Chapter 1

Commitment, Relationship, Voice: Cornerstones for an Ethics of Long-Term Care

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The lifelong task of forming a meaningful life story continues for those in long-term care, even when others must help in crafting the narrative. Whether or not they have chosen to enter residential care, persons living in nursing homes face many medical and “everyday” decisions (Caplan, 1990; Powers, 2001) that can affect how the continuity of the self is perceived. Decision-making may be complex even when residents are able to express their wishes clearly. However, staff members often must grapple with the basic question of whether or not the care receivers have decision-making capacity. Integral to this concern is the question of how to “hear” the voices of residents when they may no longer be able to tell their own stories. This chapter describes an education program developed to guide nursing home caregivers through an ethical reasoning process based on the commitments made to care recipients within the relational and narrative contexts of care in nursing homes. Among those tasks is working with care receivers whose decision-making capacity is compromised.
AUTONOMY AND DECISION-MAKING CAPACITY IN LONG-TERM CARE

Autonomy, imported into the long-term care setting from acute care, has had an evolving adaptation to the demands of long-term care. Except in situations in which the move to long-term care is clearly temporary, the long-term care setting becomes “home” to a resident, however well or poorly it fills that role and whether or not the resident had wanted or chosen to move (Laird, 1979; Reinardy, 1995; Tulloch, 1975). Because residents live in a community of residents and staff, because staff have responsibility for meeting residents’ sustained medical, instrumental, and personal care needs, and because there often are nonmedical decisions that residents face, the principle of self-determination frequently requires modification. Interpreted as noninterference, adherence to autonomy may cause residents to be left on their own when they most need guidance. If autonomy is accorded secondary status in favor of beneficence, care receivers may be denied the opportunities to make choices that are consistent with their own sense of identity (Tulloch, 1990).

Elaborations of autonomy designed to navigate these tensions and to integrate the principles of respect for residents’ values within the interdependent context of long-term care include “negotiated consent” (Moody, 1988) and defining “polarities” of autonomy (Collopy, 1988). In much of the literature devoted to reconsideration of autonomy within the context of residential care, the role of a person’s life story, as expressed in the person’s values and previous choices, has a central place.

Staff in long-term care settings who try to discern the values of residents who cannot speak clearly for themselves encounter several complex variables in the decisional process. Residents may have outlived the persons in their lives who cared for them and may not have anyone other than staff who knows them at all, or they may have always been alone (Karp & Wood, 2003). Staff members may not understand the decision-specific nature of capacity, and global assumptions may be made about the ability to choose that are unwarranted. Contextual variables such as real or perceived regulatory constraints (Kapp, 1998), the mission and values of the particular institution, the degree to which staff members understand differing cultural values and the individual’s adherence to those values (Braun, Pietsch, & Blanchette, 2000; Hyun, 2002), and staff members’ roles and attitudes (Mullins, Moody, Colquitt, Mattiasson, & Andersson, 1998) may affect the decision-making process. Families of residents may have markedly disparate views of each others’ roles and of their right to speak for residents, and family caregivers may have experienced concerns in the resident’s move from community-based to residential care (Dellasega & Nolan, 1997; Kellett, 1999). Institutions may have more or less elastic views of what is encompassed in the surrogate role and may defer all decisions, even those residents could make, to family members (Kapp, 1998).
PROMISES TO KEEP: CREATING AN ETHICAL CULTURE FOR LONG-TERM CARE

Given the inherent uncertainties in the responsibility to heed the residents’ narrative, staff members need the opportunity to build ethical reasoning skills. Promises to Keep: Creating an Ethical Culture for Long-Term Care, an ethics education program developed by the Center for Advocacy for the Rights and Interests of the Elderly (CARIE), offers a framework and decision-making process for guiding and improving ethical decision-making in long-term care.

Since 1999, CARIE has presented ethics education programs to long-term care providers across Pennsylvania. As initially designed, the programs introduced participants to the ethical framework referred to as “principlism” (Beauchamp & Childress, 1993; Clouser & Gert, 1990) and encouraged them to use this approach to resolve ethical dilemmas presented as case studies and vignettes. We observed, however, that it often seemed that a part of the case story could not be brought within the principlist framework. As we repeatedly witnessed program participants struggle to resolve ethical dilemmas by applying the standard four biomedical principles, we became convinced that what was needed was a new ethical framework that captured the special ethical nature and challenges of long-term care, as well as a process for making ethical decisions regarding care issues as they arise in the long-term care setting. The lack of comprehensive ethics education programs for long-term-care providers and the inadequacy of the prevailing biomedical ethics model were behind our efforts to develop a curriculum focused exclusively on the substance and process of ethical decision-making in long-term care.

