Use of the Quality Improvement Process in Assessing End-of-Life Care in the Nursing Home

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Objective: To report on the process and effect of a quality improvement project on end-of-life (EOL) care in a state veterans’ home.

Design: The design uses survey data from representatives of the deceased, continuous quality improvement (QI) techniques, and interdisciplinary team activities. Representatives of the deceased were surveyed using a tool that assessed symptom management, emotional states, hospice use, and satisfaction with the care provided by the home and the hospice. Using the results of the survey, the interdisciplinary EOL care team used continuous QI methods to improve EOL care.

Participants: Representatives of the deceased of the Thomas Fitzgerald State Veterans Home (TFVH) and the interdisciplinary EOL care team of TFVH, which included staff of TFVH and the hospices serving TFVH.

Measurements: The compiled survey results were compared from year to year to assess trends in the following areas: overall quality of care, pain, dyspnea, other uncomfortable symptoms, emotional need, and spiritual needs. We also assessed the degree of depression, agitation and anxiety, loneliness, and preparation and preparedness of the member for death. We surveyed for ratings on the satisfaction with staff, clergy and hospice, clarity of explanations and information provided by TFVH staff, what disciplines provided the emotional and spiritual support for the resident, whether discussions were held about advance directives, if they would recommend TFVH to other families, and use of/satisfaction with the hospice that served their loved one.

Results: The survey return rate was 8 (38%) (2000), 22 (73%) (2001), and 25 (55%) (2002). The specific areas that were improved per the survey results (which also correlated with staff perceptions) were the following: overall quality of care, spiritual care, distribution of work load, and patients’ preparedness for death. The prevalence of symptoms was reduced by 22% (pain), 25% (dyspnea), and 30% (uncomfortable symptoms of dying). A marked improvement of involvement of clergy in the spiritual care was also noted. The survey process also identified areas that did not improve or worsened such as management of depression, agitation, anxiety, loneliness, family education, and discussions. During the 2000-2002 time period, an average of 83% of the representatives responded that they would recommend the TFVH to another family.

Conclusion: EOL care in nursing homes is rated lower than care in all other venues and must be improved. EOL care can be improved using patient representative surveys as the springboard for staff and hospice interdisciplinary team QI processes. The interdisciplinary team must include the care staff of the home along with hospices serving the institution. We present here one process that we have found effective in improving EOL care. The critical issue is the dedication of the institution and staff to improve EOL care rather than the manner in which it is accomplished. (J Am Med Dir Assoc 2006; 7: S82–S87)

Keywords: Quality improvement; nursing home; end-of-life care
End-of-life (EOL) care is a high-volume and an ever-increasing activity in nursing homes (NHs). Nationally in 1993, 21% of elders died in nursing homes; this number is expected to grow to 40% by the year 2020. In Nebraska in 1989, 28% of all deaths occurred in NHs, and this increased to 35% in 1997.

Nursing homes receive the lowest ratings in quality of EOL care compared to hospitals or hospice care. Freedom from pain is the #1 wish for dying patients and 81% of elderly Nebraskans report they are afraid of dying painfully. In 1999, 33% of terminally ill cancer patients reported persistent severe pain. In 2000, 45% of Nebraska’s NH patients reported “persistent pain.”

This prevalence of pain supports the concerns expressed by family members for dying loved ones that included improved management of pain, dyspnea, and delirium. Hall et al demonstrated inadequacies in EOL care in NHs where dyspnea was not treated in 23%, opioids were used in only 27%, delirium was untreated in 38%, and noisy breathing at death was left untreated in 33% of residents. Another study demonstrated lack of support for bereaved family members.

EOL care is complex and demanding for health care providers (HCPs) and institutions. NH personnel are not prepared to provide high-quality EOL care, nor have they been encouraged to improve this aspect of their care. The Omnibus Budget Reconciliation Act of 1987 (OBRA 87) emphasized rehabilitation and restoration and improvement in function for NH residents, but made no mention of EOL care. Hence, federal and state surveillance reflects this focus and promotes NH quality improvement efforts in the areas of restoration and rehabilitation.

NH residents who require EOL care have clinical care and psychosocial needs that are vastly different from those of other residents. Principles of Continuous Quality Improvement (QI) would call for the evaluation and improvement of high-volume activities. We report our experience in a 3-year EOL QI project in a Nebraska state veterans home.

