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48-Hour Hospice Home Immersion Encourages Osteopathic Medical Students to Broaden Their Views on Dying and Death

Marilyn R. Gugliucci, MA, PhD; Divya L. Padmanabhan, OMS IV; Emily B. Silberstein, OMS IV

From the Division of Geriatrics (Dr Gugliucci) at the University of New England College of Osteopathic Medicine (Student Doctors Padmanabhan and Silberstein) in Biddeford, Maine.

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Address correspondence to Marilyn R. Gugliucci, PhD, University of New England College of Osteopathic Medicine, Division of Geriatrics, 11 Hills Beach Rd, Biddeford, ME 04005-9526.

Email: mgugliucci@une.edu

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To augment learning about interprofessional palliative and end-of-life care, the University of New England College of Osteopathic Medicine immersed 2 second-year osteopathic medical students in an 18-bed acute care hospice home in Scarborough, Maine, for 48 hours. The students worked with an interprofessional staff and independently to provide patient care, family support, and postmortem care. For data collection, students wrote in journals before the immersion experience (prefieldwork), while living in the hospice home (fieldwork), and for 10 days following the immersion experience (postfieldwork). The students recorded their subjective and objective reporting of observations, experiences, feelings, and patient/family encounters. Data analyses included a review of the journals, identifying thematic categorizations, and coding through content analysis. Three themes identified in the students' journals reflected shared experiences: (1) shifting perspectives, (2) path to family acceptance, and (3) emotional journey. The students learned how to converse with patients and families about end-of-life care while ensuring attainment of patients' goals. They also learned about the importance of helping patients enjoy life's simple pleasures like taking them outside to enjoy the sunshine, and they learned to trust themselves when handling emotional and difficult situations. Each student gained confidence in her ability to help guide patients through this stage of life.

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"I learned about a lot of things in medical school, but mortality wasn't one of them."
Atul Gawande[1]

Modern medicine embraces technological approaches to care and furthers the use of medical and drug interventions, which has changed the human lifespan (ie, length of time a person functions) and healthspan (ie, length of time a person exhibits good health). Both have aimed to reduce old-age mortality while

Table.
Identifying Features of the Culture of Death Across the Ages[3]

Period of death	Period height	Identifying features
Tame death	900 AD	• The death ritual was organized by the dying person • The bed chamber was public and included children • Rituals of dying were accepted with no great show of emotion and evoked no great fear
One's own death	11th and 12th centuries	• Death takes on a dramatic and personal meaning • It is widely accepted and expected • "Judgment and Resurrection" of the dead becomes popular with life viewed as a "stay of execution" • Each person is judged according to the balance sheet of their lives
Thy death	18th century	• Death takes on a personal meaning; it is now feared • Deathbed is not solemn/tame • Viewed as a "break"; it is dramatized with crying, praying, gesticulating • Children were banned because of hygiene issues (late 18th century) • The will takes a tone of distrust, reduced to a legal document • Bodies were kept visible in great bottles of alcohol
Forbidden death	Second half of the 19th century into the early 21st century	• Death became shameful and forbidden • Relatives no longer had the courage to tell the dying person the truth • Funeral processions, mourning clothes, spread of cemeteries, and visits to tombs come into play • Undertakers are renamed funeral directors, known as "doctors of grief" • Mourning is viewed as repugnant, morbid, solitary, and shameful and must be treated, shortened, erased by the doctor of grief

raising the maximum age at death, which has altered the processes of aging and dying.[2] These processes are often correlated with medical experiences rather than quality of life.[1]

Based on the cultural evolution and societal history of death since medieval times, death, which was once an accepted part of life, is now considered a failure in the current medical culture. The societal beliefs associated with death evolved over 4 documented periods, each with rituals and beliefs considered commonplace (Table).[3] For example, the "tame death" period, which reached its height in 900 AD, had features that included having the death ritual organized by the person who was dying. The bedchamber became a public place where children were also present, and rituals of dying were accepted with no great show of emotion or fear.[3] In the "forbidden death" period, which began in the second half of the 19th century and has continued into the early 21st century, death is expected to take place in the hospital,[3] where physicians focus on curing the patient (Table). Dying and death evoke strong and unbearable emotions, there is a desire to save the dying person from the gravity of condition, and the dying person defers his or her decision-making to the physicians.

