END OF LIFE/HOSPICE CARE

Nursing care involves the support of general well-being of our patients, the provision of episodic acute care and rehabilitation, and when a return to health is not possible, a peaceful death. Dying is a profound transition for the individual. As healthcare providers, we become skilled in nursing and medical science, but the care of the dying person encompasses much more. Certain aspects of this care are taking on more importance for patients, families, and healthcare providers. These include pain and other symptom management; psychological, spiritual, and grief/bereavement support.

Recent studies have identified barriers to end-of-life care including patient or family member's avoidance of death, influence of managed care on end-of-life care, and lack of continuity of care across settings. In addition, if the dying patient requires a lengthy period of care or complicated physical care, there is the likelihood of caregiver fatigue (psychological and physical) that can compromise the care provided.

The best opportunity for quality care occurs when patients facing death, and their family, have time to consider the meaning of their lives, make plans, and shape the course of their living while preparing for death.

CARE SETTING

Much of the care of the dying is still provided by nurses in hospitals, primarily in oncology and critical care areas. However, other care settings are becoming more common, e.g., the home, assisted living/extended care setting, or hospice inpatient unit.

RELATED CONCERNS

Cancer
Extended care
Psychosocial aspects of care
Care Plan(s) reflecting underlying pathology of terminal condition

Patient Assessment Database

Data depend on underlying terminal condition and involvement of other body systems.

EGO INTEGRITY

May report: Stress related to recent changes in ability to care for self and decision to accept hospice services
Feelings of helplessness/hopelessness, sorrow, anger; choked feelings
Fear of the dying process, loss of physical and/or mental abilities
Concern about impact of death on SO/family
Inner conflict about beliefs, meaning of life/death
Financial concerns; lack of preparation (e.g., will, power of attorney, funeral)

May exhibit: Deep sadness, crying, anxiety, apathy
Altered communication patterns; social isolation; withdrawal

SOCIAL INTERACTION

May report: Apprehension about caregiver's ability to provide care
Changes in family roles/usual patterns of responsibility

May exhibit: Difficulty adapting to changes imposed by condition/dying process

NURSING PRIORITIES

1. Control pain.
2. Prevent/manage complications.
3. Maintain quality of life as possible.
4. Plans in place to meet patient's/family's last wishes (e.g., care setting, Advance Directives, will, funeral).

NURSING DIAGNOSIS: Pain, acute/chronic

May be related to

Injuring agents (biological, chemical, physical, psychological)
Chronic physical disability

Possibly evidenced by

Verbal/coded report; preoccupation with pain
Changes in appetite/eating, weight; sleep patterns; altered ability to continue desired activities; fatigue
Guarded/protective behavior; distraction behavior (pacing/repetitive activities, reduced interaction with others)
Facial mask; expressive behavior (restlessness, moaning, crying, irritability); self-focusing; narrowed focus (altered time perception, impaired thought process)
Alteration in muscle tone (varies from flaccid to rigid)
Autonomic responses (diaphoresis, changes in BP, respiration, pulse); sympathetic mediated responses (temperature, cold, changes of body position, hypersensitivity)

DESIRED OUTCOMES/EVALUATION CRITERIA—PATIENT WILL:

Pain Control (NOC)

Report pain is relieved/controlled.
Verbalize methods that provide relief.
Follow prescribed pharmacological regimen.
Demonstrate use of relaxation skills and diversional activities as indicated.

FAMILY/SO(s) WILL:

Cooperate in pain management program.

ACTIONS/INTERVENTIONS	RATIONALE
Pain Management (NIC)	
Independent	
Perform a comprehensive pain evaluation, including location, characteristics, onset/duration, frequency, quality, severity (e.g., 0–10 scale), and precipitating/aggravating factors. Note cultural issues impacting reporting and expression of pain. Determine patient's acceptable level of pain.	Provides baseline information from which a realistic plan can be developed, keeping in mind that verbal/behavioral cues may have little direct relationship to the degree of pain perceived. *Note:* Often patient does not feel the need to be completely pain-free but is able to be more functional when pain is at lower level on the pain scale.
Determine possible pathophysiological/psychological causes of pain (e.g., inflammation, fractures, cancer process, surgery, grief, fear/anxiety).	Pain is associated with many factors that may be interactive and increase the degree of pain experienced.
Assess patient's perception of pain, along with behavioral and psychological responses. Determine patient's attitude toward/use of pain medications and locus of control (internal/external).	Helps identify patient's needs and pain control methods found to be helpful or not helpful in the past. *Note:* Individuals with external locus of control may take little or no responsibility for pain management.
Encourage patient/family to express feelings/concerns about narcotic use.	Inaccurate information regarding drug use/fear of addiction or oversedation may impair pain control efforts.

