

Engaging students as caregivers to hospice patients in community-run residential care homes

Carol Weisse, Ph.D.,
Professor of Psychology and Director of Health Professions
Union College, Schenectady, NY

Kelly Melekis, MSW, Ph.D.,
Associate Professor and Chair of Social Work
Skidmore College, Saratoga Springs, NY

Leah Rohlfen, Ph.D., Associate Professor and Chair of Sociology
St. Lawrence University, Canton, NY

Chantelle Sharpe, Ph.D.,
Visiting Assistant Professor of Human Development
Connecticut College, New London, CT

Please address correspondences to Carol Weisse at weissec@union.edu

Abstract

Palliative care is recognized as a human right (World Health Organization, 2018), yet significant barriers exist in accessing care, especially for individuals at the end of life who lack a caregiver system and safe, secure housing. To address these gaps in care, residential homes for the dying are opening across the U.S. In these “comfort care” homes, community members serve as surrogate family members providing care to hospice patients during their final days. Our presentation will provide an overview of this community caregiver model and describe how these homes are also serving as end-of-life care training sites through a Community Action, Research, and Education (CARE) Program. The CARE program connects health professions students with residential care homes and supports them as they engage in direct bedside care. The experience teaches them how to address the physical and emotional needs that change daily as patients progress toward death, while actively dying, and afterwards as families process the loss. The opportunity to journey alongside terminally ill patients and family members in a home setting provides a special lens to the dying experience in a holistic, patient- and family-centered way where death is expected and supported as a natural process, not as a medical crisis or failure. To date, the CARE program has placed students from eight undergraduate institutions as caregivers in six different residential care homes. Our data show that over time, students show increased empathy and confidence providing end of life care. In addition, they gain an understanding of how the lack of caregivers and housing insecurity can make it difficult for people to experience a dignified death. The program offers students an opportunity to support community initiatives to provide end of life care and to develop skills that will be invaluable to them as future healthcare providers.

Over the last century, major shifts have occurred in the way people die, including *where* they die and *who* provides most of the care. When asked about preferences for place of death at the end of life, most people report that they wish to die at home, a finding that is consistent across many countries (Gomes, Calanzani, Gysels, Hall, & Higginson, 2013). These preferences are not surprising given that home deaths are more likely to result in patient-centered, goal-concordant care (Khandelwal et al., 2017). While there has been a slow and steady increase in the number of deaths occurring at home in the U.S., only 30% of deaths occur at home (Cross & Warraich, 2019). Significant barriers exist in accessing care in one's home, especially for individuals at the end of life who lack a caregiver system and safe, secure housing. While hospice agencies were originally designed with the goal of supporting people wishing to die at home, services cannot be accessed unless individuals reside in a safe environment and there is evidence of a caregiver system capable of providing custodial care (feeding, bathing, toileting, administration of medications, etc.).

In response to these barriers to hospice home care, communities across the US have been working to improve access to hospice care by establishing community-run, non-profit residential homes for the dying. These homes target individuals with home or caregiver instability who lack resources. These non-medical residences, or "comfort care homes," recruit volunteers from the community to serve as caregivers and surrogate family members to terminally ill individuals and their family members. The homes enable terminally ill individuals to enroll in hospice, and hospice agencies provide all of the services to patients as they would if the patient were living in their own private residence. Currently, about 70 homes for the dying are in operation, with 40 more in development throughout the country (see Figure 1). Each home operates as a

freestanding, non-profit agency that offers care to residents free of charge. The homes function as non-medical facilities, and because their services are not covered by insurance or through federal or state funding, operating costs are covered through grants or charitable donations.

While the primary mission of residential homes for the dying is to provide a safe, caring, loving home for terminally ill members of the community, the homes also offer an untapped resource for teaching patient- and family-centered end-of-life care (Weisse, Sapienza, & Foster, 2018). Caregivers at these homes must learn to assist with all activities of daily living, including bathing, feeding, and toileting, but they also are responsible for managing multiple symptoms and following complex medication regimens prescribed by hospice. Caregivers volunteering in these homes also provide emotional support to patients and to family members visiting the home throughout the duration of the patient's dying process. As a result, volunteers serving in these homes have the opportunity to develop a set of skills that most professionally-trained clinicians may never acquire. However, recruiting and retaining volunteers is extremely challenging given the lack of comfort people have working with the dying and beliefs that care can only be provided by individuals with medical training or certification.

In their report *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*, the Institute of Medicine describes a critical need for training and education in end-of-life care and argues that patient- and family-centered care should be a national priority (IOM, 2015). However, there is a lack of training opportunities in care at the end-of-life, especially training that promotes an understanding of how to provide care in a home setting where death is expected and supported as a natural process. Professional-school training continues to emphasize the medicalization of the dying process. Training rarely includes exposure to real patients in home settings, and increasingly employs proxy techniques such as

mechanized robots or actors posing as “standardized patients” (Randall, Garbutt, & Barnard, 2018). Clinical simulation centers are considered the “gold standard” despite a recent systematic review that shows medical training interventions, particularly those aimed at increasing empathy, show greater success when using real patients (Patel et al., 2019).

