**Instruments used in End of Life (EOL) Care Education**

The attached surveys have been developed by the City of Hope researchers for their use in several current research or education projects related to end of life care. As these surveys have been developed by the investigators and are now being used for the first time, there is no reliability or validity data available for them. We are sharing these with you for your use in any way you desire for your own projects. Most of these surveys are intended for descriptive purposes only or as tools for needs assessment, thus additional psychometric testing will likely not be conducted. You may use these in their current form or modify them in any way helpful to your work.

This packet includes:

- End of Life Curriculum Survey for Nursing Schools
- End of Life Clinical Nurse Survey
- End of Life Survey for Home Care/Hospice Agencies
- End of Life Attitudes Survey for Home Care Nurses and HHAs
- End of Life Knowledge Assessment for Nurses
- End of Life Knowledge Assessment for HHA's
- Chart Audit Tool
- Case Analysis Form
End of Life Curriculum Survey for Nursing Schools

Description: This survey was designed to assess the needs for improved EOL education in nursing schools. It was used in a survey (n=725) of faculty and deans/chairpersons of nursing schools and staff of the state boards of nursing. Results of this initial survey were published in Nursing Outlook 1999; 47(6).
End of Life Curriculum Survey for Nursing Schools
City of Hope National Medical Center

1. Your role:
   _____ Dean or Chairperson of School of Nursing
   _____ Faculty Member
   _____ Consultant/Staff of Board of Nursing
   _____ Other: _________________________

2. _____ Number of years you have been involved in nursing education.

3. State _________________

4. Assess the adequacy of current content in your educational program in the following aspects of end of life (EOL) care:

<table>
<thead>
<tr>
<th>Not adequate</th>
<th>Very adequate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Goals of palliative care</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>Quality of life at EOL</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>Pain management</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>Other symptom management</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>Communication with patients/families at EOL</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>Role/needs of family caregivers in EOL care</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>Death and dying</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>Ethical issues in EOL care</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>Grief/bereavement</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>Overall content on EOL care</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
</tr>
</tbody>
</table>

5. Identify all areas in your curriculum where EOL content is currently taught. If you require more space, use the back of this page.

<table>
<thead>
<tr>
<th>Course (e.g. Med-Surg)</th>
<th>Content</th>
<th>Amount of Time spent on EOL Care Content (e.g. 2 hours)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Example: Medical-Surgical Nursing</td>
<td>Example: Pain Management</td>
<td>Example: 1 hour</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
6. What resources would be most helpful to assist faculty in improving EOL content in nursing education?

<table>
<thead>
<tr>
<th>Not helpful</th>
<th>Very helpful</th>
</tr>
</thead>
<tbody>
<tr>
<td>Textbooks</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>Computer assisted instruction</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>Audiovisuals</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>Access to speakers, experts</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>Access to clinical sites (ie, hospices)</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>Lecture guides/outlines on EOL topics</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>Case studies</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>Standardized curriculum</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>Internet Resources</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
</tr>
</tbody>
</table>

7. A) Overall, how important do you believe EOL care content is to basic nursing education?

<table>
<thead>
<tr>
<th>Not important</th>
<th>Very important</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>

B) How effective do you believe a new graduate of your program would be in caring for a dying patient?

<table>
<thead>
<tr>
<th>Not effective</th>
<th>Very effective</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>

C) How receptive do you believe your faculty would be to increased EOL care education?

<table>
<thead>
<tr>
<th>Not receptive</th>
<th>Very receptive</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>

D) As a faculty member, how effective do you feel you are in teaching EOL care content?

<table>
<thead>
<tr>
<th>Not effective</th>
<th>Very effective</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>

8. What do you consider to be the greatest barriers to improving content on EOL care?

9. Please list any other thoughts, comments, or issues regarding the needs of nursing schools in educating nurses about EOL care.

(Please continue on reverse side if needed)

Ferrell, Grant, Virani (1998)
End of Life Care

Clinical Nurse Survey

Description: This survey was used to assess the needs of clinical nurses in end of life care. The survey was administered through the attached article which appeared in Nursing 98 and on the City of Hope Pain/Palliative Care Resource Center website. It was also mailed to a random sample of oncology nurses. More than 2,300 nurses completed the survey. Results were published in Oncology Nursing Forum 1999; 26(5).
# City of Hope National Medical Center
## End of Life (EOL) Care Survey

1. How effective are the following aspects of EOL care in your setting?

<table>
<thead>
<tr>
<th>Aspect</th>
<th>not at all effective</th>
<th>somewhat effective</th>
<th>very effective</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain assessment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain management</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other symptom management</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychological support for dying patients</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attention to spiritual needs</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grief/bereavement support</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2. In your setting, how often do dilemmas occur in these aspects of end-of-life care?

