

A Delicate Balance: Self-Care For the Hospice Professional

By Sally Hill Jones, PhD, LCSW

Cindy, an experienced hospice professional, approached me one Monday morning, saying, “I think I’m losing it. Just the thought of seeing my patients today is too much.” She then described taking repeated showers but feeling that she still had the “smell of death” on her afterward. There had been an unusual number of deaths during her weekend on call, and as she named her patients, she began to cry. We devised a plan to begin her emotional processing that included taking the day off, journaling, talking to others she trusts, and saying good-bye to her patients.

Service to individuals at the end of life and their families is an experience rich with meaning. Some important tasks can be accomplished only at life’s end, providing the opportunity for life review, healing, and coming to terms with one’s legacy. It is a time of potentially profound emotions and spiritual connections, letting go of the physical self and embracing the intangible inheritance left behind.

To be involved professionally at this crucial time is deeply rewarding and yet demanding. Hospice staff regularly experience a wide range of powerful emotions, the mystical space between the physical and spiritual worlds, and the reality of loss and death. End-of-life experiences range from inspiring, graceful processes to difficult, complex situations with layers of long-standing problems, few resources, and the potential for abuse or suicide. Given the scope and intensity of hospice work, thoughtful, intentional focus on self-care is necessary for hospice professionals to remain effective.

Maturing and Maintaining Motivation

Many feel called to hospice work because of their personal experiences with the end of life. Some want to give the valuable care that hospice provided for family members, friends, or clients and patients in facilities where they worked. My 80-year-old father existed in a persistent vegetative state for a year before my family realized we had options that would allow him to die naturally. I wanted to give people the knowledge I didn’t receive. Most professionals enter hospice work envisioning the ideal death, which often includes the healing of relationships, resolution of regrets, peaceful and pain-free death for clients, and manageable grief for families. When reality falls short of the ideal and goals are unattainable or different from those of clients, what happens to motivation?

Early in my hospice career, I assisted Ms. Stevens, a 76-year-old woman who had moved in with her daughter, son-in-law, and four grandchildren upon learning that she had terminal cancer. Although the mother-daughter relationship had been difficult with long periods of estrangement, the daughter wanted to do right by her mother at this crucial time.

Ms. Stevens’ demanding and emotionally harsh behavior proved to be a challenge, and it gradually became clear that she had a long-standing untreated mental illness. After the daughter threatened to end the relationship, the family expressed strong resentment about the intrusion in their lives, and Ms. Stevens was psychiatrically hospitalized, my initial goal shifted to a more realistic one of helping this family get through the ordeal with as little damage as possible.

Ms. Stevens died fairly peacefully, and her daughter began the important process of grieving what her mother could not give her. After the funeral service, I observed Ms. Stevens’ 5-year-old grandson standing by the open casket, peering at his grandmother’s body. Ms. Stevens was fond of this grandson and treated him well, unlike other family members. So I knelt by the boy and tenderly said, “Are you going to miss her?” He turned to me in amazement and said, “Oh, no, I’m glad she’s gone. She was mean.” I realized I had a lot to learn about the countless ways people experience death.

Discovering Hospice Realities

After a few such experiences, professionals are stretched to revise ideals and broaden definitions of what it means to help the terminally ill. Working within the broad spectrum of end-of-life experiences, hospice staff may, for example, come to revel in the tender care a husband gives his wife of 60 years. They may discover a unique insight into the pride of the woman who chooses to live in substandard housing conditions or endure rather than medicate her cancer pain. Or they may even be called to take action to protect an 82-year-old man from his abusive grandson.

Rigidly holding on to original ideals engenders frustration, self-doubt, and burnout, while giving up on professionals who experience such reactions leaves them disoriented, discouraged, and possibly destined to leave hospice work. Alternatively, a balance exists between remaining open to opportunities to enable aspects of the “good death” while also respecting and even valuing the many pathways people find through death. This means encountering hospice clients with open and curious minds, developing skills to delve into reasons underlying their choices, revising goals, valuing small successes, and becoming experts at tapping into what sustains them.

Hospice professionals must also develop ways to maintain motivation in the face of obstacles to the good death, such as inadequate resources, ageism, patients referred too late for needed services, long-standing complicated situations, and being the objects of displaced anger and guilt. Resilience develops by persisting, advocating, and finding hidden strengths and successes in your clients and in yourself. Vital supervisor and peer support counter tendencies to feel inadequate. Additionally, being fully present with patients offers a powerful ability to cultivate well-being. Hospice professionals can provide valuable healing or peace to clients by being keenly attuned and present in brief interventions or even nonverbal connections. Furthermore, they need to advocate for clients with other professionals and family members around self-determination and competency issues, especially when clients choose not to complete do not resuscitate orders or advance directives. Training and role plays assist hospice professionals to deal effectively with these issues.