METHODS

The Study Population

The Thomas Fitzgerald Veterans Home (TFVH), an urban state veterans home with 120 skilled beds was the location of this study. The residents are 85% male with an average age of 76.5 years (91% are white, 5% black, 1% Asian/Pacific Islander, and 1% Hispanic). As a state veterans home it is not Medicare or Medicaid certified.

The study was approved by the VA Nebraska-Western Iowa Health Care System Research Service, Omaha, NE on June 5, 2003, and by the University of Nebraska IRB on March 28, 2003. The IRB committees agreed with the concept of the responders not being asked to give informed consent in light of the following: (1) some of the data had been collected as a prior QI project, (2) the data would be handled by TFVH HIPAA trained medical records personnel, and (3) the responders would be anonymous.

Process

The facility has performed an annual survey from 2000 through 2003. Questionnaires were mailed to a representative of each patient who had died in the preceding year. Representatives were identified by TFVH staff as an individual most attentive to the resident. The survey asks the responder to focus on the last 3 months of the resident’s life. Topics and samples of questions are presented in Tables 1 and 2, respectively. The time from death to completion of surveys ranged from 3 to 15 months.

The staff of the TFVH medical department and the facility medical director provided the labor for this survey. The time to format, mail, and compile surveys took approximately 16 hours with a cost of $130 for postage and paper. The costs were paid by TFVH.

### Table 1. Survey Question Topics

<table>
<thead>
<tr>
<th>Topic</th>
</tr>
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<tbody>
<tr>
<td>Overall quality of care</td>
</tr>
<tr>
<td>Pain</td>
</tr>
<tr>
<td>Dyspnea</td>
</tr>
<tr>
<td>Other uncomfortable symptoms</td>
</tr>
<tr>
<td>Emotional needs</td>
</tr>
<tr>
<td>Spiritual needs</td>
</tr>
<tr>
<td>The degree of depression</td>
</tr>
<tr>
<td>The degree of agitation and anxiety</td>
</tr>
<tr>
<td>The degree of loneliness</td>
</tr>
<tr>
<td>Preparation and preparedness of the member for death</td>
</tr>
<tr>
<td>The clarity of explanations and information provided by TFVH staff</td>
</tr>
<tr>
<td>What disciplines provided the emotional and spiritual support for the resident</td>
</tr>
<tr>
<td>Whether discussions were held about advance directives if they would recommend TFVH to other families</td>
</tr>
<tr>
<td>Use of and satisfaction with hospice*</td>
</tr>
</tbody>
</table>

* 2001, 2002 only.

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**We would like to know about any symptoms your loved one had.**

- On a typical day during the last 3 months of life, did your loved one experience any pain?
  - Yes, severe
  - Yes, moderate
  - Yes, mild
  - No
  - Don’t Know
- How much of the time in the last 3 months did he/she have this pain?
  - All the time
  - More than half the time
  - Less than half the time
  - None of the time
  - Don’t Know
- How much of the time in the last 3 months was he/she short of breath?
  - All the time
  - More than half the time
  - Less than half the time
  - Not at all
  - Don’t Know

Modeled after Baer and Hanson.
Survey data were compiled by the TFVH staff and medical director. Key members from each discipline were asked to review the results and prepare comments and recommendations. Results were then previewed by all staff, including hospice organizations involved in EOL care at TFVH. The preview was followed by an interdisciplinary meeting of representatives from each discipline involved in EOL care. The goal of this meeting was to develop improvement plans and to assign responsibility for tasks and was attended by representatives of nursing (care staff and administration), social work, pastoral care, pharmacy, administration, medical staff, recreation therapy, dietary, Hospice services, and psychology. Areas for improvement were referred to the institution’s quality improvement (QI) committee for further follow-up (Fig 1). The QI committee meets quarterly; work groups meet on a more frequent basis.