ACTIONS/INTERVENTIONS	RATIONALE
Pain Management (NIC)	
Independent	
Verify current and past analgesic/narcotic drug use (including alcohol).	May provide insight into what has/has not worked in the past or may impact therapy plan.
Assess degree of personal adjustment to diagnosis, such as anger, irritability, withdrawal, acceptance.	These factors are variable and often affect the perception of pain/ability to cope and need for pain management.
Discuss with SO(s) ways in which they can assist patient and reduce precipitating factors.	Promotes involvement in care and belief that there are things they can do to help.
Identify specific signs/symptoms and changes in pain requiring notification of healthcare provider/medical intervention.	Unrelieved pain may be associated with progression of terminal disease process, or be associated with complications that require medical management.
Involve caregivers in identifying effective comfort measures for patient, e.g., use of nonacidic fluids, oral swabs/lip salve, skin/perineal care, enema. Instruct in use of oxygen/suction equipment as appropriate.	Managing troubling symptoms such as nausea, dry mouth, dyspnea, constipation can reduce patient's suffering and family anxiety, improving quality of life and allowing patient/family to focus on other issues.
Demonstrate/encourage use of relaxation techniques, e.g., guided imagery, tapes/music, meditation.	May reduce need for/can supplement analgesic therapy, especially during periods when patient desires to minimize sedative effects of medication.
Monitor for/discuss possibility of changes in mental status, e.g., agitation, confusion, restlessness.	Although causes of deterioration are numerous in terminal stages, early recognition and management of the psychological component is an integral part of pain management.
Collaborative	
Establish pain management plan with patient, family, and healthcare provider, including options for management of breakthrough pain.	Inadequate pain management remains one of the most significant deficiencies in the care of the dying patient. A plan developed in advance increases patient's level of trust that comfort will be maintained, reducing anxiety.
Schedule/administer analgesics as indicated to maximal dosage. Notify physician if regimen is inadequate to meet pain control goal.	Helps maintain "acceptable" level of pain. Modifications of drug dosage/combinations may be required.
Instruct patient, family/caregiver in use of IV pump (PCA) for pain control.	When patient controls dosage and administration of medication, pain relief is enhanced and quality of life improved.
Review medicinal options to treat constipation.	Various "cocktails" are available to stimulate bowel function, reduce associated discomfort.

Refer to CP: Cancer, ND: Pain,acute/chronic for additional interventions.

NURSING DIAGNOSIS: Activity Intolerance/Fatigue

May be related to

Generalized weakness
Bedrest or immobility; progressive disease state/debilitating condition
Imbalance between oxygen supply and demand
Cognitive deficits/emotional status, secondary to underlying disease process/depression
Pain, extreme stress

Possibly evidenced by

Report of lack of energy, inability to maintain usual routines
Verbalizes no desire and/or lack of interest in activity
Lethargic; drowsy; decreased performance
Disinterested in surroundings/introspection

DESIRED OUTCOMES/EVALUATION CRITERIA—PATIENT WILL:

Energy Conservation (NOC)

Identify negative factors affecting performance and eliminate/reduce their effects when possible.
Adapt lifestyle to energy level.
Verbalize understanding of potential loss of ability in relation to existing condition.

Endurance (NOC)

Maintain or achieve slight increase in activity tolerance evidenced by acceptable level of fatigue/weakness.
Remain free of preventable discomfort and/or complications.

