“Death is still a fearful, frightening happening, and the fear of death is a universal fear even if we think we have mastered it on many levels.”

Elisabeth Kübler-Ross, MD. On Death and Dying

By virtue of its structure, Western medicine is characterized by its cure-oriented approach to the patient. We pretend to master death and the fear of death, according to Dr Elizabeth Kübler-Ross. We are uncomfortable in situations when the patient’s prognosis is poor, because as health care providers, we are instilled with the idea that the ultimate goal in patient care is curing the patient. Thus, the fear of failure looms when aggressive treatment is no longer possible and many providers are reluctant to be straightforward with families in discussing end-of-life (EOL) care options. Unfortunately, this pandemic attitude of denial and avoidance has the unintended consequence of alienating both the dying and the aged and is a true disservice to all patients. Additionally, the current approach to EOL care often fails to accept the inevitable notion that just as there is a time for living, there is also a time for dying. With the advances in medical technology, one of the real challenges of modern medicine is accepting that dying is part of life’s journey for all individuals and that death does not represent a failure of the health care system or health care providers.

While working as a nurse and social worker with cancer patients, Cicely Saunders became aware of the extremely inadequate care provided for dying patients in England. She felt that the dying patient was not approached in a holistic manner and that the spiritual and emotional aspects of the dying process were most often neglected. After becoming a physician, Dr Saunders founded the first hospice in London in 1967 and spent most of her life researching pain management. Her philosophy and tireless work on behalf of the dying ultimately led to the creation of the medical specialty of palliative care and has undoubtedly resulted in making death a more humane process for countless numbers of patients. No doubt this movement has been marked by the increasing importance of nurses in the role of direct caregivers of dying patients.

One quarter of American elders die while institutionalized and one third of those die within 12 months of admission to a facility. This certainly underscores the notion that EOL care in nursing homes (NHs) has received special attention in the past decade. Equally as important, research has revealed several barriers for quality EOL care delivery in the NH setting. The policies and regulations in the NH are generally targeted toward rehabilitative and restorative care with the goal of improving or maintaining function, which can at times conflict with the needs of dying patients. Only 27% of American NHs report specialized internal programs and trained staff for hospice or palliative care delivery. A study by Resnick et al showed that only one quarter of the NHs sampled had employee training programs on pain management. Thus, universally, NH providers have knowledge deficits regarding pain and symptom management. This heterogeneity of provider experience likely decreases the effectiveness of pain management in the NH setting, which is unfortunate, as pain is one of the key symptoms to manage at the end of life.

Deficit in NH palliative care is also evident when caring for patients with advanced dementia and end-stage renal disease on dialysis. A large prospective study by Mitchell et al, among Boston NH residents with advanced dementia, showed that in the last 3 months of life these patients received more burdensome interventions (ie, parenteral therapy, hospitalization, emergency room visit, and tube feeding) and the rate of receiving them was related to the perception of residents’ prognosis by their proxy. Six months before death, complications included eating problems, febrile episodes, and pneumonia. This was related to higher mortality, which may be used as markers for EOL in this population. Deficient EOL care in advanced dementia is a reality that not only pertains to US NHs, but other countries in the world (eg, the Netherlands) have the same situation. On the other hand, NH residents with end-stage renal disease on dialysis have higher functional decline and very poor overall outcome. It is suggested that upon initiation of dialysis, rehabilitation treatment as well as conversations around palliative care should be added as options.

In this issue of The Journal, Zheng and Temkin-Greener focused on communication between certified nurse assistants (CNAs) and other NH employees and explored how communication influenced EOL assessment and care delivery. Communication, particularly among core NH staff members, is thought to be one of the underlying barriers preventing adequate EOL care delivery and was hypothesized to play an essential role in the assessment and management of EOL symptoms. The authors focused particularly on CNAs, as they form the backbone of the NH structure and have very influential roles in overall care delivery. In fact, CNAs likely spend more time involved in direct patient care as compared with other NH employees. The study was based on a secondary analysis of data originally collected for 2 independent NH survey projects conducted in New York State NHs. One survey included a 15-item assessment and was developed to
analyze the degree of communication between CNAs and their supervisors. The other survey was directed at directors of nursing (DONs) and sought to gain insight into their perceptions on how their particular facilities performed within the area of EOL care. Both surveys demonstrated good reliability and validity. Several other factors were included in the analysis, including information on staff education, hospice use intensity, nursing-to-staff ratio, staff/resident ethnic overlap index, facility religious affiliation, and ownership status (ie, for-profit versus nonprofit).

The 2 independent variables in the study were EOL assessment, which encompassed employee recognition of emotional and physical EOL symptoms, and EOL care delivery, which was defined as the management of EOL symptoms such as pain, depression, and dyspnea. Regression models identified 4 independent variables that improved EOL assessment and care delivery. NHs with better communication between CNAs and coworkers were associated with better EOL assessment and care delivery, as perceived by DONs. This was the only independent variable that influenced both EOL assessment and care delivery, indicating its significance. Increased staff education (ie, in-service lectures on EOL topics) was the independent variable with the largest effect, but was only influential in EOL assessment. The ethnic overlap index, which demonstrates the ethnic similarity between NH residents and staff, and hospice use intensity, which illustrates the propensity of NHs to offer hospice to residents, were both related with better EOL care delivery only.

This study demonstrates the positive association between CNAs’ perception of “good” communication and the self-reported NHs’ performances on EOL care processes, further underscoring how important CNAs are to NH infrastructure and in providing exceptional patient care.

