Instrument Title: End of Life Care Survey (EOLCS)
Instrument Author: Ferrell, B. R., Virani, R., & Grant, M.
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></th>
<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>
<td></td>
</tr>
<tr>
<td>Quality of life at EOL</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>Pain management</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>Other symptom management</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>Communication with patients/families at EOL</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></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>
<td></td>
</tr>
<tr>
<td>Death and dying</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>Ethical issues in EOL care</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>Grief/bereavement</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>Overall content on EOL care</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></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>
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</tbody>
</table>
6. What resources would be most helpful to assist faculty in improving EOL content in nursing education?

<table>
<thead>
<tr>
<th>Resource</th>
<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>
<td></td>
</tr>
<tr>
<td>Computer assisted instruction</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>Audiovisuals</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>Access to speakers, experts</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>Access to clinical sites (ie, hospices)</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>Lecture guides/outlines on EOL topics</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>Case studies</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>Standardized curriculum</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>Internet Resources</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Importance</th>
<th>Not important</th>
<th>Very important</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<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>Effectiveness</th>
<th>Not effective</th>
<th>Very effective</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<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>Receptiveness</th>
<th>Not receptive</th>
<th>Very receptive</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<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>Effectiveness</th>
<th>Not effective</th>
<th>Very effective</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<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).
1. How effective are the following aspects of EOL care in your setting?

<table>
<thead>
<tr>
<th></th>
<th>not 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>
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</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th></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>
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<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>
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<tr>
<td>Withholding/withdrawing medically provided nutrition/hydration</td>
<td></td>
<td></td>
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<tr>
<td>Discontinuing life sustaining therapies</td>
<td></td>
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<tr>
<td>Legal issues at the end of life</td>
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<td></td>
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<tr>
<td>Fear of causing death by giving pain medication</td>
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<tr>
<td>Uncertainty about the patient's prognosis</td>
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</tbody>
</table>

3. Compared with 5 years ago, do you believe care of the dying today is:
   _____ worse than 5 years ago   _____ about the same   _____ better than 5 years ago

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

<table>
<thead>
<tr>
<th></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>
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</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>
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<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>
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<td></td>
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</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?

   Understanding the goals of palliative care
   Pain management at the end-of-life
   Other symptom management (i.e. dyspnea, restlessness)
   Communication with patients/families at end-of-life
   Role/needs of family caregivers in end-of-life care
   The care of patients at time of death
   Ethical issues in end-of-life care
   Grief/bereavement
   Overall content on end-of-life care

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?

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

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

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 a 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
   __ Home health care
   __ Hospice
   __ Rehabilitation
   __ Ambulatory Care/Outpatient Clinic
   __ 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
   __ Diploma
   __ RN
   __ 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 ________________________________

29. In what state/province do you live? ________________

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
   Identifying surrogate decision maker for incompetent patients  __ 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
   Physical care issues (wound care, incontinence, etc.)

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 Very important
   0 1 2 3 4 5 6 7 8 9 10

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

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

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 your 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
Overall end-of-life care for the terminally ill

- 0 1 2 3 4 5 6 7 8 9 10 very effective

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

A) Pain management

- 0 1 2 3 4 5 6 7 8 9 10 very effective

B) Other symptom management

- 0 1 2 3 4 5 6 7 8 9 10 very effective

C) Communication with terminally ill patients

- 0 1 2 3 4 5 6 7 8 9 10 very effective

D) Communication with family caregivers

- 0 1 2 3 4 5 6 7 8 9 10 very effective

E) Managing the death event at home

- 0 1 2 3 4 5 6 7 8 9 10 very effective

F) Cultural issues in end-of-life care

- 0 1 2 3 4 5 6 7 8 9 10 very effective

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

- 0 1 2 3 4 5 6 7 8 9 10 very 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 patients 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
    ___ 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
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>Symptom</th>
<th>Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agitation/Restlessness</td>
<td>Side effects of Meds</td>
</tr>
<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?
   
   0 1 2 3 4 5 6 7 8 9 10
   Not at all distressing
   Completely distressing

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?