End of Life in the Nursing Home: Redefining Roles

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In this issue of the Journal of the American Medical Directors Association, Waldrop and Nyquist present the results of a recent study on end-of-life care in the nursing home. They interviewed staff to understand perceptions and experiences in caring for nursing home residents who are in transition from chronic to end-of-life care. Their findings support and expand on similar findings from 2 previous studies that found that reports of nursing home staff indicate they are able to identify residents facing end of life as well as understanding the unique needs of dying residents. Finally, all 3 studies identify tension between traditional long-term care and care needed at the end of life.

Despite an overwhelming amount of research on end-of-life care in the nursing home, the tensions between chronic care and end-of-life care in this setting remain. Policy initiatives have been introduced and several interventions have been attempted, yet challenges still exist. The ability to identify the appropriate time to change the goals of care from rehabilitation and maintenance to palliative and comfort care are keys to understanding what is needed at the end of life. New models of care have been outlined to balance these 2 approaches, but implementation does not appear forthcoming. Despite consistent evidence outlining the need to improve care for dying residents in the nursing home, successful intervention and change still appear to be a distant dream.

Policy has moved forward that supports quality end-of-life care. The financing of additional resources (hospice) to support the delivery of specialized end-of-life care has had an impact; however, evidence continues to show less than desirable results. This speaks to a cultural tradition that ignores the reality of death and dying. For new models of care to emerge, the American way of dying and, more specifically, attitudes toward it in the nursing home are in need of major change.

One description of the cultural tension between caring for the chronically ill and the dying was presented in 2000. Using a dramaturgical model, a new role for nursing home residents was suggested. Residents not facing the end of life are considered chronically ill and therefore assume the role and expectations of functionally capable individuals. As they age and their health declines, they need to assume a new role, a dying role, and cultural expectations and behavior need to change to support it. Goals of care need to change, family systems need to realign expectations, and nursing home policy and staff need to realign care. Although this sounds quite logical, there are barriers in the recognition, acceptance and redefinition, and transition to the new role.

The first step in redefining roles and realigning systems is the identification that it is time for a transition. Key questions need to be answered: When is it time to move someone from a chronic to a dying role? And, how do we know when someone will die, how do we predict it? In recent years, several attempts have been made to answer these questions. At least one intervention attempted to identify and move residents toward conversations regarding goals of care, yet it was less than successful. In addition to predicting death and statistically identifying it through the study of the medical chart and other variables, conversations about it are essential. Discussed by Porock in a recent editorial, the value of early recognition and acceptance of eventual death is that it can initiate ongoing discussions among family members, opening communication regarding choices, and this regardless of the prediction generated by any statistical model indicating that the transition time is here.

Difficult and caring family conversations are needed to move to a new definition of roles. Recognition of the reality of death on admission to the nursing home, although death is perhaps not imminent, is an important step toward change. Family members need to be supported to understand that there will come a time for their loved one to move from a functional to a dying role, and alerted to the fact that a change in goals of care to support these new expectations will be required. Porock’s editorial compared these caring conversations about death to a birthing plan, both loving and open discussions to identify important decisions and choices, and both done in advance of the expected outcome.

Any comparison of a dying and birthing experience should include the environments in which these experiences occur. Nursing homes were designed for and became regulated facilities to improve or maintain the function of residents. This philosophy of care is challenging for residents who are dying. Continuing retirement communities have long recognized the different needs of residents as they move from independent housing to assisted living and, finally, to skilled nursing care. However, further innovations and level of care discussions seem to stop there, and so do the options. It’s as though you move to skilled care and that’s it, there is no recognition of the final step, the end of life. We suggest...
this is a golden opportunity to introduce the dying role and to consider a comfortable homelike environment that is more appropriate than the traditional one. Like birthing rooms in hospitals, rooms designed to support the dying are appropriate and needed.

We can learn from other cultures. Cecily Saunders identified the need for a special environment for the dying when she established St Christopher’s Hospice in England. Saunders, trained as a physician, social worker, and chaplain, pioneered a movement for a special kind of caring for the dying (hospice) and a special environment in which the drama could play out. The hospice movement in the US modified the UK concept and designed care to be delivered instead in individual homes. This, of course, reflected the desire of most Americans to die at home. It overlooked, however, those for whom dying in a private dwelling was not an option. For many, home is a skilled nursing facility, and although Medicare reimburses hospice care in the nursing home, it does not change or modify the culture; it only provides a supplement by adding hospice staff and expertise into the mix.

There are a few nursing homes that have attempted to create specialized environments for the dying. Usually termed, “hospice rooms,” these are usually redecorated rooms labeled as special places for those who are actively dying. There are no financial incentives, no renovation funds, and no standards guiding the construction and interior design of these environments. These innovators have attempted to support a change in culture and transitions to a new role for those who are dying.

Nursing homes were built as institutions to maintain function and independence for the chronically ill, and yet nearly every person not transferred to a hospital or receiving short-term rehab care eventually dies there. The conflict between the goals of the institution and the reality of dying is well researched. The culture, philosophy, and environment for the needs of the chronically ill (rehabilitation and maintenance) reflect different needs than those necessary to provide palliative care. Independent living and assisted living have emerged as new models and are successfully integrated yet separate from long-term care; similarly, a separate model is needed for the drama of dying. In short, a continuum of care needs to be established within nursing homes. Residents should expect that their care choices do not end with admission to a skilled nursing facility, but rather end with a transition to a dying role in an environment with a plan of care that is appropriate for the end of life. When skilled nursing facilities are proud of the care they provide for the dying as much as for the living, and proud of the environments they have created for both sets of residents, a new day will have arrived.

REFERENCES