Death in the Hospital

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Objectives: To examine symptoms and treatments among hospitalized adults in the last 2 days of life.

Methods: Review of 72 consecutive medical records of patients who died at an academic medical center and 32 consecutive medical records of patients who died at an affiliated Veterans Affairs hospital. Medical records were examined for documentation of symptoms, treatment, and orders to limit the use of life-sustaining interventions.

Results: The 104 patients who died had an average age of 68.9 years and 70 (68%) were men. The majority had neoplasms or acquired immunodeficiency syndrome, cardiovascular disease, and end-stage lung disease; the remainder died of other acute or chronic illnesses. In the last 2 days of life, pain was noted in 49 patients (46%). Dyspnea (n = 53) and restlessness or agitation (n = 50) were documented in 51% of the patients. In the last 48 hours of life 12 patients (12%) underwent an attempt at resuscitation, 26 patients (27%) were receiving ventilatory support, and 18% were restrained. Nearly half of the patients (48%) had an order or progress note specifying “comfort measures only” (CMO). Patients with CMO, compared with those without such orders, had similar levels of pain, agitation, and dyspnea. Patients with CMO were less likely to be in an intensive care unit (P = .001), receive ventilatory support (P = .001), receive antibiotics (P = .009), or be weighed (P = .001).

Conclusions: Baseline information with which to begin improvement of care for dying individuals was obtained through a brief retrospective chart review. While patients with CMO receive less aggressive care, no specific process was used to provide comfort care. The evaluation and testing of processes of care for dying patients are necessary to begin the improvement of care. We provide baseline data about processes and outcomes of care in our hospitals.

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ADVANCES in medical science during the last half century mean people survive many acute illnesses that previously would have resulted in death. The majority of deaths in the United States occur in health care institutions, although in geriatric1 and hospice practices a larger percentage of individuals die at home. For the last quarter century, the medical, legal, and lay literature have discussed the appropriate use of technology and palliation in the care of dying patients. For many, death comes either as a gradual decline from chronic illness or as an acute exacerbation in the context of significant disease. Increasingly, the importance of a systematic approach to care of dying patients has been recognized.2-4

Despite the substantial literature addressing care of dying patients, the medical management of dying has not been implemented in an organized way. Optimal decision making for a patient has been outlined,5 yet patients often die with many distressing symptoms and problems.6-8 An organized approach to the care of dying individuals may not be used.

To better understand current care for dying patients, we developed a chart review instrument that addresses clinical and other aspects of the dying process. We reviewed the medical records of patients dying in the 2 major teaching hospitals associated with our medical school. Our goals were to identify a reference point from which we can begin to improve performance of our health care system, and to which others could compare care for dying patients in other systems.

RESULTS

Overall, 70 patients (68%) were men and 34 were women. The patients from the Veterans Affairs hospital were predominantly male. Age ranged from 28 to 97 years (mean ± SD, 68.9 ± 12.6 years). Most patients (63 [61%]) were admitted from home, although 36 (35%) were transferred from another hospital. Primary diagnosis is listed in Table 1. Fifty-three patients (51%) were hospitalized with a clinical picture consistent with the terminal stage of the illness, 34 patients (33%) were hospitalized with an acute, potentially reversible illness (including acute cardiovascular events and infectious processes), and 17 patients (16%) were hospitalized with an acute illness or complication in the face of chronic disease (eg, pneumonia in the presence of chronic lung disease).
**METHODS**

We developed a chart review instrument based on a review of the literature and expert opinion with the goal of characterizing the dying experience. This instrument evaluated demographic information, presence of advance directives, presence of symptoms and symptom management, diagnostic tests and therapeutic interventions, the process of care, and involvement of medical and nonmedical disciplines in the care.* The medical records of 72 sequential adult patients who died at the primary teaching hospital for our medical school in January through March 1993 and of 32 sequential patients who died between the middle of December 1992 and the middle of July 1993 at an affiliated Veterans Affairs hospital were reviewed for symptoms, treatments, and orders to limit the use of life-sustaining care. Five charts in the Veterans Affairs hospital sample of sequential deaths were unavailable for review. Charts were excluded from the study if the patient spent less than 48 hours in the hospital (to exclude patients dying of trauma or dying outside the hospital). Chart reviews were conducted by 2 nurse researchers, a medical student (G.S.W.), and a physician (S.J.G.). Interreviewer reliability of abstraction was ensured by duplicate abstraction of all the first 20 charts reviewed, and 10% of charts reviewed thereafter. Documentation of symptoms was found in interdisciplinary progress notes and in daily nursing flow sheets. In some charts symptoms were also documented on medication administration records, particularly when medications were given “as needed.” A pain flow sheet was present in only 1 chart reviewed. Documentation of interventions was looked for in interdisciplinary progress notes, treatment records, and order sheets. Social service and chaplaincy visits were noted if there was a direct entry by these services in the medical record or a mention of their intervention by any other discipline. Bereavement services were noted for any mention of support of patient grief or anxiety or any documentation of bereavement support offered to family after death.

We mainly report rates of symptoms or interventions. When patients were compared on the basis of resuscitation order status, Pearson χ² tests were performed.

