

Using Existing Resources to Create a Successful End-of-Life Doula Program



The end-of-life doula role has emerged as an integral part of the interdisciplinary team caring for patients. The doulas provide an extra layer of support from a non-clinical lens to prevent crises, follow-up with families, and guide them through their journey. This manuscript describes how a hospice agency developed a performance improvement project to train volunteers to become end-of-life doulas through a rigorous training program, based on the Doula Model of Care. The implementation of the program was evaluated based on caregiver and staff satisfaction, and volunteer knowledge competency. The results from the pilot program showed mixed outcomes for patient and staff satisfaction, but created a rigorous training program for hospice volunteers. The COVID-19 pandemic disrupted data gathering and implementation of the program, so outcomes were varied. However, the program remains successful with ongoing training of the end-of-life doulas and an increase in new volunteers to support the program.

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The U.S. population of those 65 and older is projected to double and reach 80 million by 2040 (Mather et al., n.d.). The focus on community health and aging in place has increased dramatically, with palliative and hospice care critical for positive experiences at the end of life (EOL). The increase in the older adult population necessitates the creation of innovative methods to better utilize resources in support of patients and caregivers during critical moments. One of those emerging innovative concepts is the end-of-life doula (EOLD) role. In this role, individuals collaborate with ill patients to help guide them through the transition to death and support their loved ones through the dying process (Murphy, 2021). The EOLD, like a birth doula, provides compassionate care and assists with emotional, spiritual, and physical support to everyone involved with the EOL experience. Healthcare systems are adopting the EOLD model to recognize the growing movement and train individuals to assist patients and caregivers in providing non-medical support at the time of death.

Caregiver Burden at EOL

Care for loved ones often falls on family caregivers at EOL. The often-unanticipated increase in responsibility, emotional investment, and time spent are associated with distress (Haan et al., 2021). Extant research shows the wellness trajectories of caregivers follows the same path as those with serious illnesses. Stress in social, psychological, and spiritual domains among caregivers was similarly compared to the suffering experienced by patients (Bijnsdorp et al., 2022), and the patient's dependency and duration of care compounded stress levels among caregivers (Lindt et al., 2020). A 2022 study determined that caregiver burdens remained high or increased throughout the patient's illness, leading to caregiver burnout and illness (Bijnsdorp et al., 2022). Another study found deterioration in quality of life for caregivers of advanced cancer patients, with physical health being impacted the most (Koçak et al., 2022). These studies emphasize the need for more support and attention for caregivers to reduce the

risk of burnout and provide guidance in alleviating emotional distress.

The Doula Movement

Doulas, meaning “those who serve,” gained its modern-day definition in the 1960s with the natural childbirth movement and became widespread in the 1990s when training and certification became available (Knocke et al., 2023). Although doulas are traditionally associated with pregnancy, postpartum care, and support for the new mother and baby, doulas have emerged in EOL care to meet the needs of dying patients and their families and play a critical supportive role during this vulnerable time. The “Doula to Accompany and Comfort Program,” a grassroots volunteer-driven model launched in 2001 through the New York University Medical Center’s Department of Social Services, first formally used the term “doula” to describe a specific kind of EOL service.

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The doula role focuses on the social, psychological, and spiritual needs of individuals at risk of isolation during the dying process (Krawczyk & Rush, 2020). EOLDs provide emotional support, anticipate care needs, develop plans, suggest resources, and help coordinate care. The National End-of-Life Doula Alliance (NEDA), formed in 2018, seeks to elevate the role of EOLDs to a position that is recognized, understood, utilized, and well-integrated into mainstream EOL care practices (Brennan, 2019). NEDA has standardized the doula's scope of practice (Table 1), core competencies, and guiding principles, and created a mission synchronized with the World Health Organization's public health approach, *Compassionate Communities and Compassionate Cities*. This approach aims to motivate communities to take more responsibility for improving healthcare at EOL (Librada-Flores et al., 2020). Hospice programs throughout the United States can use the established model of birth and postpartum doulas to integrate EOL doulas into their teams for cost-effective, high-quality, patient-centered, and innovative care.