Care Within the Long-Term Care Context

Most thinking about clinical biomedical ethics has taken place within the context of acute care medicine (Collopy, Boyle, & Jennings, 1991). The nature and concerns of long-term care, however, are profoundly different from those of acute care. For example, whereas acute care focuses primarily on discrete physical problems, long-term care involves the “global” well-being of the resident, including emotional, spiritual, psychological, and social well-being, in addition to physical health. Moreover, in acute care the exclusivity of the doctor–patient relationship historically has been sacrosanct. In long-term care, the resident is understood to exist within a web of valued relationships with family members, friends, and staff, relationships that may be supported and strengthened by encouraging inclusion in rather than exclusion from care. Also, acute care encounters between physicians and patients are, for the most part, episodic and focused on the provision of medical care. Depending on a person’s health care needs, one might see a particular doctor regularly for a period of time, not see a particular physician for months or even years at a time, or may have only a single consultation. Long-term care, in
contrast, is continuous and ongoing. Within the prevailing medical ethics paradigm, the relationship between doctor and patient is conceptualized as one between independent and autonomous agents. The reality of long-term care, however, is quite different. Care recipients most often have physical dependencies and/or suffer from dementing illness. In facility-based care, the experience of dependency is magnified by the sheer variety of ways in which the quality of a resident’s daily life is reliant upon facility staff. Finally, in acute care, at least traditionally, the interests of individual patients do not compete with each other; rather, the physician’s ethical obligation to each patient is discrete. In long-term care, residents’ ethical claims can be, and regularly are, in tension with one another. When we considered the fundamental differences between the experience and goals of acute care and those of long-term care, it became evident that the prevailing bioethical model, developed to reflect the values and obligations within acute care, was inadequate to address the ethical issues confronting staff working in long-term care.

We believed that, to succeed in developing an ethical framework that more accurately reflects the reality and scope of the ethical issues entailed in providing long-term care, we needed to have long-term care providers tell us directly about their actual responsibilities. We began asking the participants in CARIE’s long-term care ethics education program to identify what they understood their duties to residents to be. More specifically, we asked the following question: When a long-term care facility opens its doors and, in effect, invites an elder to come live there, what responsibilities have the facility and its staff assumed with respect to that elder? Not surprisingly, the providers came forward with literally scores of such responsibilities. Long-term caregivers’ descriptive accounts of their responsibilities were integrated with CARIE’s concerns and experience as an elder advocacy agency and discussions of the normative values in long-term care contained in the literature. The result is *Promises to Keep: Creating an Ethical Culture in Long-Term Care*, an ethics education curriculum that proposes commitment to the resident as the ethical basis of the long-term care endeavor.

**Description of the Curriculum: The Five Commitments of Long-Term Care**

As we studied the array of responsibilities identified by long-term care providers, we noticed that they fell naturally within five overarching themes: health, safety, pain and suffering, respect for personhood, and life story. We then framed each of these themes as a commitment that the long-term care provider makes to the care recipient. These are commitments to (1) preserve and promote the resident’s health, (2) protect the resident’s safety, (3) palliate the resident’s pain and suffering, (4) practice respect and care for the attributes of personhood, and (5) provide opportunity and support for the continuation and completion of the resident’s life story. An ethical long-term care decision is one that honors these commitments. The most ethical decision is one that honors the five commitments most fully, whether the
subject matter is life-sustaining treatment or bathing. Thus, these commitments both describe the ethical nature and content of long-term care and provide a framework for making ethical care decisions.

To identify the above as the five commitments of long-term care is not to say that they necessarily define the entire universe of ethical obligations in the provision of care. Long-term care staff bring the whole of their humanity and experience through the door of the facility. The five commitments of long-term care are not in lieu of the ethical obligations we have to one another as fellow human beings. They articulate the special obligations that we assume when we choose to take on the special task of providing long-term care for another.

Of the five commitments comprising the ethical framework for long-term care, the commitments to preserve and promote the resident’s health, protect safety, and palliate pain are clinical in nature. Fulfilling these commitments requires clinical training, skill, judgment, and attention to best practice models. To honor these commitments, long-term care staff must have available the human and material resources necessary to meet residents’ clinical needs.

There are a multitude of avenues for obtaining education and training on clinical issues, and it is not a purpose of Promises to Keep to provide such training. Yet there are important ethical dimensions within these issues that are specific to long-term settings and that we discuss within the program. For example, within the context of long-term care, the preservation and promotion of health have a different emphasis and different goal than they might in the world of acute care. By and large, those receiving long-term care suffer with chronic illnesses such as diabetes, arthritis, Parkinson’s disease, cancer, congestive heart failure, chronic obstructive pulmonary disease, and/or dementia. Health in these circumstances relates more to the maximization of functional ability than to resolving the underlying condition or disease. In honoring a commitment to preserve and promote the health of the resident, therefore, we may be focusing our efforts on how disease and its various treatment options will affect residents’ ability to participate actively in their lives in the nursing home.

Whereas the preservation and promotion of health are concerned with addressing bodily processes, the commitment to protect the resident’s safety addresses the resident’s interaction with the external environment. How can the environment of the long-term care setting, human as well as physical, be created and/or arranged to provide a safe place for the care recipient to live? The commitment to protect a care recipient’s safety often is experienced as being in tension with one or all of the other four commitments. Honoring the commitment to enhance a resident’s functioning (e.g., mobility) may increase the risk of injury compared with encouraging the person to stay seated as much as possible. Similarly, protecting a resident’s safety may seem to conflict with practicing care and respect for the resident’s personhood or life story. Even adequate pain management may be viewed as incompatible with a concern for the resident’s safety. The dilemma posed by a tension between ethical commitments is irreconcilable only if one views such dilemmas
as requiring yes-or-no, this-or-that solutions. In fact, the dilemmas that arise in long-term care rarely require, or are even susceptible to, such dichotomous solutions. This will be explored more fully in the discussion below of the IDEAS for Ethical Decision-Making in Long-Term care decisional model.