<table>
<thead>
<tr>
<th>Aspect</th>
<th>not common</th>
<th>somewhat common</th>
<th>very common</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preserving patient choice/self-determination</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Use of advance directives</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Requests for assisted suicide</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Requests for euthanasia</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Withholding/withdrawing medically provided nutrition/hydration</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discontinuing life sustaining therapies</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Legal issues at the end of life</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fear of causing death by giving pain medication</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uncertainty about the patient's prognosis</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3. Compared with 5 years ago, do you believe care of the dying today is:

<table>
<thead>
<tr>
<th>Choice</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>worse than 5 years ago</td>
<td></td>
</tr>
<tr>
<td>about the same</td>
<td></td>
</tr>
<tr>
<td>better than 5 years ago</td>
<td></td>
</tr>
</tbody>
</table>

4. How much of a barrier are the following factors to providing good end-of-life care in your setting?

<table>
<thead>
<tr>
<th>Factor</th>
<th>not a barrier</th>
<th>somewhat of a barrier</th>
<th>severe barrier</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of knowledge by health care professionals</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health care professionals' personal discomfort with death</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avoidance of dying patients by health care professionals</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health care professionals fear of causing addiction by administering pain medications</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patients' avoidance of death</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family members' avoidance of death</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cultural factors influencing end-of-life care</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patients/families' fear of addiction</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Increased use of unlicensed personnel in care of the dying</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The influence of managed care on end-of-life care</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Legal restrictions placed on health care professionals in prescribing pain medications</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of continuity of care across settings</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
5. Did you care for a dying patient during nursing school? ______ yes ______ no

6. Do you care for dying patients in your current role? ______ yes ______ no

7. What have you used as sources of information about end-of-life care? 
   ______ textbooks  ______ journals  ______ internet  ______ seminars/conferences  ______ colleagues

8. How adequate do you think your basic nursing education program was in preparing you in the following aspects of end-of-life care?

<table>
<thead>
<tr>
<th>Understanding the goals of palliative care</th>
<th>Pain management at the end-of-life</th>
<th>Other symptom management (i.e. dyspnea, restlessness)</th>
</tr>
</thead>
<tbody>
<tr>
<td>not adequate</td>
<td>somewhat adequate</td>
<td>very adequate</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Communication with patients/families at end-of-life</th>
<th>Role/needs of family caregivers in end-of-life care</th>
</tr>
</thead>
<tbody>
<tr>
<td>not adequate</td>
<td>somewhat adequate</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>The care of patients at time of death</th>
<th>Ethical issues in end-of-life care</th>
<th>Grief/bereavement</th>
</tr>
</thead>
<tbody>
<tr>
<td>not adequate</td>
<td>somewhat adequate</td>
<td>very adequate</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Overall content on end-of-life care</th>
</tr>
</thead>
<tbody>
<tr>
<td>not adequate</td>
</tr>
</tbody>
</table>

9. Overall, how important do you believe end-of-life care content is to basic nursing education?

   ______ not important ______ somewhat important ______ very important

10. How effective are you in caring for a dying patient?

    ______ not effective ______ somewhat effective ______ very effective

11. How effective are your nursing colleagues in caring for a dying patient?

    ______ not effective ______ somewhat effective ______ very effective

12. How effective are the physicians in your setting in caring for a dying patient?

    ______ not effective ______ somewhat effective ______ very effective

13. How knowledgeable are you about end-of-life care?

    ______ Not knowledgeable ______ Somewhat knowledgeable ______ Very knowledgeable

14. Do you support the legalization of assisted suicide?

    ______ yes ______ no

15. Do you support the legalization of euthanasia?

    ______ yes ______ no

16. Has any patient requested your help in getting a prescription for medication to use with the primary intention of ending his or her own life?