Advance care directives were present for 49 patients (47%), with 45 (43%) having a “living will” and 36 (35%) having a durable power of attorney for health care. By the time of death, 92 patients (89%) had a do-not-resuscitate (DNR) order. For 35 patients (42% of those with a DNR), the rationale given in the record for the DNR order was that death appeared imminent. The number of days between a DNR status and death ranged from 0 to 90 (median, 5 days; mean, 11 days). Thirty-three percent of DNR orders were written within 2 days of death and 10% were written on the day of death. Forty-eight percent of patients had an order or a progress note specifying comfort measures only (CMO). Almost all patients (98%) with CMO status had a DNR order. Of those patients admitted in the terminal stage of their illness, 30 (57%) had a CMO status.

**Table 2** lists symptoms documented within the final 48 hours of life. There were no significant differences in rates of symptoms or treatments between the 2 institutions. Dyspnea was documented for more than half of the patients, as was restlessness or agitation. Pain was documented for almost half of the patients, although pain was characterized as “severe” in only 1% of the records. Anxiety and confusion were present in one third of patients. Patients with CMO status did not differ significantly from the entire group in prevalence of symptoms documented. We could not consistently discern the extent to which symptoms were relieved in the medical records.

Almost all patients had a DNR status by the time of death; those with DNR did not differ from those without in the rate of interventions. Almost all patients received intravenous fluids and medications. Narcotics were given to nearly all patients as they died. Half of the patients received antibiotics and 60% had blood samples taken within 2 days of death. Only 8 had no tube attached (ie, no intravenous line, endotracheal tube, arterial line, or Foley catheter). Almost one fifth of patients were restrained within 2 days of death. More than half were weighed in their last 2 days.

Table 2. Symptoms Within 48 Hours of Death Expressed as Prevalence*

<table>
<thead>
<tr>
<th>Symptoms</th>
<th>All Cases, % (N = 104)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dyspnea</td>
<td>51</td>
</tr>
<tr>
<td>Pain</td>
<td>47</td>
</tr>
<tr>
<td>Severe pain†</td>
<td>12</td>
</tr>
<tr>
<td>Anxiety</td>
<td>26</td>
</tr>
<tr>
<td>Restlessness</td>
<td>51</td>
</tr>
<tr>
<td>Nausea</td>
<td>19</td>
</tr>
<tr>
<td>Anorexia</td>
<td>19</td>
</tr>
<tr>
<td>Fever</td>
<td>28</td>
</tr>
<tr>
<td>Incontinence</td>
<td>18</td>
</tr>
<tr>
<td>Confusion</td>
<td>34</td>
</tr>
<tr>
<td>Bed bound</td>
<td>68</td>
</tr>
</tbody>
</table>

*There were no significant differences in prevalence of symptoms for patients with a do-not-resuscitate order, or for patients for whom a decision was made to provide comfort measures only.
†Severe pain was described as severe, excruciating, or worst (a pain score = 8 on a scale of 0-10).

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Information on which to base improvement of care for dying individuals can be obtained through a brief retrospective chart review. Pain, dyspnea, restlessness, and other symptoms were prevalent in our sample within 48 hours of death. While patients in whom a decision was made to provide CMO received less aggressive care, they did not appear to have more comfort than other patients. There were no clear, systematic approaches to dying patients discerned from the medical records that we reviewed at both institutions. We believe that evaluation and testing of processes of care for dying patients herein and elsewhere are necessary to begin the improvement of care.

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**CONCLUSIONS**

Important first steps in improving the care for the dying are to characterize current care and to identify opportunities for improvement. We report our effort to understand current care for individuals in the final 48 hours of life in our hospitals through a retrospective chart review.

The retrospective review limited us to documented information. Errors in documentation may include underreporting of symptoms, omission of report of response of symptoms to treatment, and misinterpretation of clinical presentation when a patient report of symptoms was not used. Systematic patient assessment tools were not used to record symptoms. Rates of interventions were high, and to some extent this may reflect insurance and aggressiveness of care criteria required for patients in acute care hospitals. The DNR order would not necessarily relate to a plan of care, particularly when it reflected advance care preferences of a patient.

Others' state goals of treatment for the terminally ill including relief of pain and suffering, support of the patient and family, comfort, and dignity (copies of the chart review instrument are available from Dr Goodlin). Use of a chart review tool documented rates of symptom prevalence in hospitalized patients that suggest that these goals are not consistently reached. The rate of pain is consistent with that documented in surveys of individuals and chart review in the SUPPORT study. In a palliative care service the rates of symptoms in dying patients can be substantially reduced with careful medical management. The order to provide CMO appears to be associated with limitation of interventions that might prolong life. A CMO status was designated for only half of the patients who appeared to have been admitted in the terminal stage of their illness. In our hospitals there were no organized approaches to palliative care or enhancement of comfort in the form of reduced symptoms for those patients with a CMO status. Some interventions, such as weighing the patient, seem unlikely to enhance comfort in any situation. Other interventions, such as bereavement support and chaplaincy, were documented at rates lower than expected.

**REFERENCES**