Balancing the Personal and Professional

Key to a hospice professional’s self-care is the ability to fully enter into relationships with patients while maintaining one’s personal life and well-being. Challenges to this balancing act include preserving the professional relationship framework and managing powerful emotions evoked in hospice work.

Susan, a rural hospice professional, gradually started visiting and running errands for widowed spouses of clients after hospice services ended. As this unofficial caseload grew, her family complained. When attempts to change were unsuccessful, she considered changing jobs. Susan used journaling and a peer support group to explore the reasons for her trouble and concluded that she was attempting to avoid feelings about past personal losses by not finalizing her relationship with clients. Addressing this issue enabled her to manage endings with clients and continue hospice work. She gained valuable skills in helping clients with loss because she had experienced and survived similar pain herself.

Several aspects of hospice work with older adults may result in making exceptions to usual professional limits, making the relationship more personal. These include the sense of urgency and finality of death or being with patients in their homes during this significant life juncture. Patients’ expectations, desire for a mutual relationship, or quest for companionship may also result in extending the usual limits.

Professionals can feel pulled to give or receive gifts, extend the time of visits, or share more personal information than usual. Training that includes practice handling such situations is particularly helpful.

Hospice work with older adults sometimes taps into feelings and unresolved issues from many sources. Emotions may be evoked regarding parents, grandparents, or other older adults in the lives of professionals. Some professionals may unconsciously enter this field partly to fulfill unmet childhood desires for approval, love, or recognition or to access someone to admire and emulate. While hospice work sometimes results in feeling loved and appreciated by clients, this unconscious motivation can also lead to overinvolvement in an attempt to fill a void.

It's reported that Mother Teresa said burnout is "always hunger, and the hunger is for love" (Armstrong, 1995). In addition, hospice professionals face daily realities usually kept at a comfortable distance, especially the inevitability of a loved one's dependency, loss, grief, and death, as well as one's own (Greene, 1986). Current grief experiences must also be considered in self-care, such as commonly triggered feelings from personal losses, especially if fresh or unresolved. Professional or helper grief (Larson, 1993) from client deaths is another ongoing reality for hospice workers who need time and ways to grieve and find meaning in every client's death, even those they've known only briefly.

Emotions evoked in hospice work hold the potential to enhance helpers' skills or, if kept outside awareness, interfere with a clear view of patients and their needs. Therefore, hospice professionals must acknowledge their own vulnerability and the need to process their feelings, particularly grief, along with the associated pain and enrichment it includes. This improves professionals' self-care because they have reservoirs of resources with which to respond empathetically and clearly to clients' needs rather than distancing themselves from clients or overinvesting to meet their personal needs.

Fringe benefits also accompany this journey, since self-knowledge makes for deeper, richer personal lives. Hospice work can develop an "old soul" life perspective, stemming from the privilege of witnessing many life paths and their results, as well as what ends up being important to people when all is said and done.

A hospice nurse once called me to the nursing home because a client was very close to death and had no family or friends. Ms. Wilson was a new client in a coma and could not communicate her wishes. Intent on finding a family member, I discovered that her nephew visited occasionally, so I called and left a message.

As Ms. Wilson neared death, my anxiety about her dying without family members grew, despite my not knowing whether this was an issue for her. When the nephew arrived in time to say good-bye and to be with his aunt as she died, I experienced great relief. Upon reflection about the especially strong feelings I had about this client's death, I became aware of my own fears of dying alone since I have no children. To have this occur on my birthday, a milestone in my own aging, added to the feelings. I did some deep breathing and listened to calming music. I later sat with painful feelings and came to a deeper understanding of my fears, enabling me to distinguish clients' issues from my own and contributing to more peace about my own death.

Self-Care Plan

The challenges of hospice work make self-care planning a wise choice and another fringe benefit. It involves mapping out a plan that addresses individual physical, emotional, cognitive, relational, and spiritual strengths and challenges (Jones, 2005), serving as a guide through the ups and downs of a hospice career to prevent burnout, maintain motivation, and address obstacles.