    ______ yes ______ no

17. Approximately how many patients have requested help from such a prescription from you since you began to work as a nurse? ____________ During the past 12 months? ____________

18. For approximately how many patients have you helped to obtain such a prescription since you began to work as a nurse? ____________ During the past 12 months? ____________

19. Approximately how many patients have requested that you inject them with a lethal dose of medication since you began to work as a nurse? ____________ During the past 12 months? ________
20. To how many patients have you given a lethal injection at the patient's request since you began to work as nurse? ___________ During the past 12 months? ______

21. Approximately how many times have you felt obliged by the situation to administer a lethal dose of medicine, without it having been requested by a patient or family member, since beginning to work as a nurse? ___________ During the past 12 months? ___________

22. To how many patients have you given a lethal injection due to the patient's situation, or without specific request by a patient or family, since beginning to work as a nurse? ___________ During the past 12 months? ___________

23. What year were you licensed as a nurse? ____________

24. What is your age?

25. Where do you work?
   ___ Hospital  ___ Rehabilitation
   ___ Home health care  ___ Ambulatory Care/Outpatient Clinic
   ___ Hospice  ___ Other

26. In what clinical area do you usually work?
   ___ Medical/Surgical  ___ OB/GYN/Nursery
   ___ Critical Care  ___ Pediatrics
   ___ Emergency  ___ Administration
   ___ Oncology  ___ Education
   ___ Operating Room/Postanesthesia  ___ Other

27. What is the highest level of education you've completed?
   ___ LPN/LVN  ___ RN
   ___ Diploma
   ___ ADN
   ___ BSN/BS/BA
   ___ MSN/MS/MA
   ___ PhD/EdD/DNS
   ___ Other

28. What is your title?
   ___ Staff Nurse/Clinical Nurse  ___ Nurse Director/Executive
   ___ Charge Nurse  ___ Clinical Specialist/Nurse Practitioner
   ___ Nurse-Manager  ___ Other ________________________________


30. We welcome any thoughts you have on end-of-life care.

_____________________________________________________________________
_____________________________________________________________________
End of Life Survey for Home Care or Hospice Agencies

Description: This survey was designed for use in the Home Care Outreach for Palliative Care Education (HOPE) project (see other HOPE project materials in section XXXV of the City of Hope Pain/Palliative Care Resource Center Index). The survey was completed by 134 home care agencies in California. Results were reported in Cancer Practice March/April 1998; 6(2). A representative of the agency, such as the director or administrator, completes the survey.
End of Life Survey for Home Care/Hospice Agencies  
City of Hope National Medical Center

1. Does your agency provide services to patients who are terminally ill?  
   __ Yes  __ No

2. Is your agency and/or does your agency provide (Check all that apply):
   __ Home Care Agency  __ Hospice  __ Hospital-based
   __ Private (for profit)  __ Private (non-profit)  __ Government
   __ Licensed/Certified  __ Intermittent Visits  __ Continuous Care
   __ Other

3. How many nurses are employed by your agency?

4. A) How many home care visits does your agency provide per month?  __ per year?
   B) How many patients who are terminally ill does your agency care for per month?  __ per year

5. Does your agency have access to an Ethics Committee?  __ Yes  __ No
   If yes, what is the make up of the committee?
   __ Ethics committee w/in your agency  __ Hospital based ethics committee
   __ Ethics committee in the community  __ Ethics committee shared w/ another home care agency
   What issues does the committee deal with?

6. Does your agency have policies/guidelines/resources to assist your staff with the following end-of-life issues in home care:
   DNR orders  __ Yes  __ No
   Advance directives  __ Yes  __ No
   Pain management  __ Yes  __ No
   Grief/Bereavement  __ Yes  __ No
   Hydration/nutrition at end-of-life  __ Yes  __ No
   Terminal dyspnea  __ Yes  __ No
   Death at home  __ Yes  __ No
   Spiritual care at end-of-life  __ Yes  __ No
   Identifying surrogate decision maker for incompetent patients  __ Yes  __ No

7. Does your agency have specially trained nurses caring for terminally ill patients?  __ Yes  __ No

8. Does your agency have palliative care training for your staff?  __ Yes  __ No
   If yes, how many hours of training is provided for your staff?
   What topics are included?