ACTIONS/INTERVENTIONS	RATIONALE
Energy Management (NIC)	
Independent	
Assess sleep patterns and note changes in thought processes/behaviors.	Multiple factors can aggravate fatigue, including sleep deprivation, emotional distress, side effects of medication, and progression of disease process.
Recommend scheduling activities for periods when patient has most energy. Adjust activities as necessary, reducing intensity level/discontinuing activities as indicated.	Prevents overexertion, allows for some activity within patient ability.
Encourage patient to do whatever possible, e.g., self-care, sit in chair, visit with family/friends.	Provides for sense of control and feeling of accomplishment.
Instruct patient/family/caregiver in energy conservation techniques. Stress necessity of allowing for frequent rest periods following activities.	Enhances performance while conserving limited energy, preventing increase in level of fatigue.
Demonstrate proper performance of ADLs, ambulation/position changes. Identify safety issues, e.g., use of assistive devices, temperature of bath water, keeping travel-ways clear of furniture.	Protects patient/caregiver from injury during activities.

ACTIONS/INTERVENTIONS	RATIONALE
Energy Management (NIC)	
Independent	
Encourage nutritional intake/use of supplements as appropriate.	Necessary to meet energy needs for activity.
Document cardiopulmonary response to activity (i.e., weakness, fatigue, dyspnea, arrhythmias, and diaphoresis).	Can provide guidelines for participation in activities.
Monitor breath sounds. Note feelings of panic/air hunger.	Hypoxemia increases sense of fatigue, impairs ability to function.
Collaborative	
Provide supplemental oxygen as indicated and monitor response.	Increases oxygenation. Evaluates effectiveness of therapy.

NURSING DIAGNOSIS: Grieving, anticipatory/Anxiety, death

May be related to

Anticipated loss of physiological well-being (e.g., change in body function)
Perceived death of patient

Possibly evidenced by

Changes in eating habits; alterations in sleep patterns, activity levels, libido, and communication patterns
Denial of potential loss, choked feelings, anger
Fear of the process of dying; loss of physical and/or mental abilities
Negative death images or unpleasant thought about any event related to death or dying; anticipated pain related to dying
Powerlessness over issues related to dying; total loss of control over any aspect of one's own death; inability to problem-solve
Worrying about impact of one's own death on SOs; being the cause of other's grief and suffering; concerns of overworking the caregiver as terminal illness incapacitates

DESIRED OUTCOMES/EVALUATION CRITERIA—PATIENT WILL:

Grief Resolution (NOC)

Identify and express feelings appropriately.
Continue normal life activities, looking toward/planning for the future, one day at a time.
Verbalize understanding of the dying process and feelings of being supported in grief work.

Dignified Dying (NOC)

Experience personal empowerment in spiritual strength and resources to find meaning and purpose in grief and loss.

FAMILY WILL:

Grief Resolution (NOC)

Verbalize understanding of the stages of grief and loss, ventilate conflicts and feelings related to illness and death.

