



Guidelines for Assessing the Dying Patient

Death is an immensely significant event in the life of the patient and the family. Care of the patient cannot be provided without caring also for the family who is equally suffering.

Death is defined as permanent cessation of all vital bodily functions and yet this simple definition is lacking in the societal and cultural definitions of death. Although death is a natural part of life, society, culture, and religion attach additional meanings to the death. In some cultures death can mean simply that the numbered days are up. In others it could mean that a bad spell has been cast. In the United States we tend to see death as a failure of the health care system as if death were a choice.

Death can occur at any time throughout the life cycle. This discussion will focus on deaths that are expected from chronic, terminal conditions that can occur at any age.

Kübler-Ross has aptly identified the stages of grief that patients and families go through when diagnosed with terminal illness. Not all patients neatly follow the stages. More importantly, not all members of the family are in the same stage at the same time. It is easier on the caregivers and health care workers if the patient dies in the final grief stage Kübler-Ross calls acceptance, but, in reality, some patients and/or families stay angry or in denial and the challenge to the nurse is to accept the patient and family at whatever stage they are and work with them accordingly. There are hospice agencies in all communities across the United States (and in most countries around the world) that can be called to help nurses in all settings to care for dying patients.

When patients are first told that they have a diagnosis that is not treatable, there may be outbursts of anger

Coping Mechanisms Identified by Kübler-Ross

		BEHAVIOR	SPEECH
Stage I	Denial and Isolation	Patient/family does not believe the diagnosis. Search for a second opinion.	I don't believe you. That's not true.
Stage II	Anger	With the realization of the diagnosis, the patient/family can lash out at family members or health care providers. Frequently this stage is accompanied by questions about spirituality and faith.	Why me? God has forsaken me!
Stage III	Bargaining	Once some of the anger is controlled, the patient begins to bargain—usually with God about the time of death.	"OK, but can I live long enough to witness a wedding, christening, graduation, etc.?"
Stage IV	Depression	When bargaining is over, the patient is overcome with a sense of loss—body image, independence, etc. The patient sleeps a lot and stays secluded.	What good have I done in my life? What's the use in living?
Stage V	Acceptance	Patient speaks little and sleeps a lot. The patient may motion to visitors with a hand signal instead of speaking.	Very little verbal communication. Desires touch in the way of holding a hand rather than verbal communication.

and denial from the patient or family member. As time progresses, increased sleeping and weakness is a common occurrence. Many times it is the nurse who initiates the discussion of DNR paperwork and asks about funeral arrangements. Although, when the diagnosis is made, all parties involved know these issues must be addressed, there is a fear that by talking about it, the death becomes more real and sometimes families feel this discussion will hasten the death. The nurse, as an impartial party, can discuss this with the patient and ask about preferences to free the family from making these difficult decisions at

the time of the death when emotions are likely to run high. The more the nurse knows the patient as a person, the better able he or she is to make sure the patient's wishes are followed at the time of his or her death.

As the dying patient gets weaker, he or she is usually confined to bed and may not be able to be aroused even for meals. There are normal changes that occur to prepare the body for death. Knowledge of these will help the nurse care for the dying patient as well as help the nurse educate and provide anticipatory guidance for caregivers of dying patients.

Taking a History

WHAT TO ASK ABOUT

SIGNIFICANCE/CONSIDERATIONS

Biographical Data

Name, address, gender, religion, race, ethnicity.

Issues of gender do come up in same-sex relationships. Many religions and cultures have specific practices related to death and dying. It is important to clarify with the patient what his or her specific religious/cultural needs are at the time of death.

Does the patient have Advanced Directives?
Are funeral plans in place?

These discussions are easier to have when the patient is feeling reasonably well than when the patient is in coma. It allows the patient to make choices and takes some of the burden from the family.

Marital Status

Are there any children? Where do they live?
Who has the medical power of attorney?

Identify the primary caregiver and availability of caregiver support systems. Need contact information for the medical power of attorney when the patient can no longer make decisions. If small children live in the home with the patient, their bereavement needs must be assessed as well.

Current Health History

How long has patient been ill?
What is the patient's current functional ability?
What was the patient's functional ability a week ago? A month ago?

Prolonged illness stresses the patient and the family. Caregiver needs to be assessed for caregiver burnout. Decline of function over time can indicate the speed with which the illness is progressing.