Purpose

This paper aims to describe how one hospice program trained volunteer EOLDs and integrated

them into the care team to address caregiver burnout and distress issues. The goal was to increase mutual satisfaction of the patient and caregivers, as well as the volunteers and other members of the interdisciplinary team.

The hospice agency, located in the Northeastern part of the United States, has a daily census of approximately 100 patients. The hospice serves a mix of rural and suburban towns over approximately 500 square miles. The hospice program is part of a not-for-profit community health system that includes a hospital, multiple outpatient primary and specialty practices, and a home health agency. Most of the hospice's funding comes from patients on the Medicare Hospice Benefit. Therefore, it operates according to the standard of practice delineated by the Medicare and Medicaid Programs Hospice Conditions of Participation.

According to Medicare regulations, hospice care is an approach to caring for terminally ill patients that provides physical, psychosocial, and spiritual care to the patient and their family members and caregivers, emphasizing keeping the patient home (Centers for Medicare and Medicaid Services, n.d.). The Conditions of Participation also stipulate that volunteers are integral as interdisciplinary team members in the patients' care plans. "Volunteers must provide day-to-day administrative and/or direct patient care services in an amount that, at a minimum, equals 5% of the total patient care hours." (Centers for Medicare and Medicaid Services, 2023.) At the conception of this project, our hospice agency had a volunteer participation rate of 9.8%. However, the volunteers gravitated toward caring for the inpatient hospice patients, so there was a need to create a program to shift to seeing more patients at the hospice care level at home.

The hospice program's volunteer coordinator and nurse resource manager recognized the value of volunteers and the potential to enhance the patient experience, retain seasoned volunteers, and attract new volunteers. Therefore, they proposed a pilot program to assess the feasibility of training volunteers to be EOLDs, utilizing existing resources to develop a volunteer EOLD role and assess the efficacy of employing volunteers in the doula role to improve caregiver, staff, and volunteer experiences.

Coincident with the planning of this project, the COVID-19 pandemic struck, threatening the program's robust volunteer participation, as the

Table 1. National End-of-Life Doula Alliance: Doula Scope of Practice

| End-of-Life Doula Scope of Practice |
|--|
| Provide non-medical, non-judgmental support and guidance to individuals and families through times of critical, transformative life change. |
| Nurture, inform, support, guide, empower, and comfort. |
| Work with other caregivers and members of the medical team. |
| Foster self-determination in their clients by assisting them in gathering information and encouraging them to make informed choices that are right for them. |
| Make referrals to appropriate professionals and community resources for client needs outside of the doula's scope of practice. |
| Support that is focused on and adapted to the unique needs and requirements of each family served. |

risk of COVID-19 was too high to allow volunteers to perform home visits. However, volunteers wanted to help the program's patients in any way they safely could. In addition, due to disruptions in patient care delivery, the team recognized a gap in care quality, especially in patient experience. The pandemic and its aftermath created barriers to positive patient experiences, including delays in referrals for hospice care resulting in shorter lengths of stay among hospice patients, a rising acuity among patients in home care, and heightened emotional distress for patients, families, and caregivers. Therefore, the agency developed a plan to train volunteer doulas who could initiate contact by phone and eventually include home visitation once pandemic restrictions were lifted.

Method

The first step was enlisting the health system's leadership and interdisciplinary team in the pilot program. Hospice leadership buy-in was crucial, but support was also necessary from health system executives. The program's Quality Assurance Performance Improvement committee had previously identified room for improvement in the areas of emotional support, communication provided to the family, and training the family to care for the patient based on their Consumer Assessment of Healthcare Providers and Systems Hospice survey. The latter two areas were particularly confounding, as the program had a considerable number of written materials to support the

education patients and families were provided verbally at home. The Quality Assurance committee hypothesized that the information provided in the initial days of service was overwhelming, and families did not return to these written resources once they settled into the hospice routine. The families would be exclusively assigned the same doula to provide continuity in care and deepen their connection with family members to provide emotional support.