9. Would you be interested in an educational curriculum that would assist home care health workers to care/deal with issues of terminally ill patients?  __ Yes  __ No

10. What topics would be of interest to your agency/staff? (Please rank in order of importance with 1 = most important to 10 = least important)
    __ Pain Management  __ Grief/Bereavement
    __ Symptom Management  __ Legal Aspects of Death/Dying
    __ Communication w/pt & family  __ Preparing for death at home
    __ Spiritual needs  __ Physical care issues (wound care, incontinence, etc.)
    __ Cultural beliefs re: death/dying  __ Other (list)
11. What formats does your agency prefer for staff education?
   (Rank in order of preference with 1 = first choice to 10 = last choice)
   - Full day conference (8 hour)
   - Two half day conferences (8 hour total)
   - One half day conference (4 hour)
   - Brief (half-hour to 1 hour) inservices held in conjunction w/staff meetings
   - Audio cassettes
   - Video materials
   - Computer instruction
   - Newsletter published regularly (e.g. monthly)
   - Written materials (ie, case studies or syllabus with test for CEUs)
   - Other (describe)

12. What speakers/professional expertise would be preferred by your agency/staff for education in end-of-life care issues? (Rank in order of importance with 1 = first choice to 8 = last choice).
   - Social Worker
   - Clergy
   - Ethicist
   - Attorney
   - Physician
   - Nurse
   - Pharmacist
   - Other (list)

13. A) Overall, how important is end-of-life care to your agency?
    Not at all important
    0  1  2  3  4  5  6  7  8  9  10
      Very important

   B) How effectively do you believe your agency provides end-of-life care?
    Not at all effectively
    0  1  2  3  4  5  6  7  8  9  10
      Very effectively

   C) How receptive do you believe your staff would be to end-of-life care education?
    Not at all receptive
    0  1  2  3  4  5  6  7  8  9  10
      Very receptive

14. What is the most important or urgent end-of-life care issue you deal with at your agency?

15. Please list any other thoughts, comments, or issues regarding the needs of the home care staff in caring for patients and their families at the end-of-life.

Thank you for your time in filling out this survey!!!
End of Life Surveys
Versions for Registered Nurses (RNs) or Licensed Vocational Nurses (LVN)
And Home Health Aides

Description: The first survey is designed for use by RNs, LVNs or Home Health Aides (HHA) to determine their ATTITUDES related to end of life care. There are two versions of the KNOWLEDGE survey, one for RNs/LVNs and a separate version for HHAs. There are correct answers for the knowledge survey, thus the answers are listed at the end of each survey. The survey is being used in the Home Care Outreach for Palliative Care Education (HOPE) Project at the City of Hope National Medical Center (see additional materials in section XIII and XXXV in the COHPPRC index related to the HOPE project). The content of the survey reflects the curriculum of the HOPE project.
End of Life Attitudes Survey
For RNs, LVNs or HHAs

Demographics

1. Your role:
   RN _____
   LVN _____
   HHA/Aide _____
   MD _____
   SW _____
   Other (list) _____

2. Length of time in your profession _____ years

3. Length of time in home care _____ years

4. Overall, how effective do you believe you are in the following areas:
   A) Pain management
      not at all 0 1 2 3 4 5 6 7 8 9 10 very effective
   B) Other symptom management
      not at all 0 1 2 3 4 5 6 7 8 9 10 very effective
   C) Communication with terminally ill patients
      not at all 0 1 2 3 4 5 6 7 8 9 10 very effective
   D) Communication with family caregivers
      not at all 0 1 2 3 4 5 6 7 8 9 10 very effective
   E) Managing the death event at home
      not at all 0 1 2 3 4 5 6 7 8 9 10 very effective
   F) Cultural issues in end-of-life care
      not at all 0 1 2 3 4 5 6 7 8 9 10 very effective
G) Overall end-of-life care for the terminally ill