On average, 60% of people in the United States die in acute-care hospitals, and compared with other countries, admissions to hospital intensive care units are twice as common in the United States before death.[4-6] In the United States, 20% of people who die do so in a nursing home environment.[7] Although hospice care is on the rise, increasing 14.85% from 2012 to 2017,[8] relatively few terminal patients enroll in hospice. Often, a physician suggests hospice for patients who are in the last 3 to 4 weeks of life.[4,5]

Our society is slowly shifting to what some call the "good death" period.[1,9] To make this shift, medical

education must be proactive in providing medical students with skills, knowledge, and attitudes about person-centered, end-of-life care for people with terminal illness. Meier et al[9] defined a good death as a lack of pain, religious and emotional well-being, a feeling of life completion, dignity, closeness of family, and quality of life. A good death often includes a strong desire to die at home. In this new period, death would be different for each person, and clear decision-making, preparation for death, and affirmation of the whole person would aid in honoring a person's wishes.[9] Within this scope of a good death, training future physicians in this approach would provide opportunities for their patients to live a good life to the very end.

The National Academy of Medicine (formerly, the Institute of Medicine) recommends that "educational institutions and professional societies provide training in palliative care domains throughout the professional's career."[10] However, education about palliative and end-of-life care remains underrepresented in medical school and residency curricula.[10] Although nearly all US medical schools now offer some integration of death and dying in the required curricula, fewer than 30% of schools offer dedicated courses in end-of-life care.[11,12] In 2016, Schmit et al[13] found that more than half of the residents reported inadequate end-of-life education during medical school, and 88% of medical residents in the study had little to no training for end-of-life care during residency. Content tends to be offered through intermittent lectures, case studies/problem-based learning, and brief preceptorships, which do not provide depth or extended bedside experiences to augment knowledge, skills, and attitudes in palliative and end-of-life medicine.

Hospice Home Immersion Project

The University of New England College of Osteopathic Medicine's (UNECOM) Learning by Living 48-Hour Hospice Home Immersion project (herein referred to as Hospice Home Immersion) provides medical students with avenues for knowledge advancement, skill development, and attitude change about dying and death through a voluntary immersion experience. While living in an acute care in-patient hospice home for 48 hours, medical students learn the philosophy and function of hospice and participate in person-centered care and healing. Understanding and participating in end-of-life care that embraces the art of healing is essential in a society where health care professional training tends to be focused on medical care, rather than whole-patient health care, through high technology and low touch procedures. The first of the 4 tenets of osteopathic medicine states that the body is a unit; the person is a unit of body, mind, and spirit.[14] The immersion program's design and implementation fosters an environment where living, dying, laughing, and crying are all part of person-centered interprofessional care. Students who reside in the hospice home find their "Forbidden Death" views challenged with a new understanding of dying and death.

The UNECOM Hospice Home Immersion project began in December 2014. This project was implemented as an ongoing experiential medical education research learning model by the Director of Geriatrics Education and Research in the Division of Geriatrics.[15] Pairs of medical students volunteer to be immersed at the Gosnell Memorial Hospice House (GMHH) once per month for 48 hours, allowing approximately 24 to 36 students to conduct the immersion per year. GMHH is a not-for-profit, 18-bed acute-care, in-patient hospice home owned by the Hospice of Southern Maine in Scarborough. Patients at GMHH are there for about 5 to 7 days before they either transition home, to another living environment, or die. GMHH has 3 levels of care: (1) general in-patient for acute symptom management, (2) routine care, for stabilizing care once acute symptoms are managed, and (3) respite care, a Medicare benefit whereby hospice patients who live at "home" may stay in the GMHH for 6 days and 5 nights to provide respite time for the family. During their stay at GMHH, the students participate in patient care, family support, and postmortem care either working independently or with interprofessional staff.[15]