After approval from administration and management, clinicians and staff of the hospice program were asked for feedback on the pilot proposal. Team members expressed concern that the families (and possibly the doulas themselves) would be confused by an additional role on the interdisciplinary team. They were also worried that the doulas would provide information outside their scope of practice (for instance, giving advice on medications or assisting with filling out financial aid applications). There was also some confusion about the program's EOLD volunteers as opposed to the somewhat broader role of doulas for hire in the community.

The team was encouraged to think of the EOLs as a hotel concierge, that is, someone who is an expert on where to find the information they need rather than imparting the information itself. The EOLs were trained to know every section of the Hospice Information Booklet. This manual,

provided to every family on admission, explains the hospice philosophy and program mission, patient and organization rights and responsibilities, home safety, symptom management, and guidelines on caring for their loved ones. EOLD also understood the supplementary materials provided by the agency, like a guideline explaining how to do a "Letting Go" ceremony and information on what to expect as the patient nears EOL. If families had questions beyond what the EOLs could substantiate with written materials, they would direct the caregiver to call the agency's clinical supervisor or after-hours nurse.

The interdisciplinary team (IDT) members were also tasked to find time points where caregivers would benefit from a doula. Team members gave examples, such as at the start of care when the volume of information is overwhelming or when the patient experiences physical or functional decline, particularly when death is imminent. Other indicators might include visits with caregivers who had many questions or repeated the same questions, were reluctant to allow visits to end, or had a higher volume of after-hours calls. Through this discussion, team members began to see how doulas could lighten the burden of an overwhelmed family or those with high emotional needs.

Recruitment

The volunteer coordinator contacted existing volunteers to survey those interested in participating in the pilot program and held an information session. Criteria to participate included volunteers with greater than 1 year of experience, who are/were caregivers, and had a willingness to commit to the role for 1 year. Interested volunteers were interviewed, and six were selected for the pilot program, which started in September 2020. The pilot coordinators explained the objectives of the role, training requirements, and the expectation of active participation; the volunteers fully agreed to commit prior to the first training session.

Framework

Doula Model of Care

The hospice team made use of pre-existing guiding principles for doulas caring for those at the EOL. The Doula Model of Care, developed by Brennan, describes the convergence of the principles of holistic care, family-centeredness, empowerment, non-judgmental support, non-medical support, and team collaboration (Figure 1). The six core

Figure 1. Doula Model of Care (c) Patty Brennan, LifespanDoulas.com



components of the *Doula Model of Care* define how services are delivered to patients and families based on best practice strategies for persons, populations, and groups as they progress through stages of their serious illness (Brennan, 2019).

Non-medical support clarifies that doulas refrain from performing clinical or medical tasks. Non-judgmental support implies that the doula does not impose their values or beliefs on the patient or caregiver. **A family-centered approach** focuses on the patient and family/caregivers as one unit. Doulas do not replace partners, family members, or other care providers (Brennan, 2019). This role is consistent with the hospice philosophy of empowering the family to provide care. The doulas care for family units **holistically**, including the biopsychosocial and spiritual aspects of the person and the eight domains of palliative care (Ahluwalia et al., 2018). Doulas **empower** the patient and family to advocate, make decisions based on all available information, and maximize autonomy. Finally, agency-trained doulas are members of the **hospice interdisciplinary team** and are involved in the hospice plan of care.

Curriculum Development and Education

The objectives for the EOLD volunteer program specified that doulas would:

- Become familiar with the hospice EOL doula philosophy and practices,
- Be able to disseminate information about hospice services,
- Understand the role of each member of the interdisciplinary team,
- Distinguish their role related to enhanced patient/caregiver experience, and
- Demonstrate knowledge and skills learned through training for the program.

The pilot coordinators trained the EOLD volunteers and educated the staff to deliver information on the structure and goals of the pilot program. Staff education focused on describing the role of the EOLD in the community and understanding the potential improvement in patient experience by providing an additional layer of support. This support included increased attention to patients and caregivers during transitions of care, managing patient and caregiver expectations, reinforcing teaching from the hospice staff, and providing affirmation to caregivers.

This manual, provided to every family on admission, explains the hospice philosophy and program mission, patient and organization rights and responsibilities, home safety, symptom management, and guidelines on caring for their loved ones.