- not at all 0 1 2 3 4 5 6 7 8 9 10 very effective
  effective

5. Overall, how effective do you believe your agency is in these areas:

A) Pain management

- not at all 0 1 2 3 4 5 6 7 8 9 10 very effective
  effective

B) Other symptom management

- not at all 0 1 2 3 4 5 6 7 8 9 10 very effective
  effective

C) Communication with terminally ill patients

- not at all 0 1 2 3 4 5 6 7 8 9 10 very effective
  effective

D) Communication with family caregivers

- not at all 0 1 2 3 4 5 6 7 8 9 10 very effective
  effective

E) Managing the death event at home

- not at all 0 1 2 3 4 5 6 7 8 9 10 very effective
  effective

F) Cultural issues in end-of-life care

- not at all 0 1 2 3 4 5 6 7 8 9 10 very effective
  effective

G) Overall end-of-life care for the terminally ill

- not at all 0 1 2 3 4 5 6 7 8 9 10 very effective
  effective
1. The goals of end of life care include all except
   __ a. halting the progress of the disease
   __ b. controlling the pain
   __ c. relieving emotional and spiritual distress
   __ d. enhancing patient/family choices regarding the final stage of life

2. Which approach to addressing cultural beliefs in end of life care is not appropriate?
   __ a. treat all patients in exactly the same way regardless of ethnicity
   __ b. be attentive to individual patient needs
   __ c. assess patients' values about end-of-life care
   __ d. assess who makes the important health care decisions in the patient's family

3. The role of nurses in end-of-life ethical decision-making includes
   __ a. gathering information about the patient's diagnosis and physical condition
   __ b. determining the patient's wishes about living the final stage of life
   __ c. communicating information of patient preferences, fears, and concerns to the health care team
   __ d. all of the above

4. The focus of palliative care includes
   __ a. control of physical symptoms
   __ b. psycho-social support of the patient and family
   __ c. attention to spiritual needs
   __ d. all of the above

5. All of the following are true EXCEPT
   __ a. the number of terminally ill patients being cared for at home today is increasing
   __ b. home care is becoming more high-tech
   __ c. more patients are choosing to die in the hospital
   __ d. home care patients require more care and support than ten years ago

6. The most accurate judge of the intensity of the patient's pain is
   __ a. the treating physician
   __ b. the primary nurse
   __ c. the patient
   __ d. the patient's spouse or family
7. Mr. C has terminal pancreatic cancer but he is concerned that he is becoming addicted to his pain medication. You explain to him that

   __ a. he ought not to worry about addiction because it happens to everyone on narcotics
   __ b. he is right to worry and you will speak to his physician about changing his medication
   __ c. he is not addicted to his medication
   __ d. he is terminally ill

8. Analgesia for chronic pain should be given

   __ a. around the clock on a fixed schedule
   __ b. only when the patient asks for the medication
   __ c. only when the nurse determines that the patient has moderate or severe discomfort
   __ d. only when the patient's family requests pain medication to be given

9. The recommended route of administration of opioid analgesics to patients with continuous cancer-related pain is

   __ a. intravenous
   __ b. intramuscular
   __ c. oral
   __ d. rectal

10. The most likely explanation for why a patient with pain would request increased doses of pain medication is

    __ a. the patient is experiencing increasing pain
    __ b. the patient is experiencing increased anxiety or depression
    __ c. the patient is trying to become more sedated
    __ d. the patient's requests are related to addiction

11. Which statement about medically provided hydration and nutrition (such as tube feedings or IV hydration) is untrue?

    __ a. it is always appropriate for terminally ill patients
    __ b. it may be refused by a competent adult
    __ c. it may increase a patient's suffering (i.e., accumulation of fluid in the patient's lungs)
    __ d. family members may resist discontinuing food and fluids because of the nurturing or comfort associated with these treatments

12. All of the following are interventions to relieve dyspnea at the end of life except

    __ a. administering oxygen
    __ b. discontinue oxygen to hasten death
    __ c. reduce anxiety
    __ d. administering morphine
13. Fatigue at the end of life can be a result of
   ___ a. pain
   ___ b. anemia
   ___ c. dehydration
   ___ d. bed rest
   ___ e. all of the above

14. Signs and symptoms of progressive delirium to NOT include
   ___ a. agitation
   ___ b. withdrawal
   ___ c. hallucinations
   ___ d. delusions

15. Interventions for "terminal agitation" include all the following except
   ___ a. assessing medications which may be causing agitation
   ___ b. increasing stimulus
   ___ c. decreasing stimulus
   ___ d. administering anxiolytics

16. All of the following interventions help to relieve nausea EXCEPT
   ___ a. medicating with an antiemetic only when vomiting is experienced
   ___ b. avoiding fatty or spicy foods
   ___ c. medicating with an antiemetic on a round-the-clock basis until nausea subsides
   ___ d. using relaxation or visual imagery techniques

