

Codman Awards

Developing an End-of-Life Program for Long Term Care Residents

Nina Willingham

An end-of-life program, the Butterflies Are Free Program, was developed at Life Care Center, a long term care facility in Sarasota, Florida, to provide residents with comfort and dignity during the end stage of life. The program was designed to address concerns expressed by the organization's stakeholders over the lack of involvement on the part of family and staff in the dying process of its residents and patients.* For example, residents and their families were hesitant to involve "strangers" in care at the end stage of life. Many families were emotionally unprepared for and were often surprised by the death of their family member. Finally, patients and their families often could not pay for hospice care in a skilled facility, which was covered by Medicare only in specific circumstances.

The facility's executive director [N.W.] had worked with the developer of another end-of-life program, Angels Passing By, and the leadership team at Life Care Center drew on that program's outline to develop its own program.

The development of the end-of-life program took the form of a performance improvement (PI) initiative, which is described in this article. The leaders of the organization identified the need for the initiative and its core members of the initiative.

PI Team

A PI team was formed in August 2002 to address the needs of residents who have entered the end-of-life

* The term *residents* is used to refer to long term care residents who have made the facility their home, whereas patients refers to short-term rehabilitation patients who plan to go home. For the purposes of this article, "residents" refers to both unless only residents or only patients are affected by the statement.

Article-at-a-Glance

Background: An end-of-life program, the Butterflies Are Free Program, was developed at Life Care Center, a long term care facility in Sarasota, Florida, to provide residents with comfort and dignity during the end stage of life.

PI Team: A PI team identified the goal: "Establish an end-of-life program that maintains comfort and dignity for the resident involving the family, residents, and staff in the plan of care at their personal level of comfort. The end-of-life program should put no financial strain on the family." The program entailed involving the resident and family in the end-of-life care plan, which included consideration, for example, of pain medications, spiritual support, and continuing or discontinuing routine medications. The project team began meeting in August 2002, and the program was formally implemented in December 2002.

Results: A preintervention (control group), which covered 11 months, was compared with a 2003 postintervention group, which covered 13 months. Data indicated that the number of residents receiving pain medication during the dying process increased by 27.3%. The facility team members received thank you notes and cards from 41% of the families whose loved one died. The initiative reduced the out-of-pocket expenses to the dying resident and their family by 48%.

Discussion: Review of the 2003 data prompted the development of new goals for 2004 and a refinement of the end-of-life program. This program could be easily duplicated in any long term care facility.

Table 1. Goals of the Initiative and Outcomes

Goal	2002	2003	Measure
Pain control	523	1,074	Doses of morphine sulfate
Anxiety control	7	50	Doses of lorazepam/alprazolam
Documented family comfort	72%	80%	% of deaths with documentation
Mean no. days on end of life	0	15	Days on program
Mean out-of-pocket expenses	\$1276	\$673	Dollars per patient
Mean no. of Medicare days/patient	37	24	Mean no. of Medicare days used
Family compliments	5	21	Letters, cards, gift/patient

stage. The team—the executive director, director of nursing, social worker, activities director, financial director, a licensed staff nurse, a dietary aide, a housekeeper, and family members—identified the PI initiative’s goal:

Establish an end-of-life program that maintains comfort and dignity for the resident involving the family, residents, and staff in the plan of care at their personal level of comfort. The end-of-life program should put no financial strain on the family.

The team developed a program of key activities, which the facility followed for the first year of the program. The program entailed involving the resident and family in the end-of-life care plan, which included consideration, for example, of pain medications, spiritual support, and continuing or discontinuing routine medications. The program was formally implemented in December 2002.

Implementing the Program

The leaders of the PI initiative provided education on the stages of death and dying to all staff. They arranged for hospice to provide annual in-services. For example, hospice staff provided an all-staff in-service on hospice goals and philosophy in the use of morphine and an inservice for members of the leadership team on the financial implications of working with hospice. The consultant pharmacist provided an in-service for the licensed staff and then met with other staff members individually who voiced concern over understanding the difference between “enabling a comfortable death experience versus facilitating death.” (Some of the physicians and licensed nurses were reluctant to administer pain medications to residents at the end of life.)

Data Collection

The director of nursing conducted collection of data for the PI initiative through a detailed chart review. The business office manager collected financial information through review of computerized financial data. The pharmacist consultant and the director of medical records

each reviewed 10 randomly selected charts for accuracy. When minor discrepancies became evident, a joint review of the chart confirmed that the original data collected was accurate.

Results

A preintervention (control group), which covered 11 months, was compared with a 2003 postintervention group, which covered 13 months. The outcome measures for the PI team’s six goals can be found in Table 1 (above). Thirteen months after the initiative began, the number of residents receiving pain medication during the dying process increased by 27.3%. The facility team members received thank you notes and cards from 41% of the families whose loved one died. The initiative reduced the out-of-pocket expenses to the dying residents and their families by 48%. It also helped staff members provide support and comfort to the residents and their families.

Discussion

Review of the 2003 data prompted the development of new goals for 2004 and a refinement of the end-of-life program. A description of the refined program was provided to the county’s nursing directors of long term care facilities.* This program could be easily duplicated in any long term care facility. **I**

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* A copy of the 2004 Butterflies Are Free Program can be obtained by e-mail request to Ms. Willingham.