Integration of Palliative Care in U.S. Nursing Homes

Daniel Swagerty, MD, MPH
Professor of Family Medicine and Internal Medicine
Director of Geriatric Medicine and Palliative Care
University of Kansas School of Medicine - Kansas City, Kansas USA

Background
More than 25% of Americans now die in a nursing home and there is considerable evidence that long term care residents do not receive optimal end-of-life care. (1) Fortunately, internal palliative care programs and contracted hospice services are being used more frequently in this long term care setting. The interdisciplinary support of the palliative care or hospice team can be invaluable in supporting the usual nursing home care at a time when staff, family members and the patient are facing the increased and urgent needs associated with the dying process. (2)

Benefits of Palliative Care in Long Term Care Setting
Many healthcare providers, nursing home residents, and the families of nursing home residents are becoming aware that a goal of comfort is more satisfying and reasonable for nursing home residents, than are aggressive life-prolonging goals. (3) A well defined and resourced palliative care program can make it much easier for nursing home staff, physicians, and other providers to give comprehensive end-of-life care to those residents with life-limiting and terminal conditions. A palliative care program in the nursing home could take the form of either a specific internal program developed and maintained by the nursing home or by contracting with one or more community-based hospices.

Like most patients at the end of their life, nursing home residents prefer to remain in their usual setting. This arrangement supports the natural dying process in the nursing home. The many advantages of a focused palliative care program for the near terminal and terminally-ill nursing home resident are listed in Table 1. With the long standing presence of hospices in U.S. nursing homes, all of these advantages have been demonstrated as resulting from their care.

Some nursing homes are able to provide comprehensive palliative care that includes services that are equivalent to hospice care. However, nursing homes vary widely in terms of size, financial status, and population and not all are able to develop comprehensive palliative care programs. When residents reside in nursing homes without an active palliative care service, community hospices are often able to identify multiple unmet palliative care needs. In addition, there is good evidence that nursing home residents receiving hospice services are more likely to have good pain assessment and management, have lower rates of inappropriate medication usage, and are less likely to have physical restraints. Families also perceive that hospice improves nursing home care. (4). To date, internal palliative care programs in nursing homes are less wide spread and well established then hospices. The evidence has yet to be developed that internal palliative programs can offer the same end-of-life benefits to nursing home residents and their families currently provided by hospices.

Barriers to Palliative Care in Long Term Care

Government policy and reimbursement in the U.S. emphasizes rehabilitation and restoration of function as the goals of nursing home care. Yet, at the end-of-life, all indicators of successful restoration are going to fail. Additionally, nursing homes are one of the most heavily regulated U.S. industries. Many survey domains used to measure quality in nursing homes, such as weight loss, anorexia, functional decline, and increased usage of opioids and antipsychotic medication, are common and appropriate clinical presentations in palliative care. Therefore, addressing these clinical conditions as part of a palliative care approach might be perceived as indicating poor nursing home care unless goal setting and documentation is explicit. It is imperative to recognize and avoid this "clash of philosophies" in order to advance quality end-of-life care in nursing homes.

In the U.S., reimbursement for end-of-life care has favored the growth of community-based hospices. To their credit, hospices have developed considerable expertise in delivering quality end-of-life care to terminal patients with good evidence that measurable outcomes are improved when hospice is involved in the care of terminally-ill nursing home residents. However, there is still a significant gulf between the cultures of hospices and nursing homes.

A variety of financial disincentives create barriers to referral of nursing home residents for hospice services. These barriers can make hospice an undesirable choice for residents and their families, as well as may make nursing homes less likely to refer. This is especially true for residents being admitted from the hospital after a sentential health event, some of which may indicate a life-limiting or terminal prognosis. The Skilled Nursing Home Benefit is more affordable for residents than paying privately for room and board care in the nursing home under the Medicare Hospice Benefit. In addition, when a resident elects the Medicare Hospice Benefit rather than the Skilled Nursing Home Benefit, the nursing home receives a lower reimbursement rate through private payment from the resident or Medicaid. Together, these factors create a substantial disincentive to hospice enrollment for the nursing home, as well as the resident and their family. These and related reimbursement systems need to be reevaluated and redesigned to eliminate inappropriate barriers to hospice access. Furthermore, nursing homes should be able to facilitate this choice without the concern about financial risk or losses.

