Published in final edited form as:

Am J Hosp Palliat Care. 2018 March ; 35(3): 411–416. doi:10.1177/1049909117711997.

Strategies to Improve Quality of Life at the End of Life: Interdisciplinary Team Perspectives

Rana Sagha Zadeh, MArch, PhD¹, Paul Eshelman, MFA¹, Judith Setla, MD, MPH, FACP^{2,3},
and Hessam Sadatsafavi, MS, PhD¹

¹Department of Design and Environmental Analysis, Cornell University, Ithaca, NY, USA

²Hospice of Central New York, Liverpool, NY, USA

³SUNY Upstate Medical University, Syracuse, NY, USA

Abstract

This ethnographic study draws on the experiences of members of interdisciplinary care teams working with end-of-life care patients to identify strategies to improve quality of life through care practices. We surveyed 133 staff and volunteers (physicians, physician assistants, nurse practitioners, registered nurses, social workers, chaplains, administrators, and volunteers) who provide end-of-life care to patients in both home and institutional settings for 4 organizations in 2 counties in Upstate New York. Survey responses were analyzed using qualitative content analysis. The results identified numerous strategies to enhance and safeguard quality of life for end-of-life care patients and their family members. These strategies can be categorized into 6 domains: organization philosophy and mission; organizational policies; caregivers' behaviors and practices; symptom management; facility design, operation and management; and patient, family member, and caregiver experience. 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. When all of these strategies are used in harmony, care can truly be enhanced.

Keywords

end-of-life care; terminal illness; quality of life; symptom management; patient experience;
advanced life-limiting illness; good death and dying

Introduction

Globally, 20 million individuals annually require palliative care at the end of life (EOL). Such care is an essential part of a society's continuum of care, and the World Health

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Corresponding Author: Rana Sagha Zadeh, PhD, MArch, Department of Design and Environmental Analysis, Cornell University, 2425 Martha Van Rensselaer Hall, Ithaca, NY 14853, USA. rzadeh@cornell.edu.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Organization identifies palliative care and the reduction of unnecessary suffering of patients and families as an urgent humanitarian need.¹ The central concern is enhancing the quality of life (QOL).

Over 50 years ago, Cicely Saunders launched the modern hospice and palliative care movement with her multidisciplinary concept of “total pain,” which included the physical, emotional, social, and spiritual elements of distress.^{2,3} Since then, the definition of QOL has evolved to include 5 accepted dimensions of well-being: physical, material, social, emotional, and developmental.⁴ In 2000, Steinhauser et al investigated the perspectives of patients, family members, physicians, and other caregivers on what they consider to be important factors at EOL.⁵ The study confirmed that a “good death” includes, but goes beyond, physical care and encompasses a broader psychosocial and spiritual sense. Yet, the authors explained that a good death is not universally defined but instead differs among various stakeholders and between individual cases, which may be attributable to the uniqueness of each life experience.

Further evidence of variance can be found in a 2012 study involving hospitalized patients with cancer. Evaluations of QOL based on clinical and palliative care practices in the last week of life concluded that when a cure is no longer an option, QOL was higher if patients avoided hospitalization, had lower levels of worry, practiced prayer or meditation, were visited by a pastor, or felt an alliance with their physicians (20% of the variance). Yet, the remaining 80% of variance in QOL was left unexplained.⁶ Some documented factors that may help explain the variance included high symptom burden, unnecessary treatments in the final days of life,⁷ unmet needs, and family stresses associated with providing care.⁸

The nature of QOL at EOL is complicated by the cost of EOL caregiving. Caring for individuals with multiple serious and complex conditions during their final years of life is expensive. In the United States, about a quarter of all Medicare spending is on EOL services.^{8–15} Improving care to address the multilayered dimensions of QOL at EOL has been a research priority for decades.¹⁶ However, more guidelines are needed to apply QOL definitions into care practice, thereby reducing unnecessary suffering and optimizing resource use.

Our research team learned in early conversations with care teams that looking at isolated QOL factors without understanding the interrelationships among factors and players is not effective. Therefore, this first ethnographic study aimed to identify individual and integrated strategies for improving QOL in practice by drawing on the experiences of clinical and nonclinical members of EOL care teams. This article is intended to add to the sparse but growing literature promoting QOL from a practical perspective and to act as a precursor to further research on designing and managing environments to improve QOL at EOL.