The third commitment addresses the palliation of pain and suffering for the recipient of long-term care. Although “pain” and “suffering” often are referred to as if they were a single experience, they in fact are distinct and separable (Randall & Downie, 1999). One may have great pain and yet not suffer, or one may have no pain at all and yet suffer deeply. Although pain is a physical symptom, suffering is emotional and spiritual in nature. The almost universal response to pain is to seek its reduction or, if possible, elimination, but those who suffer may seek to find meaning within the experience of suffering itself (Engelhardt, 2000). Honoring a commitment to palliate a resident’s pain and suffering requires that we be alert to the differences between the two, that we identify the most appropriate person to provide care (e.g., a physician, nurse, chaplain, social worker, psychiatrist, or psychologist), and that we acknowledge the need for effective intervention in response to these subjective feeling states as much as in response to more observable or measurable symptoms.

The last two commitments are not clinical in nature. They involve the concepts of personhood and life story, about which much has been written but which remain, despite or as a result of efforts to define them, somewhat elusive. We explore these commitments in greater depth in order to clarify their meaning within the framework we have developed.

**Practicing Respect and Care for the Attributes of Personhood**

The commitment to practice care and respect for the attributes of personhood in the resident does not entail assessing whether the resident “qualifies” as a person. It simply calls for honoring, encouraging, and supporting in the resident the qualities that are associated with personhood and, where appropriate, deferring to their expression by the resident. Stated otherwise, fulfilling this commitment involves giving deference (respect) to the resident’s exercise of the qualities of personhood when the resident is capable of exercising those qualities and giving support and encouragement (care) when the resident’s ability to express such attributes independently is impaired. The extent to which the resident possesses such attributes is not at issue, nor are any legal or ethical rights or privileges at stake.

What are these “attributes of personhood”? Within the long-term care ethics framework, they include not only cognitive qualities (self-awareness, intentionality, decision-making, agency) but noncognitive qualities as well (emotions, relationship, creativity). These qualities will be discussed individually.

**Self-awareness** (“I am aware that there is a me”) is the recognition of one’s own existence as separate and distinct from other individuals. It is the recognition that I am not you and that I hold beliefs and feelings that are my own. I am aware of my experiences, including my emotions and intentions. It is because I am aware of
myself in this way that I experience such feelings as pride, embarrassment, shyness, and shame. Respecting the attribute of self-awareness in another calls for recognizing and affirming that the other person possesses ideas, feelings, and experiences that are distinct, and possibly different, from one’s own.

For some long-term residents, dementing illness has impaired the ability to be self-aware in this way. Nonetheless, we express care for the inherent individuality of such residents when we respect their privacy, maintain confidences, are attentive to their personal needs and belongings, and ensure a sense of their dignity.

**Intentionality** ("I can think about what I want to do") is the ability to formulate purposes rather than behave purely instinctually. Practicing care and respect for resident intentionality involves identifying, acknowledging, and/or supporting the resident’s purposes or designs. In some cases, the resident will be able to articulate those intentions. In other cases, we must learn to assist residents in their formulation, as well as appreciate and respond to nonverbal expressions of intentions.

**Decision-making** ("I can decide what I want to do") is the process of considering the possible ways of accomplishing one’s intentions and making a choice among them. When a resident has the capacity required for a particular decision, a commitment to practicing care and respect for personhood often involves providing education (Engelhardt, 2000) to promote informed decision-making and then deferring to the resident’s decision whenever possible. When a resident’s decisional capacity is impaired, practicing care and respect for personhood means providing support for the exercise of the person’s residual capacity for decision-making. This might involve listening to help identify the problem (Engelhardt, 2000), simplifying options, exploring with the resident possible choices, selecting a particular time of day for discussing the matter, and choosing language that will be more easily understood.

**Agency** ("I can make it happen") refers to the capacity to initiate action. To say that we exercise agency means that we have the capacity to act in accordance with our intentions and decisions rather than be acted upon. I am exercising agency when I effectuate a decision on my own; I am also exercising agency when I invite someone to help me effectuate it. To fulfill a commitment to respect and care for the resident’s personhood requires recognizing residents as actors in themselves rather than as objects of others’ actions. Honoring this commitment, we do not set up impediments to residents’ acting in furtherance of their own intentions and decisions. Beyond that, we make available to residents the means and opportunity for executing their own decisions. When needed, we provide assistance to residents in carrying out their intentions and decisions, not those of their caregivers. Respect and care for the agency of residents means refraining from acting upon them in ways not consonant with their own purposes or decisions.

How are the attributes of personhood manifested in everyday life in a nursing home? The following vignette is a simple example: It is two o’clock in the afternoon, and Mrs. Smith is sitting in her room. She is aware that she is feeling lonely and bored. She forms an intention to get out and find some other people with
whom to talk. She considers several possibilities. She could go out to the common area and watch TV, she could join in the cooking class, or she could play bingo. She decides to join the cooking class. She walks down the hall to the kitchen if she is able, or she asks for help in getting herself there. Again, it would not be demonstrating respect for Mrs. Smith’s personhood for someone to come in and tell her that she is going to the cooking class and then take her there in her wheelchair when she has neither formulated the intention nor made the decision to go.

Although philosophers’ definitions of a “person” usually stress cognitive abilities, our experience makes us keenly aware that a whole person is comprised of more than intellect. We are emotional and creative beings essentially connected to one another through relationships. Thus, honoring a commitment to respect and care for the personhood of a resident also requires being sensitive to, and empathetically responding to, the resident’s feelings. It means respecting and protecting the relationships that the resident brings into long-term care as well as the relationships formed within the long-term care setting, both with care providers and with other residents. It calls for providing opportunities for creative expression and experience and giving recognition to such efforts.