Are there any known medication allergies?
If so, to what drug and what happens when the drug is taken?

If the patient reports an allergy to a drug it is important to differentiate between a true allergy and a side effect. Nausea and vomiting when taking opioids are side effects and would not preclude use of these drugs for pain management if needed.

What is the list of current medications being taken?

Examine list and assess patient/family knowledge about the medication and administration.

Assess patient's comfort level.

McCaffery and Pasero define pain as "whatever the person says it is, experienced whenever they say they are experiencing it." Pain is a subjective response and includes dimensions of psychological, social, and spiritual distress in addition to physical pain. Patients with chronic pain do not demonstrate the same behaviors as those with acute pain, which is the model for pain we have in acute care settings. If the patient has had oral doses of opioids over the course of his or her illness and is now unable to take anything by mouth, it is imperative that opioids be continued in the sublingual or rectal route to prevent opioid withdrawal at a time that the body is preparing for death.

Past Medical History

Past illnesses and surgeries.

Other diagnosis may affect the course of the terminal disease. Identify coping strategies with past events.

Family History

Determine exposure of family members to death and dying. Identify if the patient/family dealt with this illness in other family members and may have a preconceived idea of how dying will occur.

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Taking a History (continued)

WHAT TO ASK ABOUT	SIGNIFICANCE/CONSIDERATIONS
Review of Systems	
<i>Skin</i>	
Changes in the skin?	With immobility and impaired nutrition comes the risk of skin breakdown.
<i>HEENT</i>	
Any visual or auditory losses?	Visual or auditory losses must be considered when planning communication patterns with the patient.
<i>Respiratory</i>	
Breathing problems?	Coughing or difficulty breathing may be indicative of fluid overload or dysphagia depending on when these symptoms are occurring.
<i>Cardiovascular</i>	
Chest pain?	Chest pain or changes in heart rate or blood pressure may signify decline or need to make adjustment to some medications.
<i>Genitourinary</i>	
Continence problems?	Is the patient continent? Answer to this will alert the nurse to check for skin breakdown and identify need for additional supplies like diapers, blue pads, etc.
<i>Gastrointestinal</i>	
Appetite?	Decrease in appetite is normal in the dying process. Create opportunity to teach caregiver about nutrition and hydration at the end of life.
Bowel patterns?	Use of opioids for pain management frequently causes constipation.
<i>Musculoskeletal</i>	
Weakness?	Assess ability of caregiver to assist with ambulation and other ADLs.
Ability to do activities of daily living (ADLs)?	Perform a safety assessment for falls. May need to provide assistive devices such as wheelchairs, walkers, bedside commodes to help caregiver.
<i>Neurological</i>	
Change in mental status?	Decrease in level of consciousness, talking to deceased family members, confusion are all part of the dying process.
Confusion?	Behaviors described by family members will help to determine the stage of grief the patient is in.
Affect?	Affect may correlate with Kübler-Ross stages of death and dying.

Performing the Head-to-Toe Physical Examination

AREA/ASSESS FOR:	SIGNIFICANCE
<p>General Survey Assess for general appearance, cleanliness, behavior, overview of immediate environment.</p>	Evaluates the ability of caregiver to provide care and identify teaching needs for caregiver.
<p>Vital Signs</p>	In the days preceding death, body temperature goes up, pulse rate frequently goes up, and blood pressure decreases, and respirations become faster and uneven.
<p>Integumentary Inspect skin color.</p> <p>Inspect pressure points for skin breakdown. Palpate skin temperature.</p>	<p>As death approaches, the skin undergoes a phenomenon called Mottling, which is a bluish hue that usually appears first in the lower extremities (toes, feet, and knees) and progresses to other parts of the body.</p> <p>Other areas may be sallow, yellow, or pale. With fever, skin may be warm and moist. Skin may be cool.</p>
<p>HEENT Assess mouth for dryness or secretions.</p>	<p>Mouth breathing at the end stages of life cause lips and tongue to become dry. Secretions at the back of the throat contribute to noisy respirations known as the 'death rattle'.</p>
<p>Eyes Assess eyes, note appearance.</p>	Eyes may be closed or half-opened; glassy or tearing. Appearance "look past you".
<p>Respiratory Auscultate lungs.</p>	<p>As death approaches, patient will have Cheyne-Stokes respirations with progressively longer periods of apnea.</p> <p>If the patient has continued to receive fluids by IV or Peg after his body systems have started shutting down, respirations will be labored with crackles throughout.</p>
<p>Cardiac Assess pulses.</p>	As blood pressure decreases, peripheral pulses will be harder to palpate. Pulse rate becomes rapid and thready as the heart tries to compensate for the drop in blood pressure.
<p>Gastrointestinal Assess bowel sounds.</p>	Initially the patient reports poor appetite and early satiety. As death approaches, peristalsis slows and then stops so that no bowel sounds will be heard. It is very important to teach the caregiver that any attempts at hydrating or feeding the patient at this point will lead to a more uncomfortable death. Once body systems begin to shut down, fluid infused accumulates ultimately in the lungs adding to the characteristic death rattle and contributing to discomfort at the time of death.