Methods

Participants

From November 2013 to January 2015, we conducted a survey of multidisciplinary teams of EOL providers in 4 organizations that collectively provide care in either home or

institutional settings in urban and rural areas of Tompkins and Onondaga Counties in New York State. The organizations included an inpatient hospital's palliative EOL care division (site 1); a hospice and palliative care organization that provides care in homes, an EOL shelter, assisted living facilities and nursing facilities but does not have an exclusive location (site 2); a palliative EOL care hospice organization with an exclusive residence (site 3); and a community shelter exclusively for terminally ill patients (site 4). The staff who participated delivered care to patients in a variety of settings including hospitals, hospice inpatient residences, nursing homes, assisted living communities, community shelters, and private homes.

The participants were representative of a multidisciplinary team of EOL providers, including clinical and nonclinical staff, both full-time and part-time. Volunteers were later added to the pool based on feedback from focus groups. Participants provided either direct care (positions such as physician, nurse practitioner, registered nurse, physician assistant, social worker, chaplain, and aide) or indirect care (positions such as administrator, harpist, massage therapist, and gardener) during day or night shifts. Volunteers were defined as family members of former patients or residents who were recruited 2 years subsequent to the passing of their loved ones to help with EOL care by providing company to residents.

Survey Development

Following an integrative literature review, we conducted interviews with leaders at the 4 organizations and a supervised field observation of each organization. We developed a draft survey with demographic and open-ended questions, which was edited based on feedback by clinical leaders who improved the language and content to match the organizations' culture, demographics, and terminology. The survey was piloted at each organization in focus groups that, when combined, included at least 1 representative of every job title category. The final survey included structured demographic questions, a semi-structured question including 6 topics, and a nonstructured question. The demographic questions asked about age group, gender, current professional role, and the EOL setting where the respondents currently provide care. The semistructured sections focused on features of the care environment that promote 7 areas of QOL: reduction of confusion, improvement of sleep, spiritual well-being, personhood, comfort and pain management, emotional well-being, and social connection. The open-ended question asked participants to describe what makes a good EOL care experience and provided a section for additional comments.

Data Collection Procedure

Our university's institutional review board approved the study prior to initiation. Focus group participants included a total of 38 individuals at site 1 (n = 12), site 2 (n = 8), site 3 (n = 12), and site 4 (n = 6). After the focus groups were completed and the surveys were adjusted, the main study was conducted. For the main study, leaders at each organization recruited professional staff to participate in meetings with the researchers. The researchers presented the study, answered questions, provided each staff member with a copy of an information sheet and the blank survey, and placed a sealed survey drop box in a common area. The recruitment of volunteers was via a web invite sent to a list of potential eligible

volunteers provided by the facility leaders. We developed an identical online version of the survey for volunteers.

Qualitative Data Analysis

We applied a content analysis method of qualitative inquiry to synthesize and summarize the survey responses. Content analysis is a standardized process to decode data patterns and to cluster similar concepts into a reduced number of categories inductively.^{17–19} All handwritten survey responses were typed and any illegible text was reviewed by multiple team members. The initial coding and synthesis of the data were done manually via hard copy prints of the typed transcripts and reviewed by 2 parties. The surveys and coding were imported digitally into Atlas.ti Qualitative Data Analysis Software. The initial coding was revised via software by 2 researchers, reviewed by a third party, and disagreements in coding or categories were evaluated by the entire research team. On areas where consensus was not achieved, a meeting was held with clinical and administrative representatives from the facilities to resolve conflicts. The output containing the emerging domains and the relationship was documented regardless of frequencies. Finally, the facility representatives were invited to review the emergent domains and structures and finalize the categories and subcategories.

Results

A total of 131 caregivers participated. Table 1 summarizes the response rate, demographics, and job titles. Six domains and several subdomains emerged from the content analysis of care-givers' responses regarding ways to improve QOL for EOL patients, reduce staff burden, and enhance the experiences of family members (Table 2).

Organization Philosophy and Mission

Ideal EOL care requires an organizational approach that promotes “understand[ing] patient/family religion, belief, [and] culture” and customizing solutions according to individual needs, including preferences regarding “language” and “church members or social groups visiting or privacy [conditions].” This requires a system that tolerates some inefficiency in order to align with the patient's needs.

Respondents emphasized prioritizing patient comfort over work routines and “a policy of doing medical interventions as little as possible and only as needed for patient comfort” with “minimal intrusion on [the] patient within the bounds of good care.”

