Death in Very Old Age: A Personal Journey of Caregiving

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This paper describes a personal journey of caregiving for a very old family member during dying and death. The phenomenology of caregiving reveals the inner struggle experienced by all caregivers, lay and professional, between the needs to support both the living and the dying of the terminally ill person. The lived experience unfolds in phases of caregiving that support a stage theory of development in professionals' work with dying persons. The concept of presenting or connecting is a vital component of terminal care and has implications for occupational therapy practice. Occupational therapists can use their knowledge and understanding of occupation to bring about connecting in the dying experience. The contributions of all participants in the dying experience—family caregivers, the dying person, and health professionals—are important as sources of mutual support in the work of dying.

Death in old age is referred to as normative death (Kastenbaum, 1985; Moss & Moss, 1989); it is an expected event. More than two thirds of all deaths in the United States are of persons 65 years old or over (Brody, 1984). Caregiving for someone who is old and dying is, it appears, also a normative event (Brody, 1985). As Lynn stated, “Almost all of us will die of a chronic illness, with a time sequence that will give substantial warning” (1991, p. 69). That period of “substantial warning” is usually a time when help and care are required from another person.

Approximately one third of all deaths occur in people who are 80 years of age or older (Brody, 1984). Occupational therapists who work in geriatrics are likely to find themselves involved in the care of very old dying persons. Although dying patients are no longer routinely ignored by the health care system, professionals, patients and families continue to flounder “for lack of a clear set of goals and aspirations for the final phase of life” (Lynn, 1991, p. 70). The death of a patient may be viewed only as a negative and unsatisfying professional experience. Professionals may be hesitant to support the dying process, recognizing only their roles of continued support for life while it lasts.

This paper describes a personal journey of caregiving for a very old dying person. My mother died at age 91 on October 10, 1991. I entered that caregiving journey as a novice, with little knowledge or firsthand experience in caring for a dying person. I found myself transformed by the experience—as a private person and as a professional. It was my mother’s final legacy to me that I was able to share her last days so intensely and to be alone with her at that most intimate and sacred moment—the moment of death. The gift of that shared experience has enlarged my awareness of the many dimensions of caregiving for a dying person and helped me to define the potential role of the health professional during the dying process.

The Story

The Prelude to Dying

When a person lives for 91 years, it is likely that he or she will experience a lengthy time period of chronic illness before death. My mother, from about age 82 years onward, had lived with diminishing vision, increasingly impaired hearing, and severe degenerative joint disease. Despite progressive frailty and widowhood, she could not bring herself to seriously consider moving out of the house that she and my father had built, and instead gradually instituted a succession of mini-modifications over the years to accommodate her changing needs.

I was a caregiver from a distance during most of those years, occasionally offering suggestions derived from my occupational therapy training, but more often watching with some amazement as, time after time, she...
adapted her home and her daily activities to accommodate her changing physical capabilities. She arranged to have her clotheslines lowered, purchased a bath bench, and installed a shower hose in the bathtub and railings by the outside steps. She put an extra cushion on the living room chair, purchased magnifiers and a large-numbered telephone dial, sold her car, and hired people to help with the yard and the cleaning and transportation. She no longer put daily dishes away in the cupboard between meals, but, instead, kept them conveniently in the dish rack in the sink. She asked us to help move her bedroom furniture down to the small sewing room on the first floor, and her visits upstairs became less and less frequent.

About a year and a half before she died, the first ominous signs of lymphoma appeared. My mother referred to the diagnosis warily as “this leukemia business” and we all avoided use of the word “cancer;” but she began to engage in activities that represented putting her life in order. She reminded me that I was executrix of her will. She prepared for my increasingly frequent visits (I lived an hour away) with lists of items to review—the whereabouts of her bank statements, checkbook, and key to the lockbox at the bank; the envelope in the dining room cupboard that contained the obituary she had written for herself; the small notebook in the desk in which she had enumerated household items specifically designated for me or my sister or my brother; the linens in the upstairs dresser with the lovely embroidery and tatting done by her mother; the satin and net dress she had worn when she gave her salutatorian address at her high school graduation. She told me, “I want you to know where these are; I want someone to know what these are.”