17. The most critical step in communication is
   ___ a. feedback
   ___ b. speaking
   ___ c. listening
   ___ d. use of body language

18. Communication patterns
   ___ a. are unique to each relationship and reflect age, gender, and culture
   ___ b. do not include body movements or facial expressions
   ___ c. have nothing to do with relationships
   ___ d. deal only with the person who is speaking

19. Barriers to communication include
   ___ a. fear of dying
   ___ b. isolation from family members
   ___ c. pre-existing family conflicts
   ___ d. all of the above
20. A key component of improving care at the time of death is
   __ a. informing and educating family members about signs and symptoms
   __ b. since each case is different, treat symptoms only as the symptoms appear
   __ c. avoid bothering the family with information about what might happen at the end of life
   __ d. minimize family involvement when the patient is dying

21. Communication occurs on verbal, nonverbal, interpersonal, and interpersonal levels
   __ a. true
   __ b. false

22. Signs and symptoms of impending death include all **EXCEPT**
   __ a. pupils reactive to light
   __ b. bowel incontinence
   __ c. unresponsive to stimulus
   __ d. decreased pulse and respiration

23. It is important to remember
   __ a. death is a physical, psychological, social, and spiritual event
   __ b. each death is unique
   __ c. to allow the family time with the body after the death to say goodbye
   __ d. all of the above

24. Grief
   __ a. is an individual process whereby one progresses at his/her own rate
   __ b. can be complicated by unresolved family issues related to the dying individual
   __ c. is a cumulative experience of multiple losses that have occurred during the illness experience
   __ d. all of the above

**ANSWERS**

1. a 13. e
2. a 14. b
3. d 15. b
4. d 16. a
5. c 17. c
6. c 18. a
7. c 19. d
8. a 20. a
9. c 21. a
10. a 22. a
11. a 23. d
12. b 24. d
1. “Palliative care” means care with the goal that the patient might still be cured.
   a. True
   b. False
   c. Don’t Know

2. The major goals in caring for the dying are to provide comfort and relieve any symptoms such as pain or nausea.
   a. True
   b. False
   c. Don’t Know

3. There are other ways of relieving pain besides giving medicines such as using heat, cold, or relaxation.
   a. True
   b. False
   c. Don’t Know

4. You can always judge the patient’s pain by watching for signs such as grimacing or moaning.
   a. True
   b. False
   c. Don’t Know

5. It is important to continue pushing food and fluids in caring for dying patients even in the final days or weeks to keep them comfortable.
   a. True
   b. False
   c. Don’t Know

6. There is a little that can be done to help a patient when he/she becomes short of breath.
   a. True
   b. False
   c. Don’t Know

7. Listening to what the patient and his/her family says is as important as giving information when caring for a dying patient.
   a. True
   b. False
   c. Don’t Know
8. It is better to be honest with the family about the patient’s condition and avoid giving false hope that the patient will improve.

   __a. True
   __b. False
   __c. Don't Know

9. The family should be less involved with the patient’s care as the death event approaches.

   __a. True
   __b. False
   __c. Don’t Know

10. Some of the signs/symptoms of approaching death are that the patient may experience fatigue/weakness, a lack of desire to eat, an increased need for sleep, additional assistance with personal care, and a tendency to withdraw from family and friends.

    __a. True
    __b. False
    __c. Don’t Know

**ANSWERS**

1. b
2. a
3. a
4. b
5. b
6. b
7. a
8. a
9. b
10. a
**Chart Audit Tool and Case Analysis Form**

The Chart Audit tool is used to conduct audits of current patients or to do a retrospective review of patient charts. It is a useful tool for Quality Improvement Efforts to describe current end of life care. The Case Analysis form is used in the HOPE project to analyze select home care patients and to also identify gaps in end of life care. It is also used as a teaching tool to help nurses analyze current patients during joint visits with the research nurse.
Home Care Outreach for Palliative Care Education (HOPE) Chart Audit Tool