Research Design

The Hospice Home Immersion project uses ethnographic and autobiographic research designs, whereby a unique environment or "culture" is observed, and medical students report their experiences through journaling.[15,16] The research questions posed to the medical students who engage in this project include: (1) "What is it like for me to live in this acute care hospice home for 48 hours?," and (2) "How does this contribute to my future as a physician?"[15-18]

2018-2019 Hospice Home Immersion Project

This project was exempt from institutional review board approval as student researchers collected data focused on self-reflection. The Hospice of Southern Maine Ethics Committee approved the implementation of the UNECOM 48-Hour Hospice Home Immersion project.[16-18] This project has been previously reported on.[15,16,19,20]

Participants

During the 2018-2019 academic year, 13 pairs of UNE health professions students conducted this immersion research (11 pairs from UNECOM and 2 pairs from the UNE Masters in Social Work Program). Each pair lived at GMHH for 48 hours and completed journals. However, only 2 UNECOM participants, who were each immersed with a partner on different weekends (August and September 2018), engaged in a comparison of their qualitative outcomes for this article. These medical students, both women, were in good academic standing and volunteered to be participants. Each completed the requirements to conduct the immersion, which included a registration form, a written statement about her interest in the Hospice Home Immersion project, her assumptions of what she expected to encounter during the 48-hour immersion, and a 1-hour orientation 1 week before the immersion. This orientation was provided by the project director to enhance the students' learning about hospice, describe previous student immersion experiences, explain research components, and prepare them for this experience.

Upon entering GMHH, the students were introduced to the hospice home manager, who provided an additional orientation that included information about the acute-care in-patient hospice home, the interprofessional staff, care provision practices, and a tour.[15-18] Students received a GMHH name tag and security fob that provided access to all secure areas except the room where medications were stored. The students were paired with a certified nursing assistant who provided information about each patient and helped the student acclimate to the hospice environment. Students then worked with nurses, nurse practitioners, the chaplain, social workers, volunteers, and on their own or with their student peer. Each student met all patients in the home and learned about their family and social and medical histories. Students answered call bells and assisted staff with direct patient care, including toileting, bathing, repositioning, and feeding. They also engaged with patients and family members, assisted with new admissions, sat with patients who had no family or friends present, and provided postmortem care following a death that included a procession. The procession involved accompanying the family as the deceased person was wheeled on a gurney out of the building to the funeral director's van. For each procession, the decedent was either covered with a flag (veteran) or a homemade quilt. During staff shift changes every 12 hours, students participated in the transition report of patients. Interprofessional staff team meetings occurred each morning of the student's immersion. At night, students shared a room and slept in a bed where many patients had died before.[15-18]

Data Collection

Qualitative research journal writing occurred during all 3 phases of the research project: (1) before entering the hospice home (prefieldwork), (2) during the immersion (fieldwork), and (3) for 10 days following the immersion (postfieldwork). During the prefieldwork period, students wrote their assumptions that included expectations of the immersion or their attitudes about hospice care

and dying. No hypotheses or variables are associated with qualitative research; therefore, their prefieldwork journaling brought to the forefront their beliefs and anticipations that underwent constant self-reflection throughout their immersion at GMHH.[19,20] Journal writing during each phase of the project included in-depth accounts of students' observations, thoughts, experiences, and feelings. The journals were reviewed by the project director to ensure established qualitative journal writing, posing additional questions to move students to more profound reflections, and to check on the students' well-being. The journals were reviewed the last day of the prefieldwork phase, during both nights of the immersion fieldwork, and when the final journal was submitted after the postfieldwork phase.[15-18]