The summer of that final year was precarious. My mother and I began to talk on the telephone every day, and I or another family member went home almost every weekend. Twice my mother fell in her downstairs bedroom and had to call a neighbor for help in getting up. Her visual impairment had progressed to the point where she could no longer take care of her financial records or other correspondence. My mother’s appetite and interest in cooking decreased, leading to weight loss and worry by the family about nutrition. Eventually she arranged for a helper to come in twice a week and for mobile meals to be delivered daily.

By late summer, the lymphoma seemed to be increasingly active; my mother was experiencing recurrent fluid around the lungs and edema in her lower legs. The benefits from repeated thoracenteses and medications to combat the fluid retention were short-lived. The neighbors became increasingly alarmed, telephoning my sister and me to express their concern about my mother’s ability to continue to live by herself. Finally, on Friday, September 6, 1991, on arriving at her home to find her extremely short of breath, I offered to help contact her doctor. She concurred, and later that day, she was hospitalized with congestive heart failure. We did not know it yet, but her work of dying had begun.

**The Work of Dying**

During the next 4 weeks, my mother experienced continued shortness of breath with any activity and came to rely on supplemental oxygen 24 hr a day. My brother and I visited local nursing home facilities and gathered information, and, after 2 weeks in the hospital, I transported her to a health care center in my city. The doctor expressed hope that she would show improvement with some rehabilitative therapy and close monitoring of medications. She was eating less and less, however, and her activity became limited to taking care of her basic needs and long periods of sitting quietly in her chair.

On October 3, my mother was conveyed to our large university research hospital and admitted to the hematology floor. I met the ambulance at the door, feeling relief to have her there and (in hindsight) an unrealistic hope that we would now find out what was causing this decline and be able to do something about it.

Upon the move to this hospital, my mother voiced the request that she not have visitors. For my mother, a social and talkative being all her life, the withdrawal was remarkable. We both must have felt the need to stay focused, my mother on the work of being very ill and I on the work of caregiving.

In those last days of her life, I learned the importance of sitting quietly and letting topics come up. Mother began to gradually ease me into her reality of dying. On the afternoon of the third day of her hospital stay, she reminded me again of the envelope in the dining room cupboard with information about her life. Then unexpectedly she said, “We never did have any solos.” I was not sure I understood what she said or meant, but then I realized she had shifted to talking about her funeral service. “We never had any visitation either, but you do what you want—I’d just as soon people would remember me the way I was. Some people have everyone sing a hymn, but that’s kind of hard.” Now my work had to begin; my mother was facing her dying and I needed to as well. And so I steadied myself and joined the conversation. I asked her, “Is there anything from the Bible you especially like?” She answered, “Oh, the 23rd Psalm, I always liked that.”

I talked to my brother shortly thereafter, making him aware of my mother’s state of mind and the wishes she was expressing. He mentioned the conversation to my mother’s primary hospital physician, and we were both somewhat taken aback by the doctor’s reaction. He viewed her comments as “worrisome” and as a sign of “discouragement” on her part. My brother and I were becoming a part of our mother’s reality of dying, but it seemed that her physician was not yet ready to do so. We were witnessing the classic inner struggle of professional healers—the competing claims about the patient “being
in the process' of living versus being 'in the process' of dying” (Marshall, 1992, p. 61).

During her last days, my mother continued to take care of other final matters. She expressed concern about her sterling silver flatware. She was emphatic about not wanting to be buried with her rings on. She hoped we would not argue over who would get these items. She mentioned an unfulfilled promise of giving a memento from her teacup collection to a friend, and discussed with me which cup she wanted me to give her. She talked more about the funeral service, wanting our childhood piano teacher and longtime friend to play the organ. She did not talk about what she wanted to wear for her burial, but she did express the wish that her usual hairdresser would do her hair. My mother talked of these concerns very calmly, and it was I who struggled with the almost overwhelming emotionality of the discussions.

At the same time that these new concerns evolved for my mother and for me, other lifelong interests continued. The leaves on the trees in Wisconsin turn spectacular colors in the fall. My mother’s hospital room afforded her a panoramic view over the University of Wisconsin campus and the nearby lake shore. Even with her diminished vision, she could enjoy the changing colors outside her window. I remembered the time when I was a college student and a letter from home contained not only a note but also two brilliantly colored maple leaves from the tree in our backyard—my mother’s way of sharing her appreciation of the beauty in nature with her daughter.