Organizational Policies

Methods to support QOL through organizational policies include planned activities, massage, aromatherapy, music therapy, appetizing food services, promotion of low-noise and low-light scheduling routines, appropriate numbers of staff, encouragement of caregiver well-being (including education and self-care), personalization of the care environment, 24/7 visitations, patient access to the outdoors and pets, and frequent cleaning and maintenance (including minimization of odor and germs).

Respondents expressed a need for “stress-relief programs for staff.” Break times must be incorporated such that “staff can be totally unavailable while on break and [the] residence can still meet legal regulation.” A “continuity of caregivers” is also important, making sure that “not too many different people” interface with patients.

Respondents approved of a policy that “family can bring in familiar items for [a] resident that they had at home.” One respondent mentioned that “some residents want all of their treasures around them and some may not have any—but it is so important to have the option.”

The respondents also explained that policies should “allow someone who is near death but wishes to be outside to do so.” One commenter said, “Sometimes the fresh air and being able to look or even go outside can cheer up someone who is seriously ill.” Another respondent said that “one of the residents was able to go outside in a wheelchair if she had someone to take her, and she enjoyed being pushed around the neighborhood.”

Caregivers’ Behaviors and Practices

Participants explained that “this is a very intimate and often challenging time for patients” and that “establishing trusting relationships with caregivers” is important for QOL. Therefore, care must be provided “by compassionate, selfless individuals focused on the care of the dying person.” This requires “well-trained staff and volunteers” with skills including “dignity/acceptance,” “tenderness,” “compassion,” and “empathy that facilitates emotional release.” Caregivers need the skills and means to evaluate and understand “patient/family wishes” and “meet them where they are at,” so that the patients “feel the focus is only on them.”

Ideas about skillful communication with patients and family members included actively listening, asking questions, speaking clearly, describing procedures and care, avoiding harsh language, and answering questions fully. Consistency among staff members is important. Participants recommended “peace in everything that is being done, whether from a doctor or the housekeeper.”

Participants emphasized fostering a sense of independence, “mak[ing] the patient feel useful if ambulatory,” and enabling them to be “doing as much as they can.” Privacy and dignity can be increased by giving the “patient control over environment and who comes and goes”; “offering choices with linens, music, TV, etc.”; and minimizing distractions such as “noise, motion, vibration, and door movement.” Caregivers said that “providing privacy translates [into] trust and being valued as an individual.” Patients should be provided with “knowledge of what is happening to them.” For example, “explain as changes take place [and] assure [patients] that everything is okay.”

Respondents also highlighted the importance of following protocols of physical care by frequently monitoring patients, providing timely care (as defined by patients), respecting patient sleep and rest needs, frequently repositioning patients, encouraging ambulation when possible, and ensuring proper personal hygiene.

Symptom Management

Regarding physical symptoms, both pharmacological and non-pharmacological approaches were highlighted. Medications were mentioned as often being necessary to manage symptoms of pain, circadian rhythm disruption, wound care, nausea, shortness of breath, delirium, and infection. However, respondents emphasized avoiding oversedation, frequent reviewing and adjusting medications, and administering medication in a timely manner. One respondent commented on the need for “a staff orientation [about] being very proactive in supporting comfort and being willing to risk sedation if [the] patient/family is willing to promote comfort.”

Nonpharmacological approaches were mentioned for managing pain, wound care, delirium, and sleep and wake cycles. One participant commented that “for nausea, just repositioning can make a world of difference.” Another stated that “music ... reduces restlessness, agitation, and improve comfort/decrease pain.” Another participant commented that “providing heating pads can be very comforting. I had one female patient whose abdominal pain responded very well to warm heat applied to her stomach. The facility did not provide heating pads, but [only] heated gel packs, which did not last very long and seemed to take forever to get from staff.” Regarding sleep disturbance, participants explained that “people can’t sleep well if concern[ed] about personal safety (ie, roommates or open doors) in a residence” and that “the overhead paging system interrupts sleep.” Providing the “least invasive wound management at EOL” was mentioned, as well as allowing “dressings for wounds to be left on longer to decrease unneeded movements if it causes discomfort.”

For spiritual and psychological well-being, specific recommendations included treating stress, anxiety, and depression with and without medication; providing access to alternative spiritual care and counseling; facilitating resolution and closure; assisting family members in coping with death; and providing active listening for both life review and sharing concerns. Commenters explained that it is important to “ensure [that a] proper history of patients’ spiritual needs is done” and that “ritual needs are honored and provided for.” The relief of spiritual and psychological symptoms requires “time/place to talk” or grieve with privacy and dignity.