Providing Opportunity and Support for the Continuation and Completion of the Resident’s Life Story

Why do people of all ages, by significant margins, cite nursing homes as the least preferred place to die (George H. Gallup International Institute, 1997)? Part of the answer no doubt lies in a belief by many that the move to a nursing home signals the end of one’s biographical life before one’s biological life has concluded, a distinction made by the philosopher James Rachels (Meilaender, 1995). In other words, for many, living in a nursing home represents the end of one’s individual life story even while one’s body continues to live. But surely this need not be the case. For each individual requiring long-term care, entering a nursing home is a chapter in a particular, unique, and ongoing life story. In order to understand and care for that person, we must know the life that we now are entering and of which we are necessarily becoming a part. We must ask, Who is this person? and must listen for the answer.

Too often, most of the information we have about a resident comes from sources other than the resident. Medical records, admissions forms, and information from family members often are the basis for our knowledge of the resident’s “history,” which we accept as the account of who that person has been and is now. However, each of these narrative sources speaks in a voice that is its own, reflecting its own viewpoint, concerns, even biases. To care well for the person in front of us requires that we know that person not just through the prism of others’ eyes but, much more importantly, through the person’s own perspective.

The awareness, sharing, and acknowledgment of one’s life story hold great value for any individual. Many of us spend a great deal of time engaged in giving and
receiving parts of our own and others’ stories. As explored below, this value is magnified for those who live within the context of long-term care. Bringing the resident’s own narrative into the long-term care setting is critical to the continuation of that life story in the following ways.

(a) Maintain Self-Identity

Our life story is how we know ourselves and locate ourselves with respect to the world and the people around us. Imagine, for example, that you were to awaken one morning with total amnesia about everything that had happened to you before you awoke. You have apparently suffered no injury and have the physical ability to go about your life much as you wish. How would you know what to do next? Where would you go? You would be desperate to know, Who am I?, to find the answers to such questions as, Where do I live?, Do I have a family?, and Where do I work? In short, you would be desperate to get your story back in order that you might know who you are.

The move to a nursing home often deals a profound blow to the resident’s sense of self. Literally, the person’s place in the world changes. The resident’s relationships to those people and things that gave life meaning and shape, perhaps for decades, such as home, possessions, routines, and relationships with neighbors and others in the community, disappear or are dramatically altered. Encouraging residents to tell their stories, the stories that preceded and include the move to the nursing home, provides an opportunity over time for the creation of coherence out of what may initially feel like a story, and an identity, that is irreparably fractured. It permits the revisioning of the resident’s story as a single continuing life.

Illuminates Meanings

The events and choices of our lives derive their meaning from the way they fit together with what has gone before. For example, take the statement John is walking through the park. Now suppose you are told that John’s wife left him 10 days ago. He has lost weight, his eyes are red-rimmed, and his clothes are rumpled. It is 10:00 in the morning, and there are three businessmen who had a 9:30 appointment with him sitting in his office, but John is not going to his office. He is walking through the park. In the context of this story, we give a particular meaning to the fact that John is walking through the park. Now suppose that you are told instead that 18 months ago John was in a terrible car accident. He was in a coma for 4 days. After 5 weeks in the hospital, he was moved to a rehabilitation facility, where he lived for eight months. It is 10:00 on a Wednesday morning, and John is walking through the park. The identical fact takes on a completely different meaning when we are aware of the story of which it is a part.

In order to know what something as seemingly simple as a walk in the park means to John, we need to know John’s story. In the same way, we need to know a resident’s story in order to know what the meaning of a particular decision is for him or her. What will it mean for Mrs. Logan to use a wheelchair? What will it
mean to Mr. O’Malley to eat alone? How shall we understand Mrs. Jefferson’s anger? What meaning does life-sustaining treatment have for Mr. Geffin? The meaning of any of these decisions for the care recipient can only be understood if we know the story of which it is becoming the newest chapter.

**Individualize the Resident**

Charts and protocols are absolutely essential for identifying critical data, organizing them in an efficient and useful way, and responding with efficiency and consistency to care issues. They permit standardization of practice. Charting calls for communicating information about a resident in a particular voice, one that is professional and objective. Protocols are a way of recognizing what situations or cases have in common and responding in established, effective ways. Both are an integral part of providing good and efficient care, especially when time is the resource most at a premium. In the face of incentives to create commonalities, it is the particular facts of a resident’s life that keep that person’s individuality foremost and make that person’s “case” unique. It is what enables us to recognize how Mrs. Lopez’s wandering may be different from Mrs. Lyons’, how Mr. Caruso’s depression is different from Mrs. Hartley’s. Learning the resident’s story is a counterbalance to the tendency to see only what we have seen before and therefore expect to see again, our tendency to recognize the general similarities among care recipients but to miss the specific differences.

**Guides Decision-Making**

In situations in which a resident lacks the capacity to make care decisions and decisions must be made by surrogates or, in some cases, care providers, knowledge of the resident’s story can be of great help in making a decision that gives coherence to the person’s story and carries the story forward in a way that makes sense. Knowing the resident’s life story gives us a window through which we may discern the values, people, and things that were important to that person. Knowing a resident’s past choices about how to live can guide those who now must decide in the person’s stead. It permits decision-making that is consistent with the resident’s previously lived values, with the resident’s “ways.” It expands our ability to take the resident’s perspective, to discern the choice that person would have made himself were he able.