I strived to think of ways to fill the days with some meaningful activity. We did word puzzles together from the daily newspaper—a routine activity she had practiced for years. I combed her hair and understood the sense of caring that is experienced from just such ordinary acts. I read and reread her correspondence and cards to her. I took small sewing projects along to work on while we were together. Of course, I kept my briefcase at hand with paperwork to do while she slept—trying to fulfill my other expected responsibilities during this time, difficult though that was.

My mother continued to take charge of certain aspects of her daily life. Her appetite was minimal and breathing difficulties made eating extremely exhausting. Ignoring her discomfort, the dietician consistently came during the noon meal to talk about menu choices for the next day. It was the worst possible timing for a discussion that my mother had no interest in pursuing anyway. The dietician proved to be a source of extreme irritation and my mother eventually told her so directly. Mother’s generalized anxiety about the meal trays continued, however, and on the day before she died, she asked me not to allow “them” to bring any more meals in to her room.

The Moment of Death
The telephone rang during breakfast on the morning of October 9. It was a nurse at the hospital, calling to tell me that my mother’s condition had changed; she had experienced what appeared to be a myocardial infarction that morning and had been unresponsive for a few minutes.

Though she was responsive again at the time of the telephone call, the nurse advised me to come to the hospital. That nurse became my ally and anchor during the next day and a half.

The doctors were conferring when I arrived. During the previous days of hospitalization, it seemed to me that the physicians had projected an attitude of optimism about finding an effective treatment approach to counteract my mother’s problems. My brother, sister, and I had all expressed gratitude for their diligence, but we had all also tempered the discussions with our own beliefs and those of our mother about not taking any extraordinary measures and accepting death. The nurse became the key figure at this new turning point in my mother’s health care. She told me later that as the physicians grappled with the question of what to try next, she turned to them and said, “You don’t have to do anything.”

Shortly thereafter three physicians came down the hall and took me aside. They reviewed my mother’s history to date—the litany of symptoms and treatment trials. They outlined what they would be willing to continue to try but indicated little hope that any such attempts would make a meaningful difference in her condition. None of the three actually said the word “dying,” so I finally asked them if our discussion meant that she was dying. The answer to my question was “Yes,” and they also said “We will turn our attention to supporting her while she is dying and she may remain here until she dies.” Just as I was grateful to have my husband with me during that conversation, so, too, did they seem to need the support of each other. The nurse said afterwards, “That was very difficult for them to do.”

And so the vigil began. For the remainder of that day my mother and I stayed together, holding her hand and she mostly resting. Once she pointed toward the ceiling in one corner of the room, turned to me with a lovely smile on her face, and told me she saw a “little girl crossing the street.” She fretted a bit about my having to miss work. She remarked that it was “hard to breathe.” She commented that she thought she had had a wonderful life and had always been proud of her family. Otherwise we were mostly silent.

My brother arrived late in the afternoon and I took the opportunity to go outside for a walk along the lake. Later by her bedside, I pulled out a box of candy brought by a friend and offered it to my brother. My mother, ever mindful of my brother’s tendency to be overweight, perked up enough to admonish him, “Only one.” We both smiled at this nearly final expression of her many years of mothering.

My brother and sister-in-law stayed at the hospital throughout the night. When I returned the next morning,
Mother was no longer fully conscious and her breathing was very labored. My brother and his wife went to my home to get some rest, and I was again alone with my mother. And then the nurse came into the room and did a beautiful and wonderful thing. Very tenderly, she washed my mother, combed her hair, gently rubbed lotion onto her thin body, and then dressed her in clean pajamas. To me it was like a ritual of anointment, a last rite in preparation for the imminent final moment. I thought that at some inner core of my mother's consciousness, the cleansing must have felt like a final act of readiness for death.

The doctors came in once more—all three of them. All agreed that "it" wouldn't be much longer. They offered comforting words to me, and then they all left.

I sat next to the bed again, holding my mother's hand. I counted her respirations and they were 13 per minute, with long pauses between. I told her that I loved her. I counted her respirations again and this time they were 9 per minute. I turned to gaze out the window at the beautiful autumn colors. And when I looked back, the respirations had stopped.