ACTIONS/INTERVENTIONS	RATIONALE
Grief Work Facilitation (NIC)	
Independent	
Facilitate development of a trusting relationship with patient/family.	Trust is necessary before patient/family can feel free to open personal lines of communication with the hospice team and address sensitive issues.
Assess patient/SO for stage of grief currently being experienced. Explain process as appropriate.	Knowledge about the grieving process reinforces the normality of feelings/reactions being experienced and can help patient deal more effectively with them.
Provide open, nonjudgmental environment. Use therapeutic communication skills of Active-Listening, acknowledgment, and so on.	Promotes and encourages realistic dialogue about feelings and concerns.
Encourage verbalization of thoughts/concerns and accept expressions of sadness, anger, rejection. Acknowledge normality of these feelings.	Patient may feel supported in expression of feelings by the understanding that deep and often conflicting emotions are normal and experienced by others in this difficult situation.
Be aware of mood swings, hostility, and other acting-out behavior. Set limits on inappropriate behavior, redirect negative thinking.	Indicators of ineffective coping and need for additional interventions. Preventing destructive actions enables patient to maintain control and sense of self-esteem.
Monitor for signs of debilitating depression, e.g., statements of hopelessness, desire to “end it now.” Ask patient direct questions about state of mind.	Patient may be especially vulnerable when recently diagnosed with end-stage disease process and/or when discharged from hospital. Fear of loss of control/concerns about managing pain effectively may cause patient to consider suicide.
Reinforce teaching regarding disease process and treatments and provide information as requested/ appropriate about dying. Be honest; do not give false hope while providing emotional support.	Patient/SO benefit from factual information. Individuals may ask direct questions about death, and honest answers promote trust and provide reassurance that correct information will be given.
Review past life experiences, role changes, sexuality concerns, and coping skills. Promote an environment conducive to talking about things that interest patient.	Opportunity to identify skills that may help individuals cope with grief of current situation more effectively. *Note:* Issues of sexuality remain important at this stage, e.g., feelings of masculinity/femininity, giving up role within family (caretaker/provider), ability to maintain sexual activity (if desired).
Investigate evidence of conflict; expressions of anger; and statements of despair, guilt, hopelessness, inability to grieve.	Interpersonal conflicts/angry behavior may be patient’s/SO’s way of expressing or dealing with feelings of despair/spiritual distress, necessitating further evaluation and support.
Determine way that patient/SO understand and respond to death, e.g., cultural expectations, learned behaviors, experience with death (close family members/friends), beliefs about life after death, faith in Higher Power (God).	These factors affect how each individual faces death and influences how they may respond and interact.

ACTIONS/INTERVENTIONS	RATIONALE
Grief Work Facilitation (NIC)	
Independent	
Assist patient/SO to identify strengths in self/situation and support systems.	Recognizing these resources provides opportunity to work through feelings of grief.
Be aware of own feelings about death. Accept whatever methods patient/SO have chosen to help each other through the process.	Caregiver's anxiety and unwillingness to accept reality of possibility of own death may block ability to be helpful to patient/SO, necessitating enlisting the aid of others to provide needed support.
Dying Care (NIC)	
Provide open environment for discussion with patient/SO (when appropriate) about desires/plans pertaining to death; e.g., making will, burial arrangements, tissue donation, death benefits, insurance, time for family gatherings, how to spend remaining time.	If patient/SO are mutually aware of impending death, they may more easily deal with unfinished business or desired activities. Having a part in problem solving/planning can provide a sense of control over anticipated events.
Encourage participation in care and treatment decisions.	Allows patient to retain some control over life.
Visit frequently and provide physical contact as appropriate/desired, or provide frequent phone support as appropriate for setting. Arrange for care provider/support person to stay with patient as needed.	Helps reduce feelings of isolation and abandonment.
Provide time for acceptance, final farewell, and arrangements for memorial/funeral service according to individual spiritual/cultural/ethnic needs.	Accommodation of personal/family wishes helps reduce anxiety and may promote sense of peace.
Collaborative	
Determine spiritual needs/conflicts and refer to appropriate team members including clergy/spiritual advisor.	Providing for spiritual needs, forgiveness, prayer, devotional materials, or sacraments as requested can relieve spiritual pain and provide a sense of peace.
Refer to appropriate counselor as needed (e.g., psychiatric clinical nurse specialist, social worker, psychologist, pastoral support).	Compassion and support can help alleviate distress or palliate feelings of grief to facilitate coping and foster growth.
Refer to visiting nurse, home health agency as needed, or hospice team, when appropriate.	Provides support in meeting physical and emotional needs of patient/SO, and can supplement the care family and friends are able to give.
Identify need for/appropriate timing of anti-depressants/ anxiety medications.	May alleviate distress, enhance coping, especially for patients not requiring analgesics.