Data Analysis

After the immersion, journals were reviewed and reflected on at least twice by the students and the project director to identify and define themes. A step-by-step deductive formulation of content from each journal was categorized within the appropriately identified themes.[17,18] Revision of themes and associated content continued throughout the analyses to ensure interrater reliability through formative and summative checks, such as reflection and conversations with the project director about each student's experience with death and their personality traits.[19,20] Interpretation of thematic and content analyses culminated in collective final results for these 2 students. [16-20]

Emerging Themes

The analysis resulted in various themes with associated defining quotes. However, 3 themes reflected shared experiences from each student's immersion experiences that inspired their perspectives regarding dying and death. The 3 themes were: (1) shifting perspectives, (2) path to family acceptance, and (3) emotional journey.

Theme 1: Shifting Perspectives

Student 1 (E.S.) felt comforted and put at ease when she arrived. "It almost feels like a hotel, with a welcoming reception desk and all." The notion that hospice and especially dying is depressing is a pervasive one. However, the apparent warmth at GMHH played an important role in changing her perception of what it was like to spend time at a hospice home. "I believed that there would be something sad or unpleasant about hospice before I arrived, so it was surprising to have my perspective change so soon into the immersion."

Student 2 (D.P.) expected the home to be filled with sadness and grief but found that love and hope are also a part of the hospice experience. She noted that her perception of death and dying shifted during the hospice experience and felt that many of the patients' families and friends experienced a change in perspective. Sharing this experience with the patients' families and friends allowed her to recognize the spectrum of emotions when caring for patients. For the daughter of one patient, being a part of her mother's support system helped her decide to pursue a career in medicine to move forward while keeping her mother's life and memory close to her. Student 2 recognized that "even though there is grief and sadness associated with a loved one dying, it also catalyzes change."

The students' changing perspectives about dying and death helped them consider how they would balance their careers and personal lives to maintain wellness. Before entering the hospice home, they assumed that working with patients who were dying would make the staff (and them) unhappy and prone to depression. However, during their immersion in the home, they each realized that the way the staff supported each other, the patients, and their families was unique. Every staff member had their own hospice journey or reason to be drawn to hospice service. Student 1 spoke with a nurse at GMHH who switched to hospice nursing after seeing the amount of burnout in the emergency department and felt that working in hospice care could provide a better work-life balance. Student 2 noted that the staff at GMHH were dedicated and passionate about providing patient-centered care and were supportive of each other. Other health care environments that she had served in seemed to include much

complaining about patients or job-related duties. The staff attributed this unique, supportive environment with helping them process their emotions and increase job satisfaction. The students experienced the rewards of hospice care and recognized the privilege of caring for patients during such an important life transition. The immersion offered fulfillment for the students and shifted their views of dying and death from feeling fearful to feeling a sense of honor about being present during this stage of life. Understanding that death is an important part of life was the ultimate lesson.

Theme 2: Path to Family Acceptance

Student 1 described the power of acceptance when the friends of a patient with cancer compared their current experience with a loss of another friend who had died suddenly from a drug overdose. "Reaching this point of acceptance and peace was important for family, friends, and the patient in hospice care." The nurses talked about a patient being ready to go and explained that some would die surrounded by family and others would wait to be alone.

Student 2 observed that the GMHH staff was honest, clear, and direct when families asked how their loved one was doing. She felt that this was the clarity that families needed when they were dealing with many emotions. She found that today's society emphasized positive outcomes, but she recognized the delicate balance of communicating with patients and their loved ones about their diagnosis, prognosis, and care goals. Being direct helped patients and families process the truth. The hospice immersion showed her the importance of being honest and having direct, yet compassionate, conversations with patients and loved ones. "In this situation, sugar-coating how the patient is doing helps no one and gives families and friends a false sense of hope of how much longer they have with their loved one." She witnessed how patients and families were better able to process and reflect on the information and use the resources available to them, including staff support for loved ones.