Interactions with actual dying patients during clinical training are typically limited to institutionalized settings where death is viewed as a medical crisis, a problem to be fixed, or a failure. As a result, few healthcare providers recognize that death is a process that can occur at home with proper support. The shift in end-of-life care over the last century from home to institutionalized settings has led to the loss of knowledge, skills, and confidence to support individuals choosing to die at home, not just among healthcare providers but in the general population. With fewer individuals exposed to the natural process that occurs at the end of life, there are fewer healthcare providers, children, grandchildren, friends, and neighbors who are experienced or educated in how to support the dying process, and entire communities are suffering as a result.

The Community Action, Research, and Education (CARE) Program

In response to the coexisting needs for home-based training in end-of-life care and for caregivers to serve in residential homes for the dying, we developed a Community Action, Research, and Education (CARE) Program that trains undergraduate students as caregivers to hospice patients in residential homes for the dying. In this 8-week program, students serve as surrogate family members, providing a minimum of 24 hours of direct bedside care per week. In addition, students complete 10 online learning modules, each of which emphasize different skills for providing end of life care. At the bedside, students learn directly from patients, their family members, other community volunteer caregivers and hospice staff. In addition, under the

guidance of research mentors from their home institutions, students conduct agency-driven research to benefit the home where they provide this care.

The CARE program employs a multifaceted approach that includes community-based experiential learning as caregivers to dying persons in conjunction with curricular activities including agency-based research. The program draws upon the *Learn, See, Practice, Prove, Do* model, an evidence-based educational framework that helps students gain competence in their procedural skills and transition from the role of observer to that of skilled care provider (Sawyer et al., 2015). The program also follows guidelines for teaching social determinants of health, including service learning, opportunities for reflection, and the opportunity to work with raw data (Martinez, Artze-Vega, Wells, Mora, & Gills, 2015). By engaging students as caregivers at the bedside of the dying, they must learn a critical skill: how to care when there is no cure. As a result of the experience, students gain a deeper understanding of the challenges families face when a relative chooses to die at home.

A key learning objective of the CARE program is that students recognize that quality end-of-life care includes identifying and preserving the wishes of patients as well as family members. These lessons are reinforced as they provide care to individuals over the course of the dying process in an ongoing, iterative, immersive experience that teaches them to address both physical and emotional needs that change daily as patients' progress toward death, while they are actively dying, and afterwards as families process the loss. The opportunity to journey alongside terminally ill patients and family members in a home setting provides a special lens to the dying experience in a holistic, patient- and family-centered way. Furthermore, because students must work as a member of an interdisciplinary team with hospice workers and other caregivers that include family members and members of the community without specialized medical training,

they must adopt a holistic approach regardless of their background, training, or career interests. Therefore, the experience lays a strong foundation for future interprofessional collaboration and teamwork and helps students evaluate their interests in caring for patients with complex and challenging needs. By engaging higher-education students in community-based end-of-life care, education occurs “upstream” before students enter professional school, while they are still evaluating their career interests. Therefore, the experience can shape interests in social work, medicine, nursing, public health, counseling, and pastoral care and contribute to students’ professional identity formation.

The program also engages students in the care of underserved populations in the local community, as the majority of the residents served by these homes are elderly and under-resourced. The program includes an online curriculum that challenges students to examine the cultural, social, ethical, political, and economic barriers to hospice care while encouraging them to develop skills to improve care of dying individuals in their community. The curriculum includes 10 learning modules on the biological, psychosocial, emotional, and spiritual aspects of dying conveyed through targeting communication and specific dimensions of end-of-life care. The modules include self-assessments, educational videos describing specific caregiver skills, case studies, and prompts for reflective journaling.

The immersive nature of the program, combined with consistent exposure to residents, families, veteran caregivers, and faculty/staff, enables students to practice and hone communication skills in the context of familiar and supportive relationships, especially with regard to listening skills and the use of non-verbal techniques. The online curriculum enables students placed at homes in different geographic locations to communicate with one another and learn collectively about the societal factors that make it difficult for vulnerable and marginalized

members of the community to experience a dignified, meaningful death. Therefore, the program offers students an opportunity to serve their communities while developing interpersonal and professional skills that will be invaluable to them not only as future healthcare providers should they choose this career path, but as civically engaged members of society with the skills to become agents of change.

Another important feature of this educational model is that it teaches students how to conduct research that will improve care at the end-of-life, and therefore is serving to develop of the next generation of scholars and practitioners prepared to collaborate through partnerships to improve both practice and research. Under the mentorship of faculty research mentors from students' home institutions, students conduct agency-driven research. Projects have included research on changes in diet and nutritional needs at the end-of-life; investigations into predictors of falls to improve safety; examination of burdensome transitions at the end-of-life, and studies on volunteer satisfaction and retention. Over the past four years, faculty from different institutions and from varying disciplines (i.e., Social Work, Sociology, Gerontology, Psychology) have served as research mentors, an experience that has helped inform their courses and shape their research agendas toward improving the dying process both for the patient as well as for family members and caregivers.