Physical Self-Care — Listening to the Body

Since stress is experienced physically, it is important to identify where stress manifests itself in the body, routinely check vulnerable areas, and find effective ways to counteract physical stress

with relaxation. A variety of methods exist, including simple breathing techniques (Weil, 1990), progressive muscle relaxation, acupressure, massage, exercise, yoga, and meditation (Benson, 1995; Davis, Eshelman, & McKay, 2000; Kabat-Zinn, 1995; Keating, 2002). Attending to ongoing difficulties, such as depression or insomnia, is included. New hospice professionals are susceptible to anxiety that they or loved ones have a terminal disease (Larson, 1993). Professionals need to recognize this as a common attempt to integrate heavy exposure to terminal illness and channel these worries into preventive action based on their own or loved ones' specific disease predispositions.

Emotional and Cognitive Self-Care — Express, Soothe, Release

Emotional self-care includes maximizing energizing emotions and processing grief, routinely letting it in and out of one's life. Identifying individual emotional stress indicators, such as increased crying, irritability, anxiety, numbness, self-doubt, or addictive behaviors, is important. Key to emotional self-care is routinely expressing, soothing, and releasing emotions. Allowing for more frequent crying may be appropriate for hospice professionals, even if a movie or music is needed to "jump-start" a good cry. Other methods include writing, creating, listening to music, talking with confidants, enjoying hot baths, being held, or cuddling a pet. Aromatherapy, massage, meditation, mindfulness, prayer, gardening, and cleaning offer other emotionally soothing outlets. Allowing time to soak up joyful times and successes or engaging in pleasurable activities and humor is energizing.

I recommend a simple, brief, daily release ritual to intentionally let go of emotions that professionals often carry home from clients, particularly the heavy emotion of grief. The ritual includes acknowledging the detriment of carrying others' emotions, reviewing the day's situations, and letting them go. This can be done while listening to music on the drive home or before sleep, changing clothes after work, meditating or praying, visualizing the day's concerns going down the drain while showering, or getting farther away while running or walking.

Since thoughts affect emotions, self-care includes healthy internal dialogue. Keeping a log of thoughts for one week identifies harmful patterns that, for example, polarize, self-denigrate, blame, or expect perfection, especially related to challenging hospice situations. Distorted thought patterns are then replaced with reasonable alternatives or at least with challenges to the veracity of destructive thoughts. Supervisors and peers can offer valuable feedback. Professionals may also model their internal dialogue on how they talk to loved ones or valued colleagues.

Relational Self-Care — Support, Support, Support

The emotionally demanding work of hospice care makes a strong support system essential. Stress responses include increased irritability, distance, or dependence. Finding those able to listen and support is crucial. It is helpful to educate significant others about work stresses, when "it's about work, not about you," and ways they can offer meaningful support. This means knowing what you need and being able to ask for it, which is often difficult for professionals. In addition, self-care requires setting healthy limits in personal and professional relationships. Helpful tools include identifying warning signals of overextending, practicing setting limits, and handling conflicts by dealing directly with the person when an issue first arises, while remaining focused on solutions without blaming or personalizing.

Regularly scheduled supervisory and peer sessions are vital to preventing burnout and compassion fatigue, to the extent they provide positive, constructive feedback that assists in managing emotions, maintaining confidence and self-esteem, normalizing experiences, and developing new resources and coping methods (Leon, Atholz, & Dziegielewski, 1999; Keidel, 2002; Poulin & Walter, 1993). In addition, participation in political advocacy to address gaps in care is an outlet for frustration over inadequate resources.

Spiritual Self-Care — Tuning In to the Bigger Picture

End-of-life work is often spiritually rejuvenating, since it involves clients' big-picture concerns. Sometimes, the big picture gets lost in the details of paperwork and finding resources, requiring renewed attention to one's connection to the meaning of life and hospice work. Staying attuned spiritually includes reading sacred texts, praying, attending services, connecting to nature, listening to music, meditating, and engaging in creative endeavors. Since hospice work with older adults involves a heavy focus on the end of life, it is important to balance this with involvement in other aspects of life, such as being with children and healthy older adults. Opportunities to hold babies are thoroughly relished at hospices.

Self-Care Is Not Optional

Professionals often say that although they know self-care is important, they feel selfish when setting a limit or caring for themselves. I ask hospice professionals to think about an older client's caregiver whose self-neglect has reached the point where she will soon need care herself, a common problem. Then I suggest that they will be unable to help that caregiver until they do what they are asking her to do. I propose starting with one small step and considering an accountability partner for support. Since the professional's self is the vehicle for serving clients, self-care is similar to musicians caring for their instruments, an occupational responsibility. Tending to the source of one's gifts results in a long career of privilege as a compassionate sojourner in many clients' unique lives as they approach their final passage.

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