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Performing the Head-to-Toe Physical Examination (continued)

AREA/ASSESS FOR:	SIGNIFICANCE
Genitourinary Check output.	There may not be any urine output for 2 to 3 days before death as the kidneys begin to shut down. Urine present in a Foley bag will be concentrated and dark. Patients who have struggled with edema, either peripheral or ascites, will experience a reabsorption of some of those body fluids.
Musculoskeletal Assess muscle tone.	Extremities that have been spastic become flaccid as death approaches.
Neurological Assess loss of consciousness (LOC).	<p>Not all patients are in coma for several days before death. Some (especially children) can be reasonably alert and mobile, and just die during sleep. Teach the family that death can occur in many ways and each is individual. It is common for the patient to see deceased family members in the room (usually on the ceiling) prior to the death. The patient may also experience a period of increased lucidity and alertness some time before the death giving the family some hope that the death may not be imminent.</p> <p>A symptom that is also common as death approaches is 'terminal restlessness'. The patient grows restless, trying to get out of bed even though confused and non communicative.</p>

Cultural Views of Death and Dying

CULTURAL GROUP	BELIEFS
African Americans	Death Rituals/Expectations <ul style="list-style-type: none"> ■ Strong ties between living and the dead. ■ Death does not end connections between people. ■ May have rituals regarding spirits of the deceased. ■ "Voodoo" death, death result of supernatural force. Response to Death and Grief <ul style="list-style-type: none"> ■ Body must remain intact. ■ "Falling out", sudden collapse, and paralysis with inability to see or speak. ■ Express feelings openly. ■ Emotional expression encouraged. ■ Eulogies are important.
Amish	Death Rituals/Expectations <ul style="list-style-type: none"> ■ Prefer to die at home. ■ Community event. ■ Community very supportive. Response to Death and Grief <ul style="list-style-type: none"> ■ Many visitors. ■ Community relieves family of responsibility for decision making. ■ Wakelike "sitting up" through the night. ■ Funeral ceremony simple. ■ Verbal response muted, stoic. ■ Death seen as a normal transition.

CULTURAL GROUP	BELIEFS
Appalachian	<p>Death Ritual/Expectations</p> <ul style="list-style-type: none"> ■ Important occasion. ■ Release time given to extended family members to grieve. ■ Funeral services are a social function. ■ Funerals are simple. ■ Viewing for 1 hour. ■ Buried in best clothes with personal possessions. ■ Elaborate meals follow funeral. ■ Frequent visits to cemetery. <p>Response to Death and Grief</p> <ul style="list-style-type: none"> ■ Clergy help family through grieving process. ■ Good at working through grieving process. ■ Flowers more important than donations to a charity.
Arab Americans	<p>Death Ritual/Expectations</p> <ul style="list-style-type: none"> ■ Death accepted as God's will. ■ The deceased's bed turned to face Mecca. ■ Deceased washed 3 times by Muslim of same sex, wrapped in white, and buried as soon as possible in brick or cement-lined grave facing Mecca. ■ Prayers are recited. ■ Women do not attend funeral unless deceased is spouse or close relative. ■ Women stay at home and read the Qur'an. ■ Cremation not allowed and usually do not permit autopsy. <p>Response to Death and Grief</p> <ul style="list-style-type: none"> ■ Inevitable. ■ Expression of grief and period of mourning limited. ■ Friends and relative limited to 3 days, wife can mourn 4 months and 10 days. ■ Expression of grief may be limited to weeping or more expressive.
Chinese Americans	<p>Death Rituals/Expectations</p> <ul style="list-style-type: none"> ■ Death and bereavement centered on ancestor worship, which means paying respect. ■ Believe spirit can not rest until memory of deceased is worship. ■ Fear death. ■ Number 4 is unlucky because it sounds like the word for death. ■ May delay getting insurance. ■ Color white and black are associated with death, red ultimate good luck color. ■ Believe in ghosts having great power. ■ Family and friends mourn at home. ■ Honor dead by placing objects that signify life around coffin. ■ Cremation preferred by state in China due to lack of space, but Chinese prefer to bury. <p>Response to Death and Grief</p> <ul style="list-style-type: none"> ■ More accepting of death than Westerners. ■ Death seen as a natural cycle of life. ■ Believe something good happens after death. ■ Bereavement limited to 1 to 7 days. ■ Mourners wear black arm bands and white head bands.
Cuban Americans	<p>Death Rituals/Expectations</p> <ul style="list-style-type: none"> ■ Support of extended family important. ■ Large gathering at family and friends. ■ Catholic families pray and place religious artifacts in dying person's room. ■ May adhere to santeria, death rites that include animal sacrifice.