NURSING DIAGNOSIS: Family Coping, ineffective: compromised or disabled/Caregiver Role Strain, risk for

May be related to

Inadequate or incorrect information or understanding by a primary person; unrealistic expectations

Temporary preoccupation by significant person who is trying to manage emotional conflicts and personal suffering and is unable to perceive or to act effectively with regard to patient's needs; does not have enough resources to provide the care needed

Temporary family disorganization and role changes; feel that caregiving interferes with other important roles in their lives

Patient providing little support in turn for the primary person

Prolonged disease/disability progression that exhausts the supportive capacity of significant persons

Significant person with chronically unexpressed feelings of guilt, anxiety, hostility, despair

Highly ambivalent family relationships; feel stress or nervousness in their relationship with the care receiver

Possibly evidenced by

Patient expressing/confirming a concern or complaint about SO's response to patient's health problem, despair about family reactions/lack of involvement; history of poor relationship between caregiver and care receiver

Neglectful relationships with other family members

Inability to complete caregiving tasks; altered caregiver health status

SO describing preoccupation about personal reactions; displaying intolerance, abandonment, rejection; caregiver not developmentally ready for caregiver role

SO attempting assistive/supportive behaviors with less than satisfactory results; withdrawing or entering into limited or temporary personal communication with patient; displaying protective behavior disproportionate (too little or too much) to patient's abilities or need for autonomy

Apprehension about future regarding care receiver's health and the caregiver's ability to provide care

DESIRED OUTCOMES/EVALUATION CRITERIA—FAMILY/CAREGIVER WILL:

Caregiver Performance: Direct or Indirect Care (NOC)

Identify resources within themselves to deal with situation.

Visit regularly and participate positively in care of patient, within limits of abilities.

Caregiver-Patient Relationship (NOC)

Express more realistic understanding and expectations of patient.

Provide opportunity for patient to deal with situation in own way.

ACTIONS/INTERVENTIONS	RATIONALE
Family Involvement (NIC)	
Independent	
Assess level of anxiety present in family/SO.	Anxiety level needs to be dealt with before problem solving can begin. Individuals may be so preoccupied with own reactions to situation that they are unable to respond to another's needs.
Establish rapport and acknowledge difficulty of the situation for the family.	May assist SO to accept what is happening and be willing to share problems with staff.
Determine level of impairment of perceptual/cognitive/physical abilities. Evaluate pre-illness/current behaviors that are interfering with the care of patient.	Information about family problems (e.g., divorce/separation, alcoholism/other drug abuse, abusive situation) will be helpful in determining options and developing an appropriate plan of care.

ACTIONS/INTERVENTIONS	RATIONALE
Family Involvement (NIC)	
Independent	
Note patient's emotional/behavioral responses resulting from increasing weakness and dependency (e.g., hallucinations, delusions, hostility, withdrawal, depression).	Approaching death is most stressful when patient/family coping responses are strained, resulting in increased frustration, guilt, and anguish.
Discuss underlying reasons for patient behaviors with family.	When family members know why patient is behaving differently, it may help them understand and accept/deal with unusual behaviors.
Assist family/patient to understand "who owns the problem" and who is responsible for resolution. Avoid placing blame or guilt.	When these boundaries are defined, each individual can begin to take care of own self and stop taking care of others in inappropriate ways.
Determine current knowledge/perception of the situation.	Provides information on which to begin planning care and make informed decisions. Lack of information or unrealistic perceptions can interfere with caregiver's/care receiver's response to illness situation.
Assess current actions of SO and how they are received by patient.	SO may be trying to be helpful, but actions are not perceived as being helpful by patient. SO may be withdrawn or too protective.
Involve SO in information giving, problem solving, and care of patient as feasible. Instruct in medication administration techniques, needed treatments, and ascertain adeptness with required equipment.	Information can reduce feelings of helplessness and uselessness. Helping a patient/family find comfort is often more important than adhering to strict routines. However, family caregivers need to feel confident with specific care activities and equipment.
Include all family members as appropriate in discussions. Provide/reinforce information about terminal illness/death and future family needs.	Knowledge can help the family prepare for eventualities and deal with the actual death process. Increases understanding of necessary activities/steps to be taken to deal with funeral preparations, legal/financial concerns, and survivor issues.
Collaborative	
Refer to appropriate resources for assistance as indicated (e.g., counseling, psychotherapy, financial, spiritual, respite care).	May need additional assistance in resolving family issues/ making peace and maintaining personal well-being.
Arrange for appropriate prescriptions for SO (e.g., sedative/hypnotics).	Mild medication may be beneficial in reducing anxiety/promoting sleep, which in turn can enhance coping ability.