**Create Social Connection**

The value of learning a resident’s life story lies not only in the information that is imparted but in the communication of the story itself. The act of listening as residents tell their stories, not just at one sitting but over time, creates relationships and social connections. The experience of being listened to as one recounts one’s own story can be one of deep sharing. This storytelling may call forth reactions and responses from the listener, who may then share parts of his or her own life. The
Commitment, Relationship, Voice

forming of a relationship in this way offers an antidote to the isolation that often accompanies the experience of receiving long-term care.

Help Sustain Memory
The process of reminiscing can be an aid to memory. Accurate prompts, observations, questions, and comments from the listener may elicit further memories, reinforcing residents’ experiences of their own stories and focusing on pleasurable recollections that are relatively preserved and enhance their sense of satisfaction and connectedness.

Encourage Feelings of Empathy, Compassion, and Understanding.
In hearing a resident’s life story, the challenges overcome, ways in which the person cared for others, ambitions that went unrealized, events that gave pleasure, and times that brought sadness, our own emotions are engaged. We may be able to identify having feelings similar to that person’s and may have confronted some of the same challenges. Our differences may diminish, and the ways we are alike become apparent. We gain understanding, empathy, and compassion.

Ought Implies Can
Too common in long-term care is the situation of the “unbefriended” resident suffering with dementia. These residents lack both the capacity to make decisions for themselves and a relative or friend who knows them well enough to make decisions that reflect what their own choices would have been. How do long-term care providers honor their commitments under such circumstances?

A widely accepted precept of ethics is that “ought implies can.” In other words, saying that we ought to do something presumes that it actually is possible for us to do it. For example, it makes no sense to say that as a long-term care provider I have a personal moral obligation to cure Mr. Moore’s multiple sclerosis. Very simply, I cannot do that. However, I surely do have an obligation to provide him with the best and most complete care that I can.

In the same way, with regard to the ethical framework discussed herein, the impossibility of fulfilling a particular commitment may relieve us of the moral obligation to do so. For instance, we cannot provide opportunity and support for the continuation and completion of the resident’s life story if we have no way of learning the story as the resident would have wanted it told. It may not be possible to fulfill a commitment to respect a resident’s decisions if the resident lacks decision-making capacity. When faced with a commitment it is impossible to honor, we continue to be bound by our remaining commitments, including the preservation and promotion of health, protection of safety, and palliation of pain and suffering. It is essential, however, that “impossible” not be used to mean expensive, inconvenient, time-consuming, or problematic.
IDEAS for Ethical Decision-Making in Long-Term Care

The five commitments of long-term care set forth above describe the ethical foundation of long-term care. Having been derived from the responsibilities that long-term care providers identify as those they bear toward care receivers, they reflect the substance of ethical long-term care as actually practiced and lived by staff daily in the care they provide. Every so often, however, a situation arises in which it is unclear how best to fulfill these commitments. CARIE has developed a five-step process called IDEAS for Ethical Decision-Making in Long-Term Care (IDEAS) for working through such care dilemmas to reach ethical solutions. IDEAS constitutes a companion piece to the ethical framework described above.

Each letter in the word IDEAS stands for a step in the decision-making process. These steps are (1) identify the ultimate issue(s) to be decided, stakeholders and their interests, and other decision points; (2) develop a resident narrative; (3) explore all conceivable responses to the issue; (4) assess each response in light of providers’ commitments to recipients of long-term care; and (5) select a course of action and create an implementation plan.

Step 1. Identify the Ultimate Issue(s) to Be Decided, Stakeholders and Their Interests, and Other Decision Points

It often is the case in discussions about ethics that one issue seems to raise a host of related issues. Such discussions often have great value in terms of unearthing concerns as well as expanding the understanding of the original problem and yielding insights about its solution. Nonetheless, one can lose sight of the original questions as these ancillary issues emerge. Clearly identifying the decision that ultimately needs to be made focuses and, when necessary, refocuses the ethical analysis on the resolution of the original dilemma.

Although the IDEAS process is resident-centered, that is, possible responses to the issue are evaluated in terms of how well they fulfill the long-term care provider’s commitments to the resident, any resolution of the care dilemma must take into account the concerns of others who have significant interests at stake. Step 1 of the process goes beyond identifying just the immediate behavior issue or treatment choice for which an ethical solution is being sought. It includes identifying other stakeholders, those people whose interests are affected by the issue being addressed and who will be affected by its resolution, and the specific interests they have in the matter. By identifying each of these stakeholder interests, Step 1 of the process more fully sets out the issues that need to be addressed. A complete elaboration of the problem is essential for framing an adequate solution. A response that addresses the interests of the resident but does not respond to the concerns of the family and/or staff in some way (e.g., with education, counseling, or the use of alternative dispute resolution resources) will not be a complete resolution of the problem.

Decision points are those determinations that need to be made before the ultimate issue can be fully addressed. For example, before a care issue can be fully
Commitment, Relationship, Voice

considered, it might be necessary to consult with a psychologist or psychiatrist to determine the resident’s decisional capacity (Does the person have the ability to make this decision?), with a speech therapist to obtain a swallowing evaluation (Is a feeding tube necessary for adequate nutrition?), or with a physical therapist to assess the resident’s physical functioning (Is walking safe? Is a wheelchair needed?).

**Step 2. Develop a Resident Narrative**

Step 2 incorporates the commitment to provide opportunity and support for the continuation and completion of the resident’s life story into the decision-making process. As previously discussed, our life stories are how we know ourselves. The story we claim as ours both forms and reflects our sense of our own identity. Conversely, what we know or do not know of someone else’s life story colors our expectations, feelings, judgments, and understanding of that person. The truer our knowledge of another’s story is, the closer our expectations, feelings, judgments, and understandings of the person will mirror the person’s own perceptions.