How is it possible to describe such a moment? Never before had I been present at the moment of death. Bertman said, "No matter how prepared for the event one thinks one is, how anxious for it to happen, the moment of death is unprecedented, possessing a strange majesty of its own" (1980, p. 344). I had anticipated the event with fear, and yet when it came, I felt only a powerful sense of its own" (1980, p. 344). I had anticipated the event with fear, and yet when it came, I felt only a powerful sense of communion with what was happening. After a few minutes, I pushed the call button and Mother's nurse was with me once again; she hugged me and comforted me, and then proceeded with the after-death work of a hospital nurse.

Reflections About the Story

What is the meaning of the experience of caregiving for a dying person? To care for someone who is dying is inherently paradoxical, because the caregiver must both actively engage in the helping process and actively disengage in preparation for the impending death. Professional and family caregivers must live with the contradictions of providing comfort and enhancing life while also recognizing and supporting the approaching death. Sankar, in her study of dying at home, stated that "perhaps the most vexing and difficult aspect of the care is that no matter what the caregiver does, the dying person's health, with the possibility of a few brief remissions, will continue to decline" (1991, p. 77). Yet paradoxically, Sankar's subjects overwhelmingly found caring for the dying person to be "one of the most significant accomplishments in their lives" (1991, p. 154). Such a finding is surely strong testimony to the potential for fulfillment in the process of caregiving for the dying, even in the face of the inescapable outcome.

The Caregiver-Care Receiver Relationship

Vezau and Schroeder (1991) have stated that caregiving may be approached as a means to an end or as an end in itself. They wrote that "when outcome is primary, the nature of the relationship is directed toward that goal, whatever it may be; caring becomes an instrument. When caring exists unrelated to outcome, the value is the relationship itself" (p. 14). Although it does not make sense to claim that caregiving for dying persons is unrelated to outcome—surely an approaching death yields a powerful influence on caregiving during the living-dying interval—nevertheless, caring for a dying person can serve primarily as a means to enter, understand, and share the dying experience. The fulfillment found in the caregiving-care receiving relationship itself can become the ultimate good in the experience, for both the dying person and for the person giving care.

A relationship with a dying person has dimensions of meaning that do not exist in any other relational situation. For the professional and family caregiver, the sense of doing something and helping as key components of the caregiver-care receiver relationship must be redefined. Levine contrasted the work of caring for dying persons to the traditional helping model, suggesting that the caregiver's primary goal should be to "work to dissolve the separateness ... Become one with the other. No help, just being" (1982, p. 157). Benner (1984) spoke of this goal as presenting. Presenting is a "person-to-person kind of thing, just being with somebody, really communicating with people" (p. 57).

Is it possible for professional or lay caregivers to dissolve the separateness between themselves and the dying person? Dying is a life experience that resonates with isolation in the existential sense, that is, isolation of persons from one another in an "ultimate unbridgeable separateness" (Levine et al., 1984, p. 218). Being a caregiver for a dying person hurls one into a deeply felt confrontation with the experience of separateness from others. Yalom used the term "boundary situation" to describe such a confrontation (1980, p. 159). The shared experience of approaching death starkly reveals the unbridgeable and ever-increasing separateness between the dying person and surrounding caregivers. Coincidentally, the same experience may unite the dying person and the caregiver by a powerful bond of being. Therein lies both the paradox and the fulfillment. Benner (1984) and Levine et al. (1984) urged caregivers, first and foremost, to work to dissolve that separateness by being wholly present in the dying experience.

As a daughter-caregiver for my dying mother, I entered this boundary situation with a long history of established intimacy. The encroaching sense of separateness between my mother and me that gradually but relentlessly threatened this last shared experience was counteracted by the equally powerful emotional bond already in...
place. The final moment of death was a moment of communion, not separateness.

A health professional does not have this history of intimacy to bring to the caregiving experience. In fact, because we professionals view our roles so strongly as helpers, we must work harder at overcoming the separateness that threatens the relationship. Levine (1982) has called being a helper “a trap” that promotes separatism. The trap leads to the “separatism which sometimes comes when you use another to reinforce your self-image, to make yourself feel that you are living up to who you are supposed to be” (1982, p. 168). As occupational therapists, we may feel that we must be helpers and so the differentiation between “I” and the “other” is unwittingly accentuated, thereby reinforcing an existential separateness.