The hospice team was given a detailed curriculum summary through the training process and was asked for their input. Concerns included how the EOLD would coordinate and communicate with clinicians, knowing their specific role and scope of practice, having them overlap or intrude with ongoing work being done with patients and caregivers, and making sure they have established their boundaries. These concerns were addressed by the project coordinators and staff was reassured they could provide feedback at any point during the pilot. The coordinators worked closely with the team and EOLD volunteers during the pilot to ensure clear communication occurred throughout the iterative process.

Curriculum Implementation

The coordinators provided a refresher course on core hospice concepts for the volunteers to establish a baseline. The six-member cohort had lengths of service ranging from 3 to 23 years. Based on Brennan's framework (2019), the EOLD training included education that was comprehensive and interactive. A multi-modality pedagogy approach was used, including didactic lectures, journaling, creating an "elevator pitch," role-playing scenarios, individual sessions, and supervised visits to patient/family homes.

The implementation period from May 2020 to October 2020 included presenting the curriculum and training program to various health system committees, including the Nurse Collaborative Council and the Quality Assurance Performance Improvement committees, presenting the program to staff and volunteers, gauging volunteer interest, selecting volunteers, conducting the training, and developing a procedure to match EOLD volunteers with patients/families. The estimated time for completion was 25 hours, including

attending IDT meetings, online training and follow-up meetings, ongoing support, and monitoring.

The in-person training sessions focused on an overview of the agency's hospice and palliative care program; a discussion of the patient experience scores; the role of the EOL doula, including its history and integration at this agency; and the role of the interdisciplinary team in patient-centered care. Between sessions, volunteers completed the *Online Volunteer Training Program* narrated by Gary Gardia (Gardia, n.d.). These modules focused on an overview of hospice goals and philosophy; dying, death, and bereavement; family systems, dynamics, and rights; communication and active listening; skills demonstrations; boundaries, Health Insurance Portability and Accountability Act, documentation, and self-care.

In addition to the Hospice Information Booklet, volunteers received material from the National End-of-Life Doula Alliance, books by Barbara Karnes, RN, and a copy of Medicare's condition of participation (Table 2). For homework, cohort members developed an "elevator pitch" to describe their role and identified the tools they felt they needed to support them in their role. Self-

reflection was also a critical element to allow the EOLD volunteers to understand the information and process their beliefs and emotions. The EOLD volunteers also had to attend two agency IDT meetings. The combination of education, resources, and participation in the IDT meetings resulted in well-prepared EOLD that competently expressed thought-provoking, sensitive, and creative approaches during case study discussions. In addition, EOLD were evaluated with a competency test and their development of an "elevator pitch."

Outcome Measures

Organization and Program Goals

Evaluation of patient, hospice staff, and EOLD experiences provided insight into the effectiveness of the program and changes needed for successful outcomes. Patient satisfaction was measured pre- and post-EOLD program implementation from three content areas of a satisfaction survey sent to all caregivers after a patient's death. Evaluation of staff focused on job satisfaction and teamwork collaboration before and after the EOLD volunteered with patients and families. The doula had to demonstrate competency by the end of the