Although these data are limited to NY State NH facilities, it is not far removed from data gathered in other American NHs. Parker-Oliver and Bickel performed a phone interview to administrators across 60 NHs in Missouri. Of the 40 NHs that participated (70% response rate), the overall experience with hospice was rated as “intermediate.” When asked to rate the NH staff’s ability to assess pain, DONs and administrators rated themselves as “high,” but most of the respondents acknowledged the need for additional education. Moreover, improved communication directly between hospice and NHs was recognized as a need by 15% of the respondents and the biggest barrier to hospice availability for residents was identified as an overall lack of communication in the community and among physicians. Another observational study among CNAs/registered nurses (RNs) in Florida (n = 146) from NHs and hospices found that CNAs perceived that they would influence the quality of life in dying residents further if their education and knowledge on EOL issues were more extensive.

A systematic review on EOL care in American NHs was conducted and demonstrated that most studies (43 articles) on this topic were both quantitative and qualitative. In these articles, communication among caregivers and between family and residents was identified in 7 studies as being problematic. Concerning caregivers, one study found that nursing assistants felt uncomfortable addressing dying patients’ fear of death or desire for death. Several studies determined that staff education was an area with room for improvement in their facilities. Nevertheless, after educational programs were offered, posterior analyses revealed no change in the caliber of EOL care delivery at these same facilities. This may be explained by the influence of other factors on care delivery, such as individual attitudes and beliefs, and overall work environment, including communication among employees.

Another suggestion is to develop a quality improvement (QI) process, like the one performed by Vandenberg and colleagues in a veterans home in Nebraska. The interdisciplinary team involved in the study identified key deficient areas in the EOL setting, developed specific changes, and then administered patient representative surveys. After analysis of the survey responses, the team recommended medical director in-service lectures on agitation and hospice in-service lectures for employees geared at improving the recognition and treatment of EOL symptoms. They also found that increased referrals to psychologists and social workers, earlier hospice and pastoral referrals, along with the increased use of volunteers promoted more holistic care. The team implemented these changes and was thus able to decrease the prevalence of symptoms (particularly pain and dyspnea), improve the overall quality of EOL care, including the spiritual aspects, and facilitate patients’ preparedness for death. Areas that did not change despite the interventions were depression, loneliness, and anxiety in patients, and family education.

External hospice programs have the potential to bring their experience and expertise into NH settings, enhancing the standard of care for all residents. State-level factors associated with NH and Medicare hospice collaboration, which exists in 76% of US NHs (in the 48 contiguous states), included having a lower proportion of persons older than 65 residing in rural areas, lower NH occupancy, and larger hospices, and presence of Medicaid NH reimbursement non–case mixed and paid directly to NHs for hospice-enrolled residents. However, it was really the rural composition of a state and its policies and health care market characteristics that either fostered or discouraged NH/hospice collaboration.

Currently, there are 3 ways hospice is provided in a NH. The first way is that a hospice company not affiliated with the NH comes into the NH to assist in assessment and treatment of EOL patients. In fact, in one survey looking at hospice usage in 1174 NHs, it was found that 78% have formal contracts with outside hospice services. The second way is to have a dedicated hospice unit within the NH (in the same survey, 5.5% of the NHs had specialized units), and the third way is some combination of the above. Regardless of the delivery method, it is essential to have specifically trained hospice staff for any of the venues to work properly, and this is not the norm for most institutions. Some of the NH characteristics found to be associated with increased likelihood of having special programs and trained hospice staff are having nonprofit status, location in the southern region of the United States, presence of a certified administrator, a contracted outside hospice provider, and having programs designed to address behavioral issues.
In addition to the increased presence of trained hospice staff, developing a practical tool to screen patients for their needs at end of life may be useful for all NH personnel. This suggestion is based on the fact that such tools are available for inpatient care. For example, Fischer et al. developed the CARING criteria (Cancer, Admissions ≥2, Residence in a nursing home, Intensive care unit admit with multorgan failure, ≥2 noncancer hospice guidelines) for patients admitted to the ICU who may benefit from a palliative approach. It would be useful if a similar screening tool could be developed to assess patients in the outpatient setting who would benefit from palliative care. In this screening process, the physician’s role is important. As described by Johnson, it is through physicians’ interaction with the patient, family, and staff that they have the potential to change NH culture to be more resident centered and promote care teamwork that eventually will facilitate identification of those patients who will benefit from palliative care. Levy and colleagues created the Making Advance Planning a Priority (MAPP) program, a program designed to identify NH residents at high risk of death and to evaluate EOL care outcomes for NH residents at high risk of death.

Parker-Oliver and Bickel stated, “it is time to accept the fact that nursing homes have three types of patients: Those requiring rehabilitation, those requiring treatment in order to maintain function, and those requiring palliative care/hospice.” As research shows, the hospice and palliative care options are deficient in most NHs and need to be improved, especially among residents with chronic pain, who are on dialysis, and who have advanced dementia. Along with the provision of effective, high-quality venues for further development of NH intraprofessional communication, EOL care may expand by educating the NH staff, and by establishing a QI process. If one quarter of our elders is placed in a NH, a significant proportion of them never to survive to discharge, should we not devote more time and resources into caring for them at the end of their journey? Although it may be impossible to truly master the fear of death, it is important to know that there is much that can be done to ease the anxieties of patients and loved ones once death is imminent.

REFERENCES