In order to be able to make the “right” decision for a particular resident it is necessary to appreciate the impact of the decision for that individual. Does a particular care decision make sense in light of the resident’s life story? Does it support the resident’s self-identity or threaten and perhaps even undermine it? The resident’s first-person account is central to the resident narrative. Such stories may be learned over time by eliciting and listening to the usual information about family and personal history, then going beyond that information to (1) ask questions that prompt the residents to reflect upon his or her life if he or she is able to do so (Why do people like you? What are you most proud of in yourself? In your life? What was the favorite time of your life?); (2) initiate conversations that encourage the resident to share parts of his and her past (What jobs did you have? What vacations did you enjoy?); (3) inquire about the meaning attached to precious objects, photos, special songs, particular activities, favorite foods, holidays, or special rituals; and (4) explore what age and illness or disability mean to the resident and what the resident’s hopes are for the future. The resident’s story can be shared orally and also may be expressed through writing, including a values history or advance directive, and by behavior communicating the person’s likes, dislikes, pleasure, pain, and so forth. All of these accounts should have a place in the resident’s chart. Some residents are no longer able to share their stories themselves; for them, it is not possible to develop a personal resident narrative. Even when it is possible, there may remain information that the resident simply does not have or cannot provide. Third-party information, such as medical and psychiatric history, the full psychosocial history, and anecdotal information from family and others within and outside the facility, is essential in making good care decisions but does not supplant the resident’s own account.

**Step 3. Explore All Possible Responses to the Issue**

Step 3 calls upon decision-makers’ creative energies in the form of brainstorming. Addressing the issues identified in Step 1, caregivers use imagination and the data
gathered in Step 2. To encourage inventive approaches, at this stage no offered response should be excluded and the ideas generated should be accepted uncritically. Anything that can contribute to the resolution of the issue is an appropriate suggestion at this stage. Evaluation of the possible responses will take place in Step 4.

**Step 4. Assess Each Response in Terms of Providers’ Commitments to Recipients of Long-Term Care**

In Step 4 of the IDEAS process, decision-makers evaluate the array of possible responses developed in Step 3. Each possible choice is evaluated in light of (1) how effectively it fulfills the commitments to the resident, (2) whether it violates a commitment made to the resident, and (3) how well it can be integrated into a plan of action. Although the five commitments provide the framework for assessing how well the generated care options meet care providers’ ethical obligations, good ethical decisions ultimately depend on the good judgment and good will of the decision-maker(s). How the various possible responses are ultimately weighed and evaluated lies with those charged with the care decision.

**Step 5. Select a Course of Action**

Based on the assessment of how best to fulfill the commitments of long-term care in light of the possible care options, a course of action is developed to address the ultimate issue identified in Step 1. Rarely does the best solution to a care dilemma in long-term care consist of a single act. One of the contributions of the *Promises to Keep* program is to encourage the consideration of the full panoply of possible responses to an issue, from which a comprehensive course of action may be derived. The course of action that is developed should include not only those measures that meet the commitments to the resident, but also steps that address the concerns of other stakeholders whose interests will be affected by the course of action. Such steps may include education of staff and family members, grief counseling, efforts at alternative dispute resolution such as mediation, and innovative ways of including family in the plan of care.

There also should be follow-up to evaluate how well the course of action actually addresses the issue. A record that respects the confidentiality of the resident (and complies with relevant provisions of the Health Insurance Portability and Accountability Act) should be kept of the original issue, decisions made, course of action that was implemented, and evaluation of the results. Over time, these records will develop as a resource to guide future ethical problem solving.

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**EVALUATION**

The ethics education curriculum has evolved as our thinking has evolved and as we reviewed and considered participants’ evaluation of the program. In 2003, we presented the first 1-day program based on the five commitments of long-term care
framework and the IDEAS decision-making process. The training includes an overview of applied ethics, introduces participants to CARIE’s ethical framework for long-term care, and affords the participants opportunities to practice applying the IDEAS decision-making process to ethical care dilemmas. The highly participatory training approach emphasizes the identification of ethical care dilemmas in everyday practice and the application of systematic ethical reasoning to analyze and resolve issues. Participants receive comprehensive written materials and practical tools to support their use of the IDEAS framework in their home facilities following the training.

The two principal foci of the evaluation are the participants’ ethical reasoning capabilities and their intended and actual behavior change following the 1–day session. In this chapter, we have confined our discussion to aggregated responses from evaluations conducted in April, May, and June 2003. Selected evaluation items discussed in this chapter include participants’ (1) perceptions of the most frequent and troubling ethical care dilemmas in long-term care, (2) confidence in their ethical reasoning capabilities, (3) practice changes in the home setting following training, and (4) perceptions about ethics training needs in their home facilities.

Ethical Care Dilemmas in Long-Term Care

One of our key training goals is to increase care providers’ recognition of ethical care dilemmas in long-term care settings, with particular emphasis on everyday issues that might go unnoticed or, if detected, generally elicit a standardized response in lieu of a resident-centered approach. In our pretraining survey, we asked participants how frequently they encountered ethical care dilemmas in their settings. Their responses indicated that ethical care issues were detected somewhat infrequently. As depicted in Table 1.1, the most frequent response was “more than once a year but less than monthly.” Viewed cumulatively, slightly greater than half of the respondents (64%) reported that ethical dilemmas occurred monthly or less often.

