

Researchers survey strategies to improve end of life quality

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Globally, 20 million people per year require palliative care at the end of their lives.

A new study by Cornell researchers has identified strategies that could help improve their quality of life, especially as their lives come to an end.

The team surveyed 133 staff and volunteers who provide end-of-life care to patients in home and institutional settings for four organizations in two counties in upstate New York. The study points to improvements in end-of-life care through institutional policies, palliative care practices and facility design.

The findings are highlighted in "Strategies to Improve Quality of Life at the End of Life: Interdisciplinary Team Perspectives," published in June in the *American Journal of Hospice and Palliative Medicine*. The authors are assistant professor Rana Zadeh, professor Paul Eshelman and postdoctoral associate Hessam Sadatsafavi from the Department of Design and Environmental Analysis in the College of Human Ecology, as well as Judith Setla, medical director of Hospice Central New York.

"This ethnographic study ... is intended to add to the sparse but growing literature promoting quality of life from a practical perspective and to act as a precursor to further research on designing and managing environments to improve both quality of life and end of life."

Survey responses from physicians, physician assistants, nurse practitioners, registered nurses, social workers, chaplains, administrators and volunteers identified numerous areas to enhance and safeguard quality of life for end-of-life care patients and their families.

These included organization philosophy and mission; organizational policies; caregivers' behaviors and practices; symptom management; facility design, operation and management; and patient, family member and caregiver experiences.

The recommendations included family access to 24/7 visitation, patient mobility in the facility and access to the outdoors, staff access to stress relief programs and break times, and avoiding over sedation of patients while promoting spiritual care and counseling.

The study found establishing trusting relationships with caregivers through positive social interactions was important. Optimization of facility space and layout allowing for greater interaction between family members, caregivers and patients were also seen as priorities.

"The diverse list of identified strategies indicates that improving care to address the unique, complex, multilayered dimensions of quality of life at the end of life requires a multidisciplinary approach and consistency among care providers, including administration, clinical management, front-line caregivers and support staff," the authors wrote. "One important implication of the data is that strategies should be applied in concert and tailored to the desires of the individual. When all of these strategies are used in harmony, quality of life in end-of-life care can truly be enhanced."

For example, strategies that provide residents access to the outdoors need the support of the facility's physical environment, staff commitment and regulations.

"The facility would need to have an accessible pathway as well as a pleasantly designed outdoor space protected from rain and wind," Zadeh said. "Staff would need to 'buy in' to the idea of taking patients outside, and an organizational policy would be required that allows patients to spend time outdoors. If one of the three pillars is missing, the aim of healing and soothing patients through such a strategy won't be accomplished."

The research results are neither definitive nor universal to all care settings, the authors said. But seeking knowledge from multidisciplinary teams of end-of-life care providers demonstrates an investigative approach that helps fill gaps in current research. Similar investigations can help generate guidelines to help reduce unnecessary suffering and optimize resource use.

Eshelman points to a "painfully compelling" finding from one of the study's focus groups: Progressive loss of control, not only for the patient but also for their loved ones, marks the path toward the end of life.

"If one of the goals in the design of an end-of-[life](#) care setting was to accommodate the urge to maintain control, the concept of flexibility could have relevance and be appropriate for application in the design process," Eshelman said. "A question that would be useful in informing the design process then would be, what is the nature of flexibility in an [end-of-life care](#) setting such that meaningful and manageable control actually will be realized by [patients](#), [family members](#) and staff?"

Eshelman says that similar questions seeded by the present study have the potential to frame a substantive program of research for years to come.

More information: Strategies to Improve Quality of Life at the End of Life: Interdisciplinary Team Perspectives. *American Journal of Hospice*

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