Agency Code _____

Date of audit _______________ Auditor _______________

1. Medical Record# _______________
2. Patient identified as terminally ill? ___ Yes ___ No
3. Was the patient aware that he/she was terminal? ___ Yes ___ No
4. Was the family aware that the patient was terminal? ___ Yes ___ No
5. DNR ordered? ___ Yes ___ No
6. Was there an Advanced Directive? ___ Yes ___ No
7. Was there a Durable Power of Attorney? ___ Yes ___ No
8. Date of death _______________ Location ______________________________________
9. Hospice offered as an alternative? ___ Yes ___ No
10. Reason for discharge: ___ Died on home care and at home
    ___ Died on home care but in the hospital
    ___ Transferred to hospice from home care
    ___ Other, reason _____________________________________
11. Was there interdisciplinary team involvement? ___ Yes ___ No
    c = consult   v = actual visit
    ___Chaplain ___c ___v ___OT ___c ___v
    ___CNS ___c ___v ___Pain Specialist ___c ___v
    ___HHA ___c ___v ___Pharmacist ___c ___v
    ___MD ___c ___v ___PT ___c ___v
    ___Music Therapist ___c ___v ___Social Worker ___c ___v
    ___Nursing Supervisor ___c ___v ___Volunteer ___c ___v
    ___Nutritionist ___c ___v
    ___Other _______________

12. Were funeral arrangements made in advance? ___ Yes ___ No
13. Was the nurse present the day of the death? ___ Yes ___ No
    If yes,
    ___Before the death ___At the time of the death ___Right after the death
    ___No, but within 48 hours after the death

14. Was there a plan for a follow-up phone call and/or card to be sent to the family within a month of the patient’s death? ___ Yes ___ No
Pain and Symptom Management

1. Was pain assessed every visit? ___ Yes    ___ No  Additional PRN assessments made on those with uncontrolled pain? ___ Yes    ___ No
   Comments ______________________________________________________________

2. Was pain controlled at a level 3 or less, or, at an acceptable level to the patient?
   ___ Yes    ___ No

   Meds ordered:

<table>
<thead>
<tr>
<th>Drug(s)</th>
<th>Dose</th>
<th>Schedule</th>
</tr>
</thead>
</table>

   Other Symptoms Present:

   Dyspnea ___ Yes    ___ No  Controlled? ___ Yes    ___ No
   Comments ______________________________________________________________

   Fatigue/Weakness ___ Yes    ___ No  Controlled? ___ Yes    ___ No
   Comments ______________________________________________________________

   Agitation/Restlessness ___ Yes    ___ No  Controlled? ___ Yes    ___ No
   Comments ______________________________________________________________

   Nausea/Vomiting ___ Yes    ___ No  Controlled? ___ Yes    ___ No
   Comments ______________________________________________________________

   Nutrition/Hydration ___ Yes  ___ No  Controlled? ___ Yes  ___ No
   Comments ______________________________________________________________

3. Curative interventions (those beyond comfort measures) still in place? ___ Yes    ___ No
   ___Chemo     ___Radiation     ___Parenteral Nutrition
   ___IV Hydration   ___Transfusion    ___Antibiotics
CASE ANALYSIS FORM/PATIENT INTERVIEW/
FAMILY CAREGIVER INTERVIEW
HOPE PROJECT

Date of Interview: __________________
Date of Death: __________________

I. Case Presentation
   A. Facts
      Age _______________________ Gender: Male __________ Female __________
      DX _______________________
      Treatments (e.g. chemo, radiation) _______________________________________
      Ethnicity ________________________
      Documented Medical Prognosis ___________________________________________
      Nurse's Estimated Prognosis _____________________________________________
      Prognosis: _____________________________________________________________
      Marital Status: M ____ S ____ D ____ W ___
      Primary Caregiver Yes ___ No ___
      Relationship _______________________
      Religion ________________________
      (Prior) Occupation ____________________________ RN Visits/Wk __________
      LVN Visits/Wk __________
      HHA Visits/Wk __________

II. Applying the HOPE Curriculum to Analysis of the Case
   A. Overall quality of life issues of end-of-life care
      1. Physical
         a. Positives
         b. Negatives
      2. Psychological
         a. Positives
         b. Negatives
      3. Social
         a. Positives
         b. Negatives
      4. Spiritual
         a. Positives
         b. Negatives
   B. Pain Management
      1. Assessment
         a. Patient's self-report (0-10) (Any intractable pain?)
         b. Description of pain.
         c. Type(s) of pain (bone, nerve, visceral)
      2. Bowel status
         a. ______ Normal for pt.
         b. ______ Constipated
         c. ______ Diarrhea
3. Medications
   a. Barriers (fear of addiction)
   b. Scheduled meds and route (opioids, NSAIDS, steroids, antidepressants, anticonvulsants)
   c. Breakthrough meds and route
   d. Side effects (n/v, sedation, myoclonus)
   e. Any need to change dosages, meds, routes?