Table 1.1
Frequency With Which Ethical Dilemmas are Encountered (Pretraining Baseline)

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Number (n = 75)</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Once or twice a year</td>
<td>8</td>
<td>12</td>
</tr>
<tr>
<td>More than once a year but less than monthly</td>
<td>25</td>
<td>36</td>
</tr>
<tr>
<td>Once a month</td>
<td>11</td>
<td>16</td>
</tr>
<tr>
<td>2–3 times a month</td>
<td>9</td>
<td>13</td>
</tr>
<tr>
<td>Once a week</td>
<td>6</td>
<td>8</td>
</tr>
<tr>
<td>More than once a week but not daily</td>
<td>11</td>
<td>16</td>
</tr>
<tr>
<td>Daily</td>
<td>5</td>
<td>7</td>
</tr>
</tbody>
</table>
Types of Dilemmas Encountered

In the earliest CARIE-sponsored ethics education sessions, we presented participants with an open-ended item about the types of dilemmas they encountered most frequently in long-term care. Analysis of the responses led to identification of six categories of ethical care dilemmas in long-term care. These are (1) advance directives, (2) decision-making/resident capacity, (3) decision-making/surrogacy, (4) end-of-life issues, (5) resident behavior, and (6) facility resources. These categories provided the basis for current rank-order evaluation items. As depicted in Table 1.2, resident behavior received the greatest number of rankings as the most frequently occurring care dilemma, followed by advance directives and issues concerning resident capacity for decision-making. The greatest number of respondents (n = 60) ranked decision-making/resident capacity as either first, second, or third, followed by resident behavior (n = 56). Facility resources received the fewest rankings in any category.

Most Troubling Ethical Care Dilemmas

We also were interested in the care dilemmas that participants perceived as most troubling. Using the same categories, we asked participants to identify a single category that they found “most troubling or difficult” and to provide an example. Table 1.3 illustrates the findings. As depicted, 37% indicated that resident behavior was most troubling. Although end-of-life issues reportedly occurred less frequently than decision-making/resident capacity issues, they were reported to be more troubling.

Forty-six participants responded to the question, Can you briefly describe a recent example and what it is about this issue that makes it most troubling for you? A number cited examples of residents’ “acting out,” “aggressiveness,” and “difficult behaviors,” illustrating the challenges of providing everyday care. For example, a participant wrote about “a female resident with dementia and physical aggression behavior toward others. Some people in the facility feel she should be discharged, whereas others feel her plan of care can/should be improved. . . .”
Another participant related an incident in which the resident’s behavior raised issues concerning the ethical use of restraints:

A resident . . . was combative during care to the point where he would hurt himself or others . . . . The resident’s behavior was fine at other times. (The) problem arose with type of restraints needed for the safety of the resident and staff—chemical vs. physical. Chemical would affect the resident [over the] long term and physical would only be used for short periods to complete care . . . .

Others provided examples of difficult end-of-life care issues, typically involving the intricacies of communication and challenges when residents who are approaching death cannot express their wishes:

A male resident was admitted for terminal care . . . in a comatose state . . . admitted to be kept comfortable. Not able to decide on CPR [cardiopulmonary resuscitation]/no CPR due to his comatose state and he had no durable power of attorney . . . multiple children to different spouses . . . currently married to a woman who has no ability to say no CPR but wants him kept comfortable only. When his condition deteriorated, we were forced to transfer to the hospital.

Another offered an example that depicts the frequently encountered tensions between promoting residents’ health, palliation of pain and suffering, and protecting residents’ safety at the end-of-life:

The resident’s family decided not to amputate his gangrenous foot. The difficulty for me arises related to complications . . . sepsis, etc. [Other issues include] the quality of the resident’s remaining life, pain management, and the family’s questionable motivation . . . the family refuses to accept hospice services. The difficulty is related to the resident and family not getting the best service they can.

**Building Skills in Ethical Decision-Making**

Another of our training goals was to increase participants’ self-confidence and ability in ethical reasoning. To measure changes in confidence levels, we created

### Table 1.3

**Most Troubling Ethical Care Dilemmas in Long-Term Care**

<table>
<thead>
<tr>
<th>Care Dilemma</th>
<th>Number ($N = 70$)</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advance directives</td>
<td>8</td>
<td>11.4</td>
</tr>
<tr>
<td>Decision-making/resident capacity</td>
<td>8</td>
<td>11.4</td>
</tr>
<tr>
<td>Decision-making/surrogacy</td>
<td>10</td>
<td>14.3</td>
</tr>
<tr>
<td>End-of-life</td>
<td>15</td>
<td>21.4</td>
</tr>
<tr>
<td>Resident behavior</td>
<td>26</td>
<td>37.1</td>
</tr>
<tr>
<td>Facility resources</td>
<td>3</td>
<td>4.3</td>
</tr>
</tbody>
</table>
an instrument using self-reported, serial ratings of confidence on 21 items before and after training. Participants were asked to rate “confidence in your ability to carry out each element, both before and at the completion of the training” on a 0–10 Likert-type scale (0 representing “not at all confident” and 10 representing “completely confident”). The 21 items represent critical elements of ethical problem solving in long-term care facilities that were derived from prior qualitative data and the components of the IDEAS process. Examples of items included in the Confidence Inventory are displayed in Table 1.4.