RESULTS

The numbers of completed survey responses were 8 (38%) in 2000, 22 (73%) in 2001, and 25 (55%) in 2002. According to survey results, the specific areas that were improved from 2000 to 2002 (which also correlated with staff perceptions) were the following: The number of representatives who felt the overall quality of care was excellent increased by 7%. The representatives rated that the numbers of residents who received spiritual care by a religious clergy increased by 4-fold. They also indicated that the distribution of workload improved with the numbers of volunteers increasing by 100% with no decline indicated from the representatives in the involvement by nursing or the medical staff. The representatives rated that the numbers of residents fully prepared to die increased by 14%. Also, the prevalence of symptoms was reduced by 22% (pain), 25% (dyspnea), and 30% (uncomfortable symptoms of dying).

Targeted areas for improvement from the 2000 survey of dyspnea, agitation/anxiety, emotional and spiritual care, and distribution of workload showed improvement on the 2001 survey. Similarly, symptoms of pain control and dying symptoms cited for improvement in 2001 showed improvement in 2002.

The survey process of 2002 data also identified areas that the representatives rated as not improving or worsening such as management of depression, agitation, anxiety, loneliness, family education, and discussions.

The QI data were presented to staff in graphical displays and as comments excerpted from surveys. Graphs allowed immediate visualization and were easy to share with all caregiving staff on bulletin boards and at meetings. Fig 2 shows the trend over time in pain reported by the representatives of the resident.

Motivation is a key factor in any process of change. The use of data derived from the home’s residents, combined with specific comments from the representatives, motivated caregivers to improve. Specific comments were excerpted from the surveys and tabulated according to ease of the facility to modify (Table 3). The delineation of “symptoms we can treat” versus less able to treat, allows the QI team and staff to target areas for effort with highest impact. Comparing listings from year to year allowed the QI team to identify repeating problems. This technique assisted with motivating the staff and provided specific areas to target by the QI committee. After each year’s analyses and discussion, recommendations were made by the EOL QI committee, and tasks to improve symptoms were assigned during a QI meeting involving all disciplines involved in EOL care.

We also examined the distribution of the workload of EOL care. The survey question, “In addition to family and friends who was the most important person providing emotional & spiritual support for your loved one?” allowed multiple choice answers in which the responder could circle as many as they wished of the following: Minister/Priest/Rabbi (Religious Leader); Nurse Aide; Nurse; Volunteers; Social Workers; Counselor/Psychologist; Other; MD/Nurse Practitioner; No One (Fig 3). These data allowed the QI team to determine which disciplines were carrying the “emotional work load”
and those that may be under used. Using these data, redistribution of tasks was outlined during QI meetings. This process increased the involvement of chaplains, pastors, volunteers, counselors/psychologists and medical staff, while reducing overreliance on nursing.

Additionally, positive and negative comments by the responders are tabulated and presented to give the staff encouragement (a great many were positive, appreciative, and complimentary).

During the 2000–2002 time period, an average of 83% of the representatives responded that they would recommend the TFVH to another family. On another survey performed by the state veterans homes on all residents (not just deceased), 87% of responders rated the care as “good to excellent” regarding the overall care of patients.

After each year’s analyses and discussion, recommendations were made by the EOL QI committee. Table 4 lists the areas targeted in 2002 along with the QI committee’s recommendations.

Hospice organizations were added to the care team based on 2000 data that identified the need for increased spiritual care. Also identified was the need for volunteers to attend to residents who did not have family and loved ones. The hospice-nursing home agreements initially were simple and outlined duties of each agency. As the relationship grew, the agreements matured reflecting the guidelines for survey pro-

### Table 3. Uncomfortable Symptoms That Can Be Treated

<table>
<thead>
<tr>
<th>2001 Problems We Can Affect</th>
<th>2002 Problems We Can Affect</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loss of appetite +</td>
<td>Weak</td>
</tr>
<tr>
<td>Swollen feet +</td>
<td>Sleepiness</td>
</tr>
<tr>
<td>Restricted in the hospital</td>
<td>Unable to express self +</td>
</tr>
<tr>
<td>Anxiety +</td>
<td>Stroke</td>
</tr>
<tr>
<td>Leg spasm +</td>
<td>Dyspnea +</td>
</tr>
<tr>
<td>Room by himself, ie, alone?</td>
<td>Alzheimer’s</td>
</tr>
<tr>
<td>Hearing vision and mobility</td>
<td>Memory</td>
</tr>
<tr>
<td>Immobile, tube from GB +</td>
<td>Amputation</td>
</tr>
<tr>
<td>Bowel trouble +</td>
<td>Sores</td>
</tr>
<tr>
<td></td>
<td>Colostomy</td>
</tr>
<tr>
<td></td>
<td>Feeding tube</td>
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<tr>
<td></td>
<td>Depression</td>
</tr>
<tr>
<td></td>
<td>Rectal sore</td>
</tr>
<tr>
<td></td>
<td>Urinary incontinence</td>
</tr>
</tbody>
</table>