Student 1 learned that many patients at GMHH were ready to die and that many families felt the same way. She felt that no one wanted his or her loved one to continue living when life was full of pain or discomfort and was no longer enjoyable. Student 2 wrote that one of the nurses worked with the families to make sure that they took time for themselves during the dying process and helped them not feel guilty about making that time.

Before the immersion, the students acknowledged their belief that death was sad or tragic. After the immersion, the students could honor death and recognize the sadness and tragedy that could be present, but realized that death was inevitable and could be comforting. They each witnessed many patients who transitioned into the dying phase and watched their families and friends accept this. They also recognized that acceptance was a process that takes time. Given society's expectations, it can be difficult for grieving loved ones not to feel guilty about taking time for themselves. It was important for students to see how the staff supported families through these feelings of guilt. As future physicians, the students understood how they could support the person who was dying and their families during this process. The societal taboo of death was overcome when the family expressed they were ready for a loved one to die. Death can be a gateway to end suffering, and it can also be a great comfort to family members. As osteopathic medical students, they valued the team-based care in which the person who was dying and the family were integral to the care plan in the hospice environment.

Theme 3: Emotional Journey

Student 1 felt that participating in the immersion project opened her eyes to different ways to think about death and dying. She found that it was important to reframe her thoughts about the deaths she had experienced in her personal life. "I used to frame my grandfather's death by thinking about all the negatives and how he was in pain. But I didn't take much time to consider the positives. One of which was how much time we spent with him in the last months of his life."

After the immersion, she saw death as a part of life, even though it is a difficult thing to go through when it happens. The immersion experience at GMHH taught her how to accept loss and consider it an opportunity for growth. She learned how she could bring peace, clarity, and acceptance to her future patients. "Death is not this isolated thing, it occurs in the same space as joy and growth…Communicating honestly and expressing that there is no correct way to feel about the dying process are just some of the important principles I will take with me from this research."

Student 2 was physically exhausted and napped to recharge herself within 16 hours of returning home. In hindsight, she realized that her pent up emotions manifested as physical fatigue. As she became more familiar with the environment and reflected on her feelings and emotions through conversations, experiences, and journal writing, she recognized that she was now able to be fully present for patients and families. She felt grateful for the immersion experience because it allowed her to practice talking with patients and families on a more personal level and showed her the importance of honoring her feelings and practicing self-care as a future physician. "Dying doesn't have to be an experience devoid of love and happiness. It can include components of the life that the patient has always loved. In that same way, making sure that patients are keeping up with their self-care and hobbies can be a good way to check in with patients in a nonhospice setting."

Living in the hospice home for 48 hours provided many moments of joy and laughter as well as sadness for the students. They were both surprised that levity could exist and be presented through many different avenues, such as playing with a therapy dog that visited GMHH, conversing with patients who coped with their terminal illness with humor, participating in activities similar to those the patients loved before entering GMHH, and hearing funny family stories. The staff provided mentorship to the students, which included how to help patients enjoy the simple pleasures of life. Students were surprised by the joy of a patient who got a manicure days before dying or was wheeled outside to feel the sunshine each day. The person-centered care that GMHH provided enabled the students to find love and joy in the midst of death.

Conclusion

After the immersion, the students reported that they learned how to have conversations with patients and families about end-of-life care to ensure that the goals of patients were achieved. Additionally, they learned about the healing power of seemingly simple requests, such as letting a patient feel the sun, rubbing lotion on patients' hands, or making a hot fudge sundae for a patient who then decided that seeing it was enough. Above all, they learned to trust themselves when handling difficult and emotional situations and gained confidence in their ability to help guide patients through this stage of life. As future osteopathic physicians, these students will be better able to care for the whole person and their family members by having open and direct conversations about terminal illness, dying, death, and options, such as hospice. They will be able to implement the skills to ensure that patients in their care will have the opportunity to live a good life to the very end.

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