Our early work with this instrument’s development included psychometric testing. We performed factor analysis using Varimax rotation with Kaiser normalization. Items loaded on three principal factors. Reliability of each of the three factors was high (Cronbach’s alpha = .9434, .9701, and .8347, respectively for factors 1, 2, and 3). Using this factor solution, we calculated respondent subscores for each of the three factors. We then compared mean pre- and posttraining subscores using the paired samples t-test. Mean postscores for each of the three subscales were significantly higher than mean prescores (p = .000), suggesting that participants’ confidence in their ethical reasoning capabilities increased through participation in the ethics training.

**Follow-Up Surveys**

Our third goal was to effect sustainable, individual behavior change after the education program. To evaluate posttraining behavior changes, we mailed follow-up
surveys at 3 months posttraining. We included parallel items from the pretraining survey, such as frequency of ethical care dilemmas, in addition to items evaluating use of the IDEAS process and related concepts in the home facility following training. We also asked respondents to share their perception of the need for staff training about ethical care dilemmas in their facilities. For the group of participants discussed in this chapter, our return rate was 31 of 75, or 41%.

**Dilemmas Encountered Following Training**

We asked respondents to tell us whether, in the preceding 3 months, they had identified ethical dilemmas “more frequently than before training,” “less frequently than before training,” or “no more or less frequently than before training.” One third of the respondents (10 of 29) indicated that they were identifying ethical dilemmas “more frequently than before training.” None indicated that they were identifying care dilemmas less frequently.

We again asked respondents to tell us which category of care dilemmas they had encountered most frequently and which was most troubling. Resident behavior continued to be the most frequently occurring and troubling dilemma. Table 1.5 depicts the distribution of responses.

**Application of the IDEAS Process and Concepts**

We asked respondents to tell us on average, how many times they had used the IDEAS process for decision-making to analyze an ethical dilemma in the preceding 3 months. Response categories included “never,” “used the concepts but not the process,” “1–2 times,” “3–5 times,” “6–8 times,” and “8 or more times.” We found that 30% of the participants had applied the concepts and that 26% had used the IDEAS process at least 1 or 2 times in their home settings. Finally, many respondents had taught other staff about the IDEAS process, used the IDEAS worksheet to guide discussion of an ethical care dilemma, or provided other staff with the ethics education session materials.

**Table 1.5**

<table>
<thead>
<tr>
<th>Ethical Care Dilemmas That Occur Most Frequently and Are Most Troubling: 3–Month Posttraining Follow-Up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care Dilemma</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Advance directives</td>
</tr>
<tr>
<td>Decision-making/resident capacity</td>
</tr>
<tr>
<td>Decision-making/surrogacy</td>
</tr>
<tr>
<td>End-of-life</td>
</tr>
<tr>
<td>Resident behavior</td>
</tr>
<tr>
<td>Facility resources</td>
</tr>
</tbody>
</table>
Table 1.6
Perceived Need and Desire for Ethics Training for RNs, LPNs, and Nurse’s Aides

<table>
<thead>
<tr>
<th>Group</th>
<th>Perceived need for training (N = 29)</th>
<th>Perceived desire for training (N = 29)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Very Much</td>
<td>Somewhat</td>
</tr>
<tr>
<td>RN</td>
<td>18 (62%)</td>
<td>10 (34%)</td>
</tr>
<tr>
<td>LPN</td>
<td>24 (83%)</td>
<td>4 (14%)</td>
</tr>
<tr>
<td>Nurse’s aide</td>
<td>20 (69%)</td>
<td>9 (31%)</td>
</tr>
</tbody>
</table>

Need for Training in the Facilities

Because participants in our off-site ethics education programs have almost exclusively been managers or administrators, we asked respondents to tell us about the need for ethics training for direct care providers in their facilities. We presented them with types of care providers—registered nurse (RN), licensed practical nurse, and nurse’s aide—and asked to what extent they perceived that these groups needed and desired ethics training. Respondents indicated the highest need among LPNs and aides. For all three groups, the perceived need for training was greater than the perceived desire among those groups to receive training. Distribution of responses is depicted in Table 1.6.

CONCLUSION

Any ethical framework requires that relevant factors be weighed and evaluated in accordance with some set of criteria, values, or standards, and that a judgment be made regarding the right thing to do. The five commitments to long-term care recipients discussed above describe an ethical foundation for long-term care and provide a basis for making ethical care decisions. Further, our evaluation of perceptions and actions following ethics education using the IDEAS framework suggests that participation increases participants’ recognition of ethical care dilemmas and self-confidence in addressing and resolving such issues. The consistency in numbers of participants in our off-site ethics education programs, combined with those participants’ perceptions about staff needs in their own facilities, points to a continued need for ethics education in long-term care. The five commitments and the IDEAS process offer a new framework for ethical behavior in long-term care that contributes to care providers’ ability to identify ethical care dilemmas and provide a process for systematically examining and sensitively resolving everyday issues.

ACKNOWLEDGMENTS

The development of Promises to Keep: Creating and Ethical Culture for Long-Term Care was supported with funding from the Pennsylvania County Commissioners Association.
NOTES

1. Although long-term care is provided in a variety of settings, as used in this chapter, the term long-term care is used to refer to facility-based care.

2. The Center for Advocacy for the Rights and Interests of the Elderly is a not-for-profit organization committed to improving the well-being, rights, and autonomy of older Americans through advocacy, education, and action. It is located in Philadelphia, Pennsylvania.

3. “Principlism” refers to the biomedical ethics approach that posits four fundamental principles of medical ethics: beneficence, nonmaleficence, respect for autonomy, and justice.

REFERENCES