Other common barriers to high quality end-of-life care in U.S. nursing homes include; 1) many facilities do not have established procedures for ensuring that appropriate residents receive palliative care services, 2) high nursing home staff turn-over and insufficient staffing, 3) limited staff training, and 4) most residents have multiple co-morbidities, including progressive dementia in more than half. This makes life expectancy estimates much more difficult. Nursing home residents with dementia are more likely to be referred later than residents with a cancer diagnosis, which often has a much more predictable life expectancy. (5-7)

Overcoming the Barriers

Ideally, internal palliative care programs in nursing homes would offer the best hope for wider implementation of quality end-of-care in this setting by becoming integral to the care-planning for every resident. However, reimbursement for nursing homes does not favor end-of-life care nor are most facilities currently equipped with the clinical expertise and administrative infrastructure needed to fully implement this type of care for those residents at the end of their lives. These two primary barriers would need to be first addressed before quality end-of-life care becomes part of the "fabric" of U.S. nursing home care.

Methods to meanifully merge quality end-of -life into the usual nursing home services must be sought in order to improve medical and quality of life outcomes, as well as family and nursing home resident satisfaction. First, both nursing homes and hospices must be receptive to education and cross-cultural exchange to offer the high quality end-of-life care benefits desired by nursing home residents and their families.

In the short-term, there are many impactful methods to overcome the barriers to quality end-of-life care for nursing home residents through the use of hospice; including, 1) improved communication between patients, physicians, families, nursing home staff, and hospice professionals, 2) support for advanced care planning, 3) explicit goal setting, 4) proper documentation by the hospice and nursing homes, 5) appropriate, earlier referrals to hospice, 6) education of hospice and nursing home health professionals, residents, and families.

The long term solution to providing quality end-of life care to nursing home residents is though self-directed programming by nursing homes. However, adequate financial resources must be provided both external and internal to the facility. For example, the Medicare Hospice Benefit and the Skilled Nursing Home Benefit must be placed on financial parity for residents and nursing homes for the care of residents with life-limiting or terminal conditions. This decision must be made on the basis of clinical benefits rather than financial ones. Developing and maintaining internal palliative care nursing home programs will then be contingent on facilities possessing the required clinical and administrative expertise required to deliver quality end-of-life resident care given the many competing demands on their staff.

Conclusion

There is good evidence that end-of-life care for many U.S. nursing home residents is suboptimal. It would be ideal for nursing homes to provide palliative care as part of a seamless continuum of care from restorative care and rehabilitation, through long term and dementia care, to end-of-life care as dictated by the needs of the resident. However, the U.S. reimbursement and clinical care systems have favored supplemental hospice services as an addition to the usual nursing home services for nursing home residents with life-limiting and terminal conditions. .

Barriers to hospice providers providing end-of-life care in the nursing home include the emphasis upon restoration and rehabilitation by the long term care survey process and funding sources, lack of communication between the nursing home and hospice providers, and late referrals to hospice due to the difficulty in predicting life expectancy for many nursing home residents. Improved communication, goal setting, documentation, and education can overcome these barriers in the short term. The long term solution for providing quality end-of-care in nursing homes is improved, focused and direct reimbursement to the facilities for this type of care. Clinical and administrative expertise in providing comprehensive palliative care would then need to be developed and maintained on a wide spread basis by the facilities.

References

1. Casarett D, Karlawish J, Morales K, et. Al., Improving the use of hospice services in nursing homes, JAMA 2005:294:211-217
2. Keay TJ, Schonwetter RS, Hospice care in the nursing home, Am Fam Physician 1998;57:491-497
3. The care of dying patients: a position statement from the American Geriatrics Society. J Am Geriatr Soc 1995;43:577-8.
4. Miller SC, Mor V, Teno J. Hospice enrollment and pain assessment and management in nursing homes. J Pain Symptom Manage. 2003;26:791-799.
5. Petrisek AC, Mor V. Hospice in nursing homes: a facility-level analysis of the distribution of hospice beneficiaries. Gerontologist. 1999;39:279-290.
6. Zerzan J, Stearns S, Hanson L. Access to palliative care and hospice in nursing homes, JAMA 2000;284:2489-2494.
7. Hanson LC, Ersek M. Meeting palliative care needs in post-acute care settings "To help them live until they die" JAMA 2006;295:681-686.

Table 1
Advantages of Focused Palliative Care for the Near Terminal and Terminally Ill Nursing Home Resident

- Better Pain Assessment and Management
- Lower Rates of Inappropriate Medication Usage
- Less Physical Restraints
- Resident Kept in his/her Own Environment
- Services Provided Beyond those Usually Offered in Nursing Homes
- Medical Goal becomes Pain Relief and Symptom Control.
- Management of the Residents Increasing Hygienic Needs.
- End of Life Education for the Family and for the Nursing Home Staff.
- Bereavement Support for the Family, and the Nursing Home Staff
- Prolonged Visits for Compassionate Listening and Companionship.
- Providing Medications and Medical Supplies Related to the Terminal Diagnosis.
- Spiritual Support.
- Limiting Hospitalizations and Life-Prolonging Therapies.
- Greater Satisfaction of Surviving Family with the Nursing Home.
- Education of the Nursing Home Staff on End-of-Life Care.