Table 2. Curriculum Materials for End-of-Life Doula Training

| Material/Title | Information |
|--|--|
| Hospice Information Booklet | Information given to all patients upon admission with guidance on pain and symptoms management, resources, and emergency procedures. |
| Letting Go with Love Brochure | A brochure with poems, scripture readings, and words of comfort to assist caregivers verbalize assurances to patients to let go. |
| Gone from My Sight: The Dying Experience By Barabara Kearns, RN | A resource that clarifies the stages of dying in simple terms. https://bkbooks.com/collections/booklets/products/gone-from-my-sight-the-dying-experience?variant=36961181171868 |
| The Eleventh Hour: A Caring Guide for the Hours to Minutes Before Death By Barabara Kearns, RN | An accompanying resource to the above book that gives ideas for what to do, say, and care for a person at the end of life. https://bkbooks.com/collections/booklets/products/the-eleventh-hour-a-caring-guideline-for-the-hours-to-minutes-before-death?variant=36961177075868 |
| My Friend, I Care: The Grief Experience By Barabara Kearns, RN | A resource for those that are newly grieving with guidance through the stages of grief and moving forward into a meaningful life. https://bkbooks.com/collections/booklets/products/my-friend-i-care-the-grief-experience?variant=36961175863452 |
| Section 418 - Hospice from the Medicare Conditions of Participation | Medicare policies and regulations in hospice care. https://www.ecfr.gov/current/title-42/chapter-IV/subchapter-B/part-418 |
| Sample Patient Bill of Rights for EOLDs to Use | This statement by the National End-of-Life Doula Alliance addresses patient rights in quality care, safety, privacy, and information. https://www.nedalliance.org/ |
| At the Ready: How end-of-life doulas can support hospices By Lee Webster with Merilynn Rush, Suzanne O'Brien, Patty Burgess, and Deanna Cochran | https://www.nedalliance.org/learn-more-about-eolds.html https://www.nedalliance.org/uploads/1/0/9/9/109917739/at_the_ready_eolds_and_hospice.pdf |

training by completing and passing a quantitative exam and an individual interview with the program coordinators.

Patient Experience

Patient experience, measured by Consumer Assessment of Healthcare Providers and Systems surveys delivered to caregivers 3 months after the patient's death, is regulated by the Centers for Medicare and Medicaid Services. These surveys have a standard set of questions that measure the quality of communication with the family, getting timely help, treating the family with respect, addressing their emotional needs, and providing training for families to assume care for their loved ones, among other metrics. Barriers to meeting these outcomes include patient short lengths of stay on hospice, rising acuity of patients in home care, delayed referrals, and patients and caregiver information overwhelm at the initial visit. In addition, the impact of the pandemic necessitated an environment that provided additional support to patients and caregivers, maintained volunteer engagement without direct patient contact, and utilized the volunteer and coordinator's time effectively.

Patient experience also aligns with the goals of the hospice program and health system. The health system has achieved the American Association College of Nurses Magnet status for five terms and is currently completing an evaluation for its sixth. This pilot highlights one of the standards of the AACN Magnet tenets by adding an innovative initiative. Specifically, the following questions measured outcomes:

1. Did the hospice team give you as much information as you wanted about what to expect while your family member was dying?
2. While your family member was in hospice care, when you or your family member asked for help from the hospice team, how often did you get help as soon as you needed it?
3. How often did the hospice team listen carefully to you when you talked with them about problems with your family member's hospice care?

Staff Experience

The pilot focuses on the patient experience and goals of the health system but also addresses the satisfaction of the hospice staff. Initiating the pilot program could have been perceived as burden-

The six core components of the *Doula Model of Care* define how services are delivered to patients and families based on best practice strategies for persons, populations, and groups as they progress through stages of their serious illness.

some to staff as it was a change in practice. Team members expressed concern about having to correct misinformation if the EOLD did not relay information correctly. The program coordinators decided to focus on the variables of a) staff job satisfaction and b) teamwork collaboration. Data were collected from October 2020 through August 2021 and staff rated their satisfaction with job-related tasks and teamwork collaboration for individual hospice cases on a Likert scale (5 [strongly agree] to 1 [strongly disagree]). The scores were averaged and analyzed quarterly. The EOLD volunteers started working with patients in November 2020; therefore, initial data gathering occurred 2 months after these services began.

Volunteer Experience

The input of the volunteers trained to be EOLD volunteers was also critical. Volunteers were considered a specialty subgroup of hospice volunteers. Prospective doulas completed interest forms, which included questions such as their interest in becoming an EOLD, perceptions of their role with the hospice interdisciplinary team, their role in advocating for patients and families, and methods to maintain professional boundaries. Common answers included "being able to support people during transition" and "having direct involvement to support patients and families in the present." A recurring response to challenges as a volunteer included "setting boundaries" and "getting attached to patients and families." Finally, each volunteer gave examples of advocating and boundary-setting from previous life or work experiences. They described how they used skills from other experiences to apply them to current problems, showing the techniques they had developed in addressing difficult situations.