Social connections and cognitive stimulation can be supported by encouraging the presence of a caring staff member, volunteer, or visitor at the bedside; encouraging physical touch that promotes reassurance; supporting extended duration and frequent visitations; facilitating and encouraging the presence of children and pets; and providing entertainment and objects for cognitive stimulation and positive distraction. Respondents explained the need to help the patient be “surrounded by their loved ones.” One respondent commented that it is effective if “sometimes someone just holds the resident’s hand until he/she falls asleep.”

Facility Design, Operation, and Management

Recommendations related to the ambient environment include optimizing air quality, airflow, and thermal comfort; providing operable windows to allow outdoor air to enter patient rooms; and providing flexible lighting. Optimization of space and layout includes providing spaces for interaction between family members and formal caregivers, spaces for

overnight stays, and communal areas, as well as installing durable surfaces and frequently cleaning them for infection control. Maximizing patient mobility, both indoors and outdoors, is also important. Comfortable furniture that can be rearranged with ease and space to allow furniture or objects to be brought from home can support family presence and patient comfort. Other strategies include providing audiovisual entertainment, communicating time of day and season for orientation, and providing technology for social contact.

Respondents explained “the room needs to be comfortable for multiple visitors for long periods of time,” and “furniture [must enable the] caregiver to rest in close proximity to [the] patient and to facilitate touch.” Caregivers commented that “technology like Skype or conference calling to communicate with family at a distance” could support connections with loved ones. Respondents explained that “patients are less likely to feel anxious when their space is not cluttered,” that “quiet settings will allow for sleep and not create anxiety,” and that “delirium can be exacerbated by [a] loud, busy environment.”

Patient, Family Member, and Caregiver Experience

End-of-life staff explained the need to provide positive experiences and to shield patients from interruptions and distractions by limiting unwanted visual, auditory, social, or sensory stimulation. Examples include equipment noise, odors, crowding, and motion. Respondents explained that they aimed to “make a person feel they are on a cruise ship,” to “feed the senses,” and to provide positive distractions to bring comfort. One respondent commented that “I always talk to our residents about their families and their hobbies or sometimes even watch a TV show with them.” One example of stimulating the senses was “home-cooked meals—comfort from smelling fresh-baked bread, cookies, bacon, [and] turkey.”

Discussion

The list of strategies identified by our respondents indicates that improving QOL at EOL requires a highly multidisciplinary approach and consistency among the components of care. 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, QOL in EOL care can truly be enhanced. For example, facilitating presence at the bedside must be supported by policies, caregiver behavior, and physical environment.

A concerted effort was made to secure participants and survey responses from 4 representative types of organizations providing EOL care. However, the significance of the work is not that the results are definitive and generalizable to all conceivable care settings but rather that our method of seeking knowledge from multidisciplinary teams of EOL care providers demonstrates an approach that is needed to fill the gaps in research.

Limitations

This study was limited to staff and volunteers. Perspectives from family members and patients would be desirable but logistically more difficult. We only accessed 4 organizations, all in Upstate New York and with the required multi-disciplinary composition of job titles. Other EOL organizations in various regions might provide a broader perspective. Additional research is needed to provide detailed guidelines for each stakeholder group to improve

effectiveness of EOL care for patients and families and reduce burdens on staff. Moreover, research with a larger participant pool is needed not only to understand the collective voice of caregivers but also to show how opinions differ among job titles.

Clinical Significance

This analysis adds to earlier work attempting to determine strategies that allow the best possible QOL and death for EOL individuals, their families, and their caregivers. The study's combination of focus groups and surveys with both specific and open-ended questions issued to a wide variety of experienced EOL professionals resulted in a comprehensive list of such strategies. Although a number of these may seem obvious, EOL care around the world often fails to incorporate them. The insights from the study's participants can inform EOL caretakers in hospitals, private homes, nursing facilities, and other settings. Cicely Saunders said, "You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully but also to live until you die." We hope this information allows more people to live until they die.