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Cultural Views of Death and Dying (continued)

CULTURAL GROUP	BELIEFS
Egyptian Americans	<ul style="list-style-type: none"> ■ Candles are used to light the path for the spirit to the afterlife. ■ Wake lasts for 2 to 3 days before funeral. ■ Burial in cemetery common. <p>Response to Death and Grief</p> <ul style="list-style-type: none"> ■ Express emotions openly. ■ Grieving socially acceptable. ■ Occasion for far-away relatives to visit. ■ Visitors bring candles and floral wreaths (coronas), and assist with chores and funeral arrangements. ■ Deceased birthday and death anniversary are remembered with prayer, candles or flowers at grave site. <p>Death Rituals/Expectations</p> <ul style="list-style-type: none"> ■ Islam calls for burial as soon as possible. ■ Body cleansed and wrapped in white cotton. ■ Readings from the Qur'an. ■ Buried in a simple tomb. ■ Night of burial family and friends gather to pay respect; no food is served. ■ Forty days after burial another mourning ritual takes place and then annually on the anniversary of death. <p>Response to Death and Grief</p> <ul style="list-style-type: none"> ■ Expected to openly express grief. ■ Death seen as inevitable. ■ Death brings shock and despair. ■ Believe in afterlife and expect to be rewarded for good deeds.
Filipino Americans	<p>Death Ritual/Expectations</p> <ul style="list-style-type: none"> ■ Wake may last 3 to 7 days (time for arrival of family). ■ Family and friends gather, food provided. ■ Burial rites consistent with religious traditions. ■ Catholic families may say pabasa, novena, 9 days of prayer, with the last day as a fiesta, celebration. ■ First anniversary of death family and friends reunite. This marks end of ritualistic mourning. ■ Most women wear black for months or up to 1 year. ■ Deceased may be remembered annually on All Souls' Day. ■ Usually buried, but may cremate. <p>Response to Death and Grief</p> <ul style="list-style-type: none"> ■ Open expression of grief. ■ May include uncontrollable crying and fainting.
French Canadians	<p>Death Rituals/Expectations</p> <ul style="list-style-type: none"> ■ Closely related to Christian religious practices, especially Roman Catholics. <p>Response to Death and Grief</p> <ul style="list-style-type: none"> ■ Support for those who suffered loss. ■ Right to openly grieve, be physically present, refer to religious leaders, and encourage interpersonal relationships.
Greek Americans	<p>Death Rituals/Expectations</p> <ul style="list-style-type: none"> ■ Last rites administered by priest. ■ Relatives and friends expected to attend wake, klama. Ends with priest saying prayers. ■ Funeral, kikhia, follows next day with interment in cemetery. ■ Family and friend gather for meal of fish, symbolizing Christianity, wine, cheese, and olives.