After selecting volunteers for the first cohort, the group completed the training in approximately 2 months. The evaluation of the volunteers consisted of a quantitative assessment and individual meetings with the coordinators to review course content, answer questions, and confirm their readiness to support patients and caregivers in their new role.

Data Analysis

Patient Experience

Analysis of patient satisfaction scores showed changes from 2020 to 2021 from survey data gathered from Strategic Healthcare Programs, a third-party performance improvement organization (Strategic Healthcare Programs, n.d.). During the fourth quarter (October to December) of 2020, a review of survey information created baseline data points before the EOLD volunteer began to work with patients. A comparison of data from the fourth quarter of 2021, approximately 1 year after implementing the pilot, showed slight changes in quarter scores. All scores from the three questions (mentioned above) were benchmarked with national scores to derive a percentage compared to national patient satisfaction scores. In 2021, caregivers receiving as much information on what to expect when a family member was dying increased by 3% compared to the same time in 2020. Satisfaction scores decreased by 2% for caregivers' perceptions of getting help as soon as needed but increased by 4% regarding hospice team

members listening carefully about their problems (Figure 2). Although these changes are slight and caregivers' perceptions about getting help as soon as needed decreased, the overall satisfaction of caregivers moved toward a positive trend. It is also critical to note that this was during the height of the pandemic and other factors likely contributed to the changes in scores.

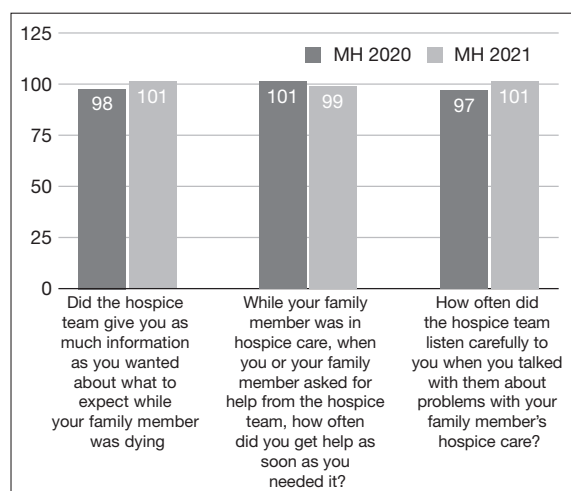
Staff Experience

Program coordinators tracked staff's perceptions of the EOLD program from October 2020 through September 2021. In October 2020, satisfaction was high for both job-related work and teamwork collaboration. Both averaged 4.7 out of 5. In January 2021, staff were dissatisfied overall with their jobs and how the team worked together. Scores averaged 3.86 for job satisfaction and teamwork at 4.1. However, scores increased throughout 2021, with average job satisfaction reaching 4.47 and teamwork at 4.7 (Figure 2).

Volunteer Experience and Competence

To evaluate the EOLD, post-training evaluations were completed. Each volunteer completed a competency assessment that included knowledge of hospice policies, procedures, structure, boundary scenarios, and EOLD scope of practice. After completing the assessment, each volunteer met individually with the program coordinators to review each question and answer. Most EOLD scored 80% or higher. The individual meeting ensured that all EOLD questions were addressed and the coordinators could discuss their knowledge and understanding of their role in the hospice interdisciplinary team with each volunteer.

Figure 2. Patient Satisfaction Scores Pre- and Post-EOLD Implementation



Discussion

The pilot program for training volunteers to be EOLDs was a significant endeavor to provide extra support to patients and families at the EOL. The program in its current state is thriving. Although improvements in patient satisfaction scores between 2020 and 2021 have been incremental, anecdotal feedback from families and caregivers has been instrumental in continuing the program and assessing each case individually. Caregivers reported increased satisfaction about receiving information from the team when their loved one was dying, and for feeling they had been listened to carefully. This showed that the EOLDs could

provide an additional layer of support as projected at the beginning of the pilot.