Acknowledgments

The authors would like to thank Laura Kennedy, Nicole woody, Chriss Cherny, and Aleksa Basara at Cornell University for support in data management and analysis. This study was possible because of the valuable contributions of staff and leadership at Hospice of Central New York, Francis House of Onondaga County, NY; Hospicare and Palliative Care Services of Tompkins County, NY; and Cayuga Medical Center in Tompkins County, NY. The authors would particularly like to recognize the support of Nancy Light, BSN, RN, MPS, Executive Director at Francis House; Dale B. Johnson, Executive Director of Hospicare and Palliative Care Services of Tompkins County; and Debra Parker Traunstein, LMSW, MBA, Palliative Care Program Coordinator at Cayuga Medical Center.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: Research reported in this publication was supported by the National Institute on Aging of the National Institutes of Health under Award Number P30AG022845. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. The project also received support from the College of Human Ecology Building Faculty Connections Program, Engaged+ Learning Cornell and Lawrence and Rebecca Stern Family Foundation through the Translational Research Institute for Pain in Later Life (TRIPLL), an National Institute of Health-funded Edward R. Roybal Center with a focus on chronic pain.

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Table 1

Breakdown of Participant Demographics, Job Titles, and Response Rate.

Category	N (% of Total Participants)	Total Eligible	Response Rate, %
Professional caregiver	103 (100)	153	67
Age			
20–29	7 (5.3)		
30–39	16 (12)		
40–49	27 (20.3)		
50–59	34 (25.6)		
60–69	27 (20.3)		
70–79	12 (9.0)		
80–89	1 (0.7)		
Not specified	9 (6.8)		
Gender			
Female	98 (73.7)		
Male	17 (12.8)		
Not specified	18 (13.5)		
Job title			
Physician	4 (3.9)		
Nurse practitioner	4 (3.9)		
Registered nurse	36 (35.0)		
Physician assistant	1 (1.0)		
Social worker	11 (10.6)		
Chaplain	5 (4.9)		
Aide/caregiver	10 (9.7)		
Administrator ^a	21 (20.4)		
Other ^b	11 (10.6)		
Informal caregiver	28 (100)	130	18
Volunteer	28 (100)		
Total caregivers	131	283	46

Abbreviation: EOL, end of life.

^aMost administrators come from a clinical background, have delivered direct EOL care, and are now acting higher up the organizational chart. In addition to a clear understanding of EOL care, administrators' views can help identify and subsequently address key organizational issues such as policies, resource use, staff scheduling, staff support, staff training, security, and building comfort. Examples would be a nursing supervisor, a clinical director, or a chief executive officer (CEO) who was a former registered nurse (RN).

^bThe "other" category included the following: recreation therapist, registered dietitian, certified therapeutic harpist, bereavement counselor, social work student or intern, gardener, and building manager.

Table 2Strategies to Improve QOL at EOL, Organized by Stakeholder Role According to EOL Caregivers.^a

Major Domains	Subdomains
I. Organization philosophy and mission	Honor and provide for diverse religions, cultures, beliefs, and rituals Reduce burdensome medical intervention Be accepting of alternative care Encourage early adoption of hospice
II. Organizational policies	Provide supportive programs and services Optimize staffing Optimize scheduling Minimize patient transfer to another environment Provide patients and families with control and privacy Follow measures to control infection
III. Caregivers' behaviors and practices	Support the development and implementation of care plans Give patient and family control Follow routine protocols for physical care Educate patient and family on end-of-life issues Build relationships with patient and family Communicate skillfully with patient and family Care effectively with patient and family with empathy Proactively attend to patient needs while giving personal care by minimizing interruptions and giving privacy Provide patients with unconditional love, dignity, respect, reassurance, and a sense of safety Proactively collaborate with entire care team
IV. Symptom management	Manage physical symptoms Improve spiritual and psychological well-being Build social connection and stimulation Create cognitive stimulation and positive distraction
V. Facility design, operation, and management	Optimize ambient environment and maximize interaction with nature Optimize spatial layout Provide appropriate furniture, objects, and amenities Design clear and simple interior surroundings Maintain cleanliness and prevent infection transfer Create pleasant, peaceful, cheerful, and home-like spaces Design fostering privacy, flexibility, and control
VI. Patient, family member, and caregiver experience	Reinforce positive user experience Minimize interruptions and distractions

Abbreviations: EOL, end of life; QOL, quality of life.

^aFamily members were excluded from the study; however, 2 family members from the inpatient facility completed and dropped the survey forms in the sealed survey boxes. After discussion with the facility leader, the research team decided not to delete the data from the 2 surveys filled out by the family members because of the potential value of the family voices. The analysis of these 2 surveys revealed that the data from these surveys did not change the overall domains or add any categories. All concepts were repeated by the eligible participant pull.