### Table 4. Example of the 2002 QI Plans

<table>
<thead>
<tr>
<th>Assessments</th>
<th>QI Team Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. AGITATION (terminal delirium). Need to increase:</td>
<td>● Medical director in-service on topic</td>
</tr>
<tr>
<td>a) Awareness of all staff in recognition;</td>
<td>● Hospice in-services</td>
</tr>
<tr>
<td>b) HCP/nursing ability to treat</td>
<td>● Increase awareness through reminders</td>
</tr>
<tr>
<td>2. IMPROVE CLARITY of explanations &amp; advance directive</td>
<td></td>
</tr>
<tr>
<td>3. Improve:</td>
<td>● Medical staff discussions</td>
</tr>
<tr>
<td>● EMOTIONAL care</td>
<td>● Chart review by SW of current documentation</td>
</tr>
<tr>
<td>● DEPRESSION care</td>
<td>● Increase referral to psychologist &amp; social work</td>
</tr>
<tr>
<td>● LONELINESS care</td>
<td>● Earlier hospice referral</td>
</tr>
<tr>
<td></td>
<td>● Earlier pastoral referral</td>
</tr>
<tr>
<td></td>
<td>● Hospice in-services (“Hospice 101”)</td>
</tr>
<tr>
<td></td>
<td>● Use “crisis care” offered by Hospice</td>
</tr>
<tr>
<td></td>
<td>● Increase use of volunteers</td>
</tr>
<tr>
<td></td>
<td>● TFVH will recruit and train more volunteers</td>
</tr>
<tr>
<td></td>
<td>● Hospice will provide more volunteers</td>
</tr>
<tr>
<td></td>
<td>● Local parish recruitment of volunteers</td>
</tr>
<tr>
<td></td>
<td>● Improve environment for member</td>
</tr>
<tr>
<td></td>
<td>● Private room</td>
</tr>
<tr>
<td></td>
<td>● Attention to details in rooms (reduce clutter, enhance music, lighting, etc)</td>
</tr>
</tbody>
</table>

14) In addition to family and friends who was the most important person providing emotional & spiritual support for your loved one?

![Figure 3](image-url)
cедures for the Long Term Care Facilities Regarding the Hospice Benefit (Section 2082 through 2084 SOM). The number of residents attended by hospice in 2000 was none (0%). In 2001 that number was 2 (10%), increasing to 4 (8%) in 2002. Representatives’ satisfaction with hospice in 2001 was not surveyed. In 2002, 3 of 4 (75%) representatives responded satisfactorily.

**DISCUSSION**

This process has provided the means to improve quality of care, symptom management, staff participation, and hospice involvement. The QI process addresses a commonly overlooked area in nursing home EOL care. This QI project allowed the facility to examine its care using the perspective of outside observers and involving experienced and interdisciplinary staff.

Using a family member or loved one as the source of information has both benefits and limitations. It has been demonstrated that proxies can reliably report on the quality of services and on observable symptoms, but less accurately on the patient’s experiences such as pain, anxiety, and depression. The benefits we received include (1) personal observations by a loved one highly motivated and involved in the care of the deceased, (2) information from the standpoint of the respondent who is not part of the institution’s care team, and (3) an opportunity for responders to give both positive and negative comments that would not only assist the home in improvement, but also potentially help in the responders’ grieving. In fact, many responders wrote they appreciated the opportunity to comment on the care provided.

A limitation to this process is the fact that for some of the responders it may have been up to 12 months since the events occurred and recollections could be affected. For others it may have been so soon after the death that their acute grieving could have affected their observations. Nevertheless, this informational source has proven to be a very effective stimulus for change in our institution.