The program did not have a positive effect on family perception of receiving help as soon as needed; however, the ongoing COVID restrictions and shorter lengths of stay of patients on hospice services may have offset any gains the doula program may have offered. The pandemic prevented individuals from seeking medical care due to the dangers of contracting the virus (Czeisler et al., 2020). As a result, agencies saw a decrease in patients admitted to the hospice program due to a lack of referrals from physicians in the community. This delay resulted in an increase in acuity due to an influx of critically ill patients referred to hospice, but only staying on service for a few hours to a few days (Rogers et al., 2021). Many of these patients could only partially benefit from the services offered by hospice due to their short lengths of stay. For those patients who had a shorter stay, there was often no time for the EOLD to be introduced. In the current iteration of the program, doulas are making check-in calls in the first week of service to gauge the primary caregiver's understanding of the program and the arrival of durable medical equipment and the comfort pack medications. These introductory calls allow the doulas to establish their relationship with the caregivers earlier on and are expected to demonstrate a stronger impact on the "help as soon as needed" metric.

Similarly, staff satisfaction decreased from October 2020 to January 2021 and increased thereafter for the remainder of 2021. Many of the comments noted by staff when completing the qualitative evaluations included notations about COVID restrictions and their effect on job satisfaction. As mentioned above, the period after the first and second waves of COVID resulted in sick individuals who were not able to see their providers. This caused an increase in the number of patients who were severely ill resulting in new and difficult challenges.

Conclusion

The EOLD volunteer pilot aimed to extend additional support to caregivers experiencing the insecurity of caring for a patient at the EOL. As non-clinical personnel, they provide a bridge to understanding the more overwhelming clinical aspects of care by normalizing the dying process and gently reinforcing the teaching and resources

A multi-modality pedagogy approach was used, including didactic lectures, journaling, creating an "elevator pitch," role-playing scenarios, individual sessions, and supervised visits to patient/family homes.

provided to families on admission. Through their training and prior experience with dying patients, the doulas can support families, listen to frustrations, and guide care for a vulnerable population. In addition to demonstrating the use of hospice materials and resources to extend the work of the interdisciplinary team, they provide feedback to the team on areas where additional teaching may be needed.

For programs hoping to employ this model, it would be important to have interested volunteers complete a rigorous training program that assesses competency before introducing the role to patients and caregivers. Table 1 offers suggestions for a curriculum to prepare volunteers for this important role.

Plans for the pilot started before the pandemic surged in March 2020. However, administrators and those leading the program realized the value of the EOLD role and how it could serve patients and caregivers and proceeded to implement the program despite operational restrictions. The need for additional support was even more invaluable as the pandemic restricted home visits, provided an uncertain landscape on its impact, and sheltered patients and caregivers together. The EOLD volunteer, initially through phone calls and virtual methods, helped struggling families by assuaging frustrations of those restricted environments. This laid the groundwork for establishing the role that eventually transitioned to a hybrid of telephonic and in-person home visits.

Each situation for the EOLD volunteers has been unique, and ongoing training is crucial. A key part in retaining EOLDS is monthly check-in meetings where the EOLDS meet with the program coordinators to discuss challenges and successes, and to continually stay current on patient-centered initiatives within the program.

As non-clinical personnel, they provide a bridge to understanding the more overwhelming clinical aspects of care by normalizing the dying process and gently reinforcing the teaching and resources provided to families on admission.

The EOLD program is in its third year, and multiple cohorts of volunteers have been trained and matched with patients and caregivers. Through continuous evaluation of this quality improvement initiative, the position of the EOLD evolves to meet the program's needs. The retention of EOLD volunteers is at 90%, which has attracted new volunteers to the role. Staff have fully integrated the EOLD into the development of their patient care plans. Other agencies starting a EOLD program may benefit from analyzing outcome data 18 to 24 months after the initial implementation, as it may be difficult to determine accurate outcomes in a short period of time. In addition, during interim points, qualitative data should be gathered from EOLD, patients and families, and staff members, which could give insight into satisfaction, changes needed, and potential curriculum reorganization. Although the outcomes have yet to display the full impact of the EOLD role, the extra support and care given to these families has been invaluable and an essential part of the hospice care team. ■

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DOI:10.1097/NHH.0000000000001281

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