Invited Commentary

Palliative Care in the Nursing Home—Shifting Paradigms

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When asked about their preferred location of death, most people say they would like to die at home. Few people say they would like to die in the hospital. Nobody ever says they want to die in a nursing home (NH). But the reality is that many people will live out their final days and take their last breaths in the NH setting. In 2009, more than 1 in 4 decedents in the United States died in an NH.[1] This number is only expected to grow with population aging.

For years, death in the NH has been viewed as a bad outcome resulting from poor-quality care. Since the middle of the 20th century, NHs have been subject to regulatory scrutiny that viewed any sign of resident's decline as an indicator of NH negligence. This fact, combined with financial incentives that reward rehabilitative care, has resulted in NHs that are justifiably skittish about acknowledging death and decline in their residents. However, the truth is that most people who enter the NH are in their final months or years of life.[2] Decline and death are expected and inevitable outcomes. Denial of death and dying in the NH makes it impossible to recognize and address the many palliative care (PC) needs of this population.[3] Limited access to high-quality end-of-life (EOL) care means these vulnerable individuals are deprived of services that could ameliorate their symptoms, provide anticipatory guidance, and offer social and emotional support in their final days.

We are beginning to see a paradigm shift in acknowledging serious illness and death in the NH setting. Efforts to improve the quality of EOL care for NH residents are underway. Results from the PACE study reported in the study by Van den Block et al[4] demonstrate how the scope of these efforts is expanding. This ambitious, multinational, cluster-randomized clinical trial aimed to test whether a train-the-trainer PC intervention could improve quality of EOL care for NH residents in 7 European countries. Although this study showed slight improvements in staff knowledge of PC, there was no difference in NH resident's comfort in the last week of life—the study's primary outcome. Although these negative findings are perhaps disappointing to the study investigators and readers, they raise important questions and issues that inform the path forward.

Why did the intervention fail to reach its intended outcomes? The short and rather vexing answer is: we do not know. The authors propose several reasons: (1) the intervention was too complex; (2) the intervention implementation was suboptimal; and (3) the intervention components and primary outcome measure did not align. In another recently published article,[5] the PACE investigators discuss in greater detail challenges they faced in recruiting and collecting data in NHs in England, providing useful clues as to what may have happened internationally. Three quarters of eligible nursing homes in England did not respond or refused to participate. Managers for NHs who agreed to participate were often not present or forgot about the study at the time the researcher made the prearranged on-site visit. Most importantly, the investigators rightly noted that a single visit by the research team hampered the development of a relationship between the NH and research team. Thus, enthusiasm for the study may have been low to begin with, and was not helped by the scant contact between the research team and study NHs. What these findings underscore is just how critical it is to address, monitor, and document intervention fidelity and implementation processes in clinical trials, especially for multicomponent behavioral interventions intended to address complex multifaceted constructs, such as EOL care. Without robust data on implementation processes from other international sites beyond England, we are left wondering what happened.

Furthermore, this study highlights how challenging it is to affect patient-centered outcomes in palliative and EOL care research, particularly in the complex environment of the NH. The limited availability of appropriate measurement instruments, recall and proxy bias, and ceiling effects are all methodological challenges to measuring patient-centered outcomes in PC research. Add to this the challenges of conducting research in the NH—including high rates of staff turnover, lack of incentives for engaging in research, remote family members—it is remarkable that even this limited degree of research succeeds in the NH. The PACE investigators should be commended for undertaking such a large-scale, thoughtfully designed, and analytically rigorous study in which the primary outcome was a patient-centered measure of NH residents' experience at EOL.

Despite the challenges, it is imperative that we continue to try to improve patient-centered PC and EOL outcomes in the NH. First, we need to continue to test a variety of interventions to improve PC in this setting. A number of other studies testing novel PC interventions, such as telehealth PC consultations, are currently underway. We cannot know whether interventions will work until they are tested rigorously in the real-world setting with validated and responsive outcome measures. We should expect some of these trials will have negative findings and continue to publish these findings so that we can learn from them.

Second, we need to think about how to adapt already existing programs and infrastructure to improve the EOL experience of NH residents. In the United States, hospice is a model of care that has provided EOL care in the NH setting for decades. However, there have been concerns about the role of hospice in the NH setting, which has prompted attention from federal regulators. Concerns have focused on discrepancies between payments for hospice and the intensity of services required of NH residents, resulting in high profit margins for hospices and increased costs for Medicare.[6] Recent changes to the Medicare hospice reimbursement structure are intended in part to address these issues. As hospice reform efforts proceed, it is critical that we ensure that access to NH hospice services is not compromised. Furthermore, we must also work to integrate PC models earlier in the disease course, with seamless transitions to hospice when appropriate. Such an approach could help to ensure timely and cost-effective access to high-quality care for NH residents across the trajectory.

Finally, at the policy level, NH regulation and quality measures should include metrics on palliative and EOL care for NH residents. In the United States, all NH residents must have an assessment, referred to as the Minimum Data Set, completed at regular intervals. Although some assessment items include measures in PC domains (eg, pain and dyspnea), key elements are missing, such as documentation of preferences for EOL care and treatments. Surveys of quality of care solicited from bereaved family members, such as those collected for NH decedents in the Veteran's Affairs health care system, should be required of all NH decedents. Other quality metrics could include rates of PC involvement, hospice referral, and unwanted burdensome transitions to the hospital at the EOL.

An increasing number of people are dying in the NH. Failing to acknowledge that most NH residents are approaching the EOL deprives them of opportunities to access high-quality palliative and EOL care. We need to continue to invest in rigorous and high-fidelity research, model development, and policies that help NH residents live their final months and years in comfort and dignity.

ARTICLE INFORMATION

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