9, we examine how having a family with
a history of addiction can have an impact on how team members work together.

As mentioned earlier, end-of-life care and addiction treatment share certain similarities; in particular, both carry with them a sense of taboo. Perhaps this is the reason that they are not usually addressed together, as we are doing here. Certainly, both the experiences of being addicted and of coming to the end of one’s life bring with them a common experience of *shame*. In our society, there are often layers of shame that accompany a terminal prognosis, including a sense of shame over mortality as such. Matters of shame are woven throughout the fabric of addiction, its experience, and its treatment. In our final chapter we address this overlap.

Finally, in the Afterword, we review our interpretation of The 12 Steps and reflect on them in terms of how they might contribute to a deepened experience of the end of life. This book is intended not just for the members of families with histories of addiction, but for all persons—those dying, and those caring for the dying, whether as laypersons or professionals.

**SUMMARY: WHAT FAMILIES WITH HISTORIES OF ADDICTION CAN TEACH US**

In our willingness to address addiction and dying, we encourage others to speak candidly about their family histories and personal experiences with their health care providers, so that we might all give (and receive) better health care. This is especially important when it comes to end-of-life care. Health professionals who address this phase of care participate in an historic moment in a family’s life. Our goal is to improve treatment and understanding and to provide adequate theoretical bases for addressing shame and abating judgment.

Our aim is to learn as much as we can about living, caring, and loving. Families with histories of addiction can teach us not only about themselves, but also about what it means to be a *family* in general. We believe that persons in recovery teach us not just about what it takes to recover from addiction, but also, perhaps, what it is to face one’s own mortality, and thus to make the most of the last chapter of one’s life. Of course, from everyone hospice serves, we learn what it means to participate in the human family.
REFERENCES