How can we as professionals be more wholly present to another in the dying experience? Clayton, Murray, Horner, and Greene (1991) discussed the phenomenon of connecting as a catalyst for professional caregiving. Strategies for connecting include the creation of meaningful experiences shared by the patient and professional; sensitive responses by the professional to the needs and wishes of the patient; facilitation of continued community linkages; the enabling and acceptance of the patient’s need for reciprocity; the showing of honest affection, and the inclusion of family, friends, and other important persons in the circle of care. Often, the family member already has all of these means of connecting. The professional, however, does not, and so he or she must create strategies to help bridge the separateness and to be present in the dying.

**Stages of Professional Growth**

Harper (1977) conceptualized the development of the health professional’s learning to work in dying and death as a five-stage process. Stage I in Harper’s schema is Intellectualization. In this stage, the worker obtains “a professional grasp and understanding of the diagnosis, illness, treatment, and prognosis” (p. 102). Occupational therapists in Stage I wrap themselves in their professionalism and helper roles and are ruled by the traditional treatment model of assessment, goal setting, treatment, and outcome evaluation. During Intellectualization, the professional’s need to provide tangible services prevails.

Harper’s Stages II and III, Emotional Survival and Depression, reflect difficult growth periods for the helper. In Stage II, the professional begins to understand the magnitude of the dying experience, becomes increasingly uncomfortable with the dying process, and experiences sadness and guilt. This initial emotional involvement expands into Stage III, during which grieving, depression, and exploration of feelings about the professional’s own death occur. Stage III is a critical period in which the professional may either “grow or go” (p. 57). If no sense of satisfaction for the professional accompanies the pain and grieving, then the worker is likely to retreat from practice with dying patients, that is, to go.

If the professional can continue to grow, then Stage IV, Emotional Arrival, offers a sense of freedom—not from the pain but from its incapacitating effects. Stage IV is characterized by increasing comfort with the dying and an ability to cope with the approaching loss of the relationship. Finally, in Stage V, the professional reaches Deep Compassion, and is able to comfortably participate in “death talk” (funeral arrangements, wills, unfinished business) (p. 103). During Deep Compassion, the helper no longer views the death as a personal failure, but experiences a sense of self-fulfillment and satisfaction in the shared dying experience.

The professional caregivers for my mother illustrated the full continuum of Harper’s stages of growth and development. The physician’s use of the term “worrisome” to describe my mother’s discussion of her funeral service seems to suggest his position in Stage I. He viewed my mother’s death talk as problematic. He was in his professional role of diagnostician and healer, seeking to provide tangible services. Not until the day before my mother died did the physicians engage in death talk. I appreciate now more than ever the personal passage that occurred within each physician during those few days, as each gradually yielded to the dying experience, to sharing it and being present in it. The yielding was seen as concern about keeping my mother pain free, about offering solace to me and my brother, and about making decisions that would enable my mother to die in relative comfort.

I think my mother’s nurse helped the physicians to complete their journeys. She seemed comfortable with the dying much earlier, she talked openly about death and, in effect, suggested to the physicians that they relinquish their professional roles (“you don’t have to try anything”). This nurse exemplified the full dimensions of the Deep Compassion stage. She shared in and also created important aspects of the unfolding experience. Together we created a repertoire of experiences and meanings. We shared and showed honest affection for each other and for my mother. We connected with each other and with my mother, and as a result, we achieved a sense of fulfillment and satisfaction from the experience.

**Contradictions in Occupational Therapy**

The hospice literature of occupational therapy suggests an ambivalence about the professional’s role with a dying patient. The paradox of the patient’s dual state of being, both living and dying, is revealed in the contradictory statements of the purposes of occupational therapy in terminal care. For example, the American Occupational Therapy Association position paper titled “Occupational Therapy and Hospice” (AOTA, 1986) strongly emphasized a treatment philosophy of “helping people with life-
threatening diseases adapt to changing life situations in order to live as fully and comfortably as possible" (p. 839).