The true educators in the CARE Program, however, are the residents in these homes and their family members. For example, when one resident (a former teacher) learned that her caregiver was a student in an educational program aimed at improving care at the end-of-life, her response was "So I guess I'm the professor here!" Until the day she died, she referred to herself as the professor, and whenever she could seized the opportunity to share important lessons with students who were working toward honing their caregiver skills. Therefore, in this educational

training model, the terminally ill residents can, and often choose to, take center stage in the training of students. Research has shown that patients with a terminal illness are generally positive about being involved in undergraduate medical teaching (Harris, Coles, & Willoughby, 2014). The opportunity to educate undergraduate students provides terminally ill residents a sense of worth, legacy, and generativity, all shown to reduce suffering and isolation commonly experienced at the end-of-life.

Over the last 5 years, this educational program has shown strong potential for growth, as it has already engaged students and faculty from multiple colleges/universities and recruited homes in both urban and rural locations in upstate New York. The program was piloted in 2015 as a joint initiative between Union College in Schenectady, NY and the Joan Nicole Prince Home in Scotia, NY. The following year, a second college participated by placing its students in a second home in their local community. In the third year, an additional home joined the program and hosted students from two new partnering schools. To date, 45 students from eight different institutions of higher education (Colgate University, Connecticut College, Hobart and William Smith Colleges, Siena College, Skidmore College, St. Lawrence University, Union College, and Wells College) have completed the program. Six separate non-profit homes in upstate New York have hosted student caregivers, and two new homes will be piloting the program in the summer of 2020, including one home in Massachusetts, the first home outside of New York State.

Our vision is to expand the CARE Program in the next 5-10 years so there is at least one end-of-life care training hub in each region of the country, and that these partnerships will be able to operate independently from the original partnership that trained them. Data gained by mapping the locations of colleges and universities in close proximity to residential homes for the

dying across the U.S. reveal that there is a strong infrastructure in place for expansion of the CARE program. Using ArcGIS technology (see Figure 1), we could identify homes in greatest need of caregiver support (i.e., those in rural settings) as well as those in close proximity to institutions of higher education so that this project may build on the capacity of partnerships to make educational change.

The CARE Program offers a model for how institutions of higher education can enhance their communities by partnering with agencies in local communities to improve the care of individuals at a vulnerable time in life. In addition, we have found that students who have participated in the CARE program exhibit increases in empathy and report increased self-efficacy to provide end-of-life care upon program completion (Weisse, Melekis, & Hutchins, 2018). After 8 weeks of providing bedside care to terminally ill residents, students indicated a greater comfort managing symptoms, supporting family, understanding dignity, communicating, and providing direct bedside care. These are vital skills for future healthcare professionals and for the community at large.

Conference goals

The aim of this presentation is to discuss the value of engaging young adults in direct bedside care of individuals at the end of life and to describe an educational model that accomplishes this through partnerships between community-run residential homes that care for the dying and institutions of higher education. We hope to generate ideas for sharing and scaling the CARE program and to solicit input on ways of developing end-of-life care training hubs through local educational and community partnerships rather than through traditional academic medical centers. Additional topics for discussion in this session and throughout the conference could be 1) the use of digital technology to facilitate communication and collaboration among

community partners, 2) expanded discussion of the learning objectives of our online curriculum, and 3) scholarly endeavors made possible through research-practice partnerships. We would also welcome the opportunity to discuss educational approaches aimed at de-medicalizing death, as we recognize that when end-of-life care training is provided through specific academic disciplines or clinical specialties (i.e., nursing, medicine, social work etc...), the message is reinforced that care of the dying belongs exclusively in the hands of those with licensure or specialized certification.

Conclusion

As Atul Gawande (2014) states in his book *Being Mortal* "...our most cruel failure in how we treat the sick and the aged is the failure to recognize that they have priorities beyond merely being safe and living longer; that the chance to shape one's story is essential to sustaining meaning in life; that we have the opportunity to refashion our institutions, our culture, and our conversations in ways that transform the possibilities for the last chapters of everyone's lives." In order to improve end-of-life care, we must not overlook the contributions of young adults or exclude them from the conversations about the way people are dying. Medicalization of the dying process results when exposure to individuals who are dying occurs exclusively in institutionalized settings. Partnerships between institutions of higher education and residential homes for the dying are one way to engage the next generation in developing ways of fostering patient- and family-centered care. Through the CARE program, we hope to build the next generation of healthcare providers and palliative care scholars whose research agendas have been informed by experiences at the bedside. Through this program, we hope to cultivate communities of compassionate caregivers.

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Figure 1. Map of community-run residential homes for the dying, including 70 active homes (black) and 40 in development (blue). Interactive map available [HERE](#)