CULTURAL GROUP	BELIEFS
Iranians	<ul style="list-style-type: none"> ■ Believe in physical resurrection of the body hence no cremation. <p>Response to Death and Grief</p> <ul style="list-style-type: none"> ■ Pictures and mirrors may be turned over. ■ Women chant or scream, miroloyi, during wake. ■ Wear black for 40 days. ■ Memorial service held 40 days after burial, and at 3 months, 6 months, and annually. ■ Boiled wheat with sugar, koliva, served at end of service. ■ Service conducted with joyful reverence. ■ Family members experience visitation of deceased in dreams. <p>Death Rituals/Expectations</p> <ul style="list-style-type: none"> ■ Deathbed turned toward Mecca, readings from the Qur'an. ■ Ritual washing of deceased, wrapped in white cotton, and all body orifices packed. ■ Non Muslims must wear gloves. ■ In Iran, deceased not embalmed, buried directly into the earth. <p>Responses to Death and Grief</p> <ul style="list-style-type: none"> ■ Openly express grief. ■ Support from family and friends. ■ Gather together on day 3, 7, and 40 days after death. ■ Prayer and special food served. ■ Wear black, no make-up. ■ Spouses or parents visit grave weekly, usually on Thursday or Friday.
Irish Americans	<p>Death Rituals/Expectations</p> <ul style="list-style-type: none"> ■ Celts denied death and ridiculed it with humor. ■ Irish are fatalist. ■ Family should stay with dying person. ■ Funeral follows. <p>Response to Death and Grief</p> <ul style="list-style-type: none"> ■ Wakes. ■ Women openly express grief, men socialize with drinking and smoking pipes.
Jewish Americans	<p>Death Rituals/Expectations</p> <ul style="list-style-type: none"> ■ Judaism believes in afterlife, but most Jews give little thought to it. ■ Active euthanasia and suicide are forbidden. ■ Death expected part of life cycle. ■ Dying person should not be left alone. ■ Prayers for dying may include Shema. ■ Ultra-Orthodox Jews may perform rituals such as placing wrapped body on floor with feet toward door and candle at head. ■ No flowers, no wake, no viewing. ■ Prayers for dead, the kaddish. ■ After funeral, meal of condolence provided by neighbors. ■ Sit shiva for 7 days. ■ Mourning lasts for 30 days for relatives, 1 year for parents. ■ Tombstone erected after 1 year, the unveiling. ■ Anniversary of death called "yahrzeit". ■ Amputated body parts must also be buried. ■ No cremation. <p>Response to Death and Grief</p> <ul style="list-style-type: none"> ■ Open expression of grief accepted. ■ Common sign of grief is tearing of the garment one wore before funeral service.

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Cultural Views of Death and Dying (continued)

CULTURAL GROUP	BELIEFS
Mexican Americans	<p>Death Rituals/Expectations</p> <ul style="list-style-type: none"> ■ Death seen as natural part of life. ■ Family members arrive and take turn sitting vigil over dying person. ■ Burial is common practice. <p>Response to Death and Grief</p> <ul style="list-style-type: none"> ■ Velorio, festive watch over body before burial. ■ Usually bury within 24 hours. ■ Openly express grief. ■ Ataque de nervios, hyperkinetic shaking, and seizure-like activity. ■ May erect altars or memorials in home to honor dead.
Navajo Indians	<p>Death Rituals/Expectations</p> <ul style="list-style-type: none"> ■ Death rituals vary with tribe. ■ Body must go to afterlife. ■ Do not bury body for 4 days. ■ Cleansing ceremony. ■ Dead buried with shoes on wrong feet and rings on index fingers. ■ Never tell a patient he or she is dying; always speak in the third person. <p>Responses to Death and Grief</p> <ul style="list-style-type: none"> ■ Fear power of death. ■ Expression of emotions depends on tribe.
Vietnamese	<p>Death Rituals/Expectations</p> <ul style="list-style-type: none"> ■ Accept death as normal part of life. ■ Buddhism influence of reincarnation. ■ Prefer to die at home. ■ If death occurs outside of home, soul wanders with no place to rest. ■ Family members provide comfort and care for dying person. <p>Response to Death and Grief</p> <ul style="list-style-type: none"> ■ Family gathers around deceased. ■ Wear white clothes for 14 days, then men wear black arm bands and women wear white head bands. ■ Yearly celebration at the ancestral graves. ■ Ritual cleansing. ■ Flowers are reserved for rites of the dead.

Source: Purnell, L., Paulanka, B. (2003). *Transcultural health care: A culturally competent approach* (2nd ed.). Philadelphia: F.A. Davis.

It is important to note that death, like birth, is an individual experience. The time of death cannot be predicted with any accuracy although families ask that question regularly. Death is a process, and by understanding that process, the nurse can help families deal with the burden of caring for and ultimately losing a loved one.

References

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