The focus in this approach is on continued participation in life, maximizing remaining abilities, and maintaining involvement in daily tasks and roles (AOTA, 1986; Fernstrom, 1990; Lloyd, 1989; Picard & Magno, 1982; Pizzi, 1984). Flanigan (1982) and Gammage, McMahon, and Shanahan (1976) tempered their focus; they advocated helping dying persons to live each day with a concurrent goal of "helping a person prepare for death" (Flanigan, 1982, p. 275). As the terminal illness progresses, the dying person must be helped to "downgrade" activities to match waning energies and capabilities (Flanigan, 1982, p. 275). Gammage et al. (1976) proposed a unique occupational therapy role for "assisting a dying client to relinquish his [sic] occupational roles" (p. 294). Within this context, the therapist and dying client work together to continually reevaluate the status of occupational roles so that expectations for occupational participation remain appropriate to the client’s functional capacity.

Thus we see in the occupational therapy literature on care of the dying the same paradoxical dictum to provide comfort and quality of life while also recognizing and supporting approaching death. The ability to be comfortable with the latter role is most likely the distinguishing characteristic of the health professional who is fully competent to work with patients who are dying.

**Presencing in Occupational Therapy**

Occupational therapists, because of a focus on the everyday meanings of life, have powerful avenues available for connecting with clients. Pizzi (1984) described a case study that exemplified many of the components of connecting. The patient, a 78-year-old former chef and restaurant owner, was dying. He and the occupational therapist engaged openly in death talk and in discussions about activities of special interest for his remaining days. The patient’s list of desired activities included playing cards, wearing street clothes, and preparing an Italian dinner. All three activities were realized during his final days, through the help of the therapist, but it was the Italian dinner that best exemplified a deep sense of presencing. The patient’s presence, the responsibilities of caring, the worries and conflicts—all of which were orienting cues to the way life was to be lived before death—are now gone" (p. 132). Further, because in death the central figure is absent, surviving caregivers replay the final act of relating to the dying person over and over again until "finally we are able to grasp at the conscious and also the unconscious levels the extent of loss. Only after this has been realized can we relate in new ways to our world" (Davidson, 1985, p. 131). And so it was for me.

For health professionals, as well as for family caregivers, the death of a patient may be experienced as a profound loss. Perhaps ironically, the more connected and present the professional is in the dying experience, the more intense may be the grief response. Vachon (1985) discussed staff stress in hospice care, citing deaths that were difficult or that did not go as planned as especially stressful to staff members. According to Vachon, the death of a patient who had a special meaning to the staff person may lead to the need temporarily withdraw from other patient contact "to escape the further loss of psychic energy" (1985, p. 119). Harper (1977) and Wetle (1990) suggested the need for structured opportunities for debriefings and support for staff members when patients die. "After a death occurs, debriefing provides opportunity for sharing feelings and concerns, expressions of sadness or relief, and a sense of closure" (Wetle, 1990, p. 131).
Thus, the professional, too, struggles to reorganize his or her life space before gaining a sense of release and freedom from the loss. Davidson (1985) asserted that in this struggle, the professional engages in the normal and universal grieving process of remembering and caring, ultimately discovering renewed energy and new life with which to continue caregiving for others. Davidson urged the health care community to recognize and support grieving as a health-promoting and adaptive response (p. 220).

Conclusions

Caregiving for my dying mother helped me to grow professionally in my understanding of the dying experience. My mother’s gradual physical decline over a 10-year period was typical of the chronic nature of illness in old age. Uncertainty about the life-threatening aspects of these illnesses, together with my own inexperience in the care of people who are dying, probably delayed my presence with my mother until those final days. Those of us involved in that caring time—the nurse, my mother, the physicians, my brother and sister, and I—helped each other be present for the dying. Together, we worked to shape the care being given and the care being received. With the sense of mutual sustenance, we were ultimately able to comfortably support the approaching death.

Lynn, a hospice physician, stated, “More than any other criterion, what ‘dying well’ requires is that the life being lived as death comes near be one that is ‘befitting’ to the life that was being lived before serious terminal illness” (1991, p. 70). Only through connecting can we know what is befitting to “the life that was being lived before.” As occupational therapists, let us learn how to use occupation to dissolve the separateness and to reach a sense of communion in that final moment of death.

References