Motivation for change is often the rate-limiting step in any QI process. The use of charts and graphs for visual display of information motivated the staff to improve. This information was easily disseminated to all NH staff and provided feedback on their efforts. The specific item list (Table 5) provides very specific criticisms and positive comments that “hit home” with the caregiving staff and was useful for both identifying areas of improvement and for motivation to carry out the improvement plans.

We believe the steps to the success in the process of change are the following:

- **Step #1.** Ability of all parties to review the consolidated data;
- **Step #2.** Interdisciplinary meetings to review data, ask questions and mutually form strategies;
- **Step #3.** Divide up responsibilities;
- **Step #4.** Follow through by the QI team.

Hospice care was also evaluated and improved. The data derived from the hospice-related questions allowed the QI process to attain some independent information on the perceptions of the family/loved ones concerning hospice care and their satisfaction with specific hospice providers. The NH at that time was served by 2 hospices. These data, along with staff input, assisted in the process of awarding contracts with the hospice agencies. This can be a powerful tool to monitor and motivate each hospice’s efforts. Through the use of the hospice satisfaction questions and NH staff input, one hospice contract was not renewed. Since one hospice was chosen, we were able to develop a close “team” working relationship with that hospice, develop common strategies for improvement, and work together to implement improvement plans. Since hospices must also monitor the quality of their care, the QI processes can be shared with them.

Hospice organizations involved in NH EOL care should be held accountable to demonstrate their frequency of visits, type of professionals involved, and their effectiveness. Additionally, hospices are an excellent source of education for NH staff on key issues in EOL care. The bereavement follow-up by hospice is important as well since NHs often lose contact with families/loved ones after death, and the hospice can assist those grieving in their transitions. In our opinion, bereavement follow-up responsibility should also include NH staff that may have known and cared for the patient for many years.

To rely totally on survey results and staff opinion would at times provide inadequate data to make decisions in specific areas. Chart audits can be used to evaluate documentation of (1) symptom (pain, delirium, dyspnea, depression, etc) con-

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**Table 5.** Representatives’ Comments about EOL Care in Nursing Homes

<table>
<thead>
<tr>
<th>Areas Valued</th>
<th>No. of Responses</th>
<th>Areas of Concern</th>
<th>No. of Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social work very good</td>
<td>1</td>
<td>Pool nurses gave poor care</td>
<td>1</td>
</tr>
<tr>
<td>No bad odors</td>
<td>1</td>
<td>Need more volunteers</td>
<td>1</td>
</tr>
<tr>
<td>Clean facility</td>
<td>3</td>
<td>Bathroom in rooms</td>
<td>1</td>
</tr>
<tr>
<td>Wanted to say “thank you”</td>
<td>8</td>
<td>Christmas gifts stolen</td>
<td>1</td>
</tr>
<tr>
<td>Friendly staff</td>
<td>3</td>
<td>Need new nursing home</td>
<td>1</td>
</tr>
<tr>
<td>“Felt at home”</td>
<td>1</td>
<td>Need more staff</td>
<td>4</td>
</tr>
<tr>
<td>Member happy</td>
<td>2</td>
<td>No opinion</td>
<td>1</td>
</tr>
<tr>
<td>Nice memorial service</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff treated all with respect</td>
<td>1</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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trol; (2) advance directives; (3) discussion with patient/fam-
ilies/loved ones regarding advance directives, interventions,
and so forth; and (4) frequency and type of assistance from
hospice organization. These audits can provide additional
data to either validate or dispute the survey results or staff’s
opinion

CONCLUSION

EOL care in NHs is rated lower than care in all other
venues and must be improved. The current emphasis by
federal regulations and survey process does not adequately
address this and many homes may overlook this aspect of care.
The traditional QI process of studying the problem, formulating
change, educating the staff, implementing the changes, and reevaluating the effect was used to promote change.
Through surveys of representatives of the deceased, we used
the data to promote improvement in overall quality of care,
spiritual care, distribution of workload, patients’ preparedness
for death, reduction in symptoms of pain, dyspnea, and other
uncomfortable symptoms of dying. This process used an in-
terdisciplinary QI team that analyzed the data, designated
modifications, and implemented the changes.

Presented here was one such process. However, there are
many schemes available to reach the goal of improving EOL
care. The critical issue is the dedication of the institution to
improve EOL care rather than the manner in which it is
accomplished.

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