
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

City of Hope National Medical Center

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:

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

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

Course (e.g. Med-Surg)	Content	Amount of Time spent on EOL Care Content (e.g. 2 hours)
Example: Medical-Surgical Nursing	Example: Pain Management	Example: 1 hour

6. What resources would be most helpful to assist faculty in improving EOL content in nursing education?

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

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

Not important **Very important**
 0 1 2 3 4 5 6 7 8 9 10

B) How effective do you believe a new graduate of your program would be in caring for a dying patient?
Not effective **Very effective**
 0 1 2 3 4 5 6 7 8 9 10

C) How receptive do you believe your faculty would be to increased EOL care education?
Not receptive **Very receptive**
 0 1 2 3 4 5 6 7 8 9 10

D) As a faculty member, how effective do you feel you are in teaching EOL care content?
Not effective **Very effective**
 0 1 2 3 4 5 6 7 8 9 10

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?

	not at all effective	somewhat effective	very effective
Pain assessment	_____	_____	_____
Pain management	_____	_____	_____
Other symptom management	_____	_____	_____
Psychological support for dying patients	_____	_____	_____
Attention to spiritual needs	_____	_____	_____
Grief/bereavement support	_____	_____	_____

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

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

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?

	not a barrier	somewhat of a barrier	severe barrier
Lack of knowledge by health care professionals	_____	_____	_____
Health care professionals' personal discomfort with death	_____	_____	_____
Avoidance of dying patients by health care professionals	_____	_____	_____
Health care professionals fear of causing addiction by administering pain medications	_____	_____	_____
Patients' avoidance of death	_____	_____	_____
Family members' avoidance of death	_____	_____	_____
Cultural factors influencing end-of-life care	_____	_____	_____
Patients'/families' fear of addiction	_____	_____	_____
Increased use of unlicensed personnel in care of the dying	_____	_____	_____
The influence of managed care on end-of-life care	_____	_____	_____
Legal restrictions placed on health care professionals in prescribing pain medications	_____	_____	_____
Lack of continuity of care across settings	_____	_____	_____

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?

	not adequate	somewhat adequate	very adequate
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

	not effective	somewhat effective	very effective
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 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?
- | | |
|---|--|
| <input type="checkbox"/> Hospital | <input type="checkbox"/> Rehabilitation |
| <input type="checkbox"/> Home health care | <input type="checkbox"/> Ambulatory Care/Outpatient Clinic |
| <input type="checkbox"/> Hospice | <input type="checkbox"/> Other |
26. In what clinical area do you usually work?
- | | |
|--|---|
| <input type="checkbox"/> Medical/Surgical | <input type="checkbox"/> OB/GYN/Nursery |
| <input type="checkbox"/> Critical Care | <input type="checkbox"/> Pediatrics |
| <input type="checkbox"/> Emergency | <input type="checkbox"/> Administration |
| <input type="checkbox"/> Oncology | <input type="checkbox"/> Education |
| <input type="checkbox"/> Operating Room/Postanesthesia | <input type="checkbox"/> Other |
27. What is the highest level of education you've completed?
- | | |
|----------------------------------|--------------------------------------|
| <input type="checkbox"/> LPN/LVN | <input type="checkbox"/> RN |
| | <input type="checkbox"/> Diploma |
| | <input type="checkbox"/> ADN |
| | <input type="checkbox"/> BSN/BS/BA |
| | <input type="checkbox"/> MSN/MS/MA |
| | <input type="checkbox"/> PhD/EdD/DNS |
| | <input type="checkbox"/> Other |
28. What is your title?
- | | |
|---|---|
| <input type="checkbox"/> Staff Nurse/Clinical Nurse | <input type="checkbox"/> Nurse Director/Executive |
| <input type="checkbox"/> Charge Nurse | <input type="checkbox"/> Clinical Specialist/Nurse Practitioner |
| <input type="checkbox"/> Nurse-Manager | <input type="checkbox"/> 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 Hydration/nutrition at end-of-life Yes No
Advance directives Yes No Terminal dyspnea Yes No
Pain management Yes No Death at home Yes No
Grief/Bereavement 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)

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
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 +

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 +

RN End of Life Knowledge Assessment
RN/LVN Version

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 |

Home Health Aides (HHAs)
Version for End of Life Knowledge Assessment

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 | ___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:

<u>Drug(s)</u>	<u>Dose</u>	<u>Schedule</u>
----------------	-------------	-----------------

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

- | | | | |
|--------------------------|--------------------------------|--------------------------|-----------------------------|
| <input type="checkbox"/> | Agitation/Restlessness | <input type="checkbox"/> | Side effects of Meds |
| <input type="checkbox"/> | Altered Mental Status/Delirium | <input type="checkbox"/> | Skin Integrity |
| <input type="checkbox"/> | Anxiety | <input type="checkbox"/> | Spiritual Distress |
| <input type="checkbox"/> | Depression | <input type="checkbox"/> | Vomiting |
| <input type="checkbox"/> | Dysphagia | <input type="checkbox"/> | Weakness/Fatigue/Immobility |
| <input type="checkbox"/> | Dyspnea | <input type="checkbox"/> | Wounds |
| <input type="checkbox"/> | Incontinence | <input type="checkbox"/> | Other: |
| <input type="checkbox"/> | Nausea | <input type="checkbox"/> | Nutrition/Hydration |

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

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?