4. Use of nondrug interventions

C. Symptom Management

<table>
<thead>
<tr>
<th>Agitation/Restlessness</th>
<th>Side effects of Meds</th>
</tr>
</thead>
<tbody>
<tr>
<td>Altered Mental Status/Delirium</td>
<td>Skin Integrity</td>
</tr>
<tr>
<td>Anxiety</td>
<td>Spiritual Distress</td>
</tr>
<tr>
<td>Depression</td>
<td>Vomiting</td>
</tr>
<tr>
<td>Dysphagia</td>
<td>Weakness/Fatigue/Immobility</td>
</tr>
<tr>
<td>Dyspnea</td>
<td>Wounds</td>
</tr>
<tr>
<td>Incontinence</td>
<td>Other:</td>
</tr>
<tr>
<td>Nausea</td>
<td>Nutrition/Hydration</td>
</tr>
</tbody>
</table>

D. Communication

1. Does patient understand diagnosis and prognosis? _____ yes _____ no
2. What nonverbal behavior did you notice?
3. What concerns and/or fears did the patient and family have and were they addressed? How?
4. Did the nurse consider other factors, i.e. culture, religion, family dynamics, roles?
5. Interdisciplinary team used?
   Who?

   What was the impact of the illness on the family system?

   What strategies or interventions were utilized to assist the patient and family in dealing with the illness?

6. Cultural factors assessed (describe)

7. Impact of illness upon the family:

E. Death Event

1. Nurse's personal awareness, beliefs, and fears about death and dying
2. Signs and symptoms of approaching death
3. Psychosocial and/or spiritual issues
4. Patient/family fears
5. Interventions (including spiritual)
6. Post-death issues
III. Evaluation

A. Overall Strengths of Care

B. Areas Needing Improvement

C. Should this Patient Be/Have Been Referred to Hospice?

   Why/Why Not?

IV. Patient/Family Caregiver Interview

Pain Management

   Patient

1. Can you describe your pain? What does it feel like?

2. Can you tell me about your treatments?
   a. drug
   b. nondrug

3. How distressing is the pain?

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all distressing</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

4. Do you have any concerns about your pain?

   Family Caregiver

1. How would you describe your family member’s pain?

2. In what ways have you been involved in helping to control the patient's pain?

3. What is most distressing to you about the patient’s pain?

4. Do you have any concerns about what will happen in the future concerning the patient?

Symptom Management

   Patient

1. Can you describe any other symptoms you may be having?

2. How are these symptoms being treated?
   a. Drug
   b. Non-drug
3. Do you have any concerns about these symptoms?

4. Can you describe any other symptoms you may be having?

5. How are these symptoms being treated?
   c. Drug
   d. Non-drug

6. Do you have any concerns about these symptoms?

**Family Caregiver**

1. Can you tell me about any symptoms your family member may have?

2. In what ways have you been involved in helping control the patient's symptoms?
   a. Drug
   b. Non-drug

3. Do you have any concerns about the symptoms?

**Communication**

**Patient**

1. Do you understand what the nurses have been telling you about your illness and care?
   a. If not, how could that be improved?
   b. Do you feel comfortable asking for clarification?

2. Do you feel your needs are being heard and met?
   a. What areas could be improved?

**Family Caregiver**

1. Have you been able to understand the information given to you by the nurses?
   a. If not, how could that be improved?
   b. Do you feel comfortable asking for clarification?

2. Do you feel your needs are being heard and met?
   a. What areas could be improved?
**Death Event**

**Patient**

1. Do you have any physical concerns or fears regarding the future?
2. In what ways do you feel prepared or unprepared for the future?
3. Do you have any plans for the future that you may not get to accomplish?
4. Do you have any spiritual concerns or fears regarding the future?
5. What is holy or sacred to you?

**Family Caregivers**

1. Do you have any fears or concerns about the future?
2. In what ways do you feel prepared or unprepared for the future?
3. In what ways has your home health nurse helped you prepare for the future?
4. How does this situation change your plans for the future?
5. What is holy or sacred to you?