2.4: Care at the Time of Death

What we have done for ourselves alone dies with us; what we have done for others and the world remains and is immortal. -Albert Pike

Learning Objectives

- To understand the role of the nurse during the dying process and death.
- Describe the phases and associated signs/symptoms involved in the dying process.
- Explain various nursing interventions to facilitate a good death.

Dying is a process. It involves the cessation of physical, psychological, social and spiritual life here on earth. What happens beyond death is unknown to those reading this book. Typically, before a person dies, there is a cascade of events that are collectively known as the dying process. The dying process is the transition that a person goes through that ultimately ends in death. Each person’s dying process and death is individual to that person. Dying is an individualized experience and each person dies in their own way and time (ELNEC, 2010). Patients who know that they are dying will usually make their wishes known about where they want to spend their final days and hours. It is vital that the nurse involved in that patient’s care advocate for the patient’s wishes for their end of life.

Every nurse has an obligation to facilitate their patient’s wishes regarding their care preferences at the end of life. As nurses, we cannot with 100% certainty ensure that each of our patient’s dying process will go smoothly without any problems. Advanced illnesses and diseases that are terminal differ in the way they progress from person to person. An intervention that works well for one person dying of cancer might not work for another person. What we can do is to be armed with the best knowledge about management of symptoms during the dying process and utilize them appropriately as needed. It is the goal of this book that all nurses regardless of practice setting will be informed about the best nursing care practices at the end of life. This is so we can facilitate a “good death” for our patients, remembering that a good death means ensuring that patients’ preferences are met and symptoms are managed through the use of open
communication.

One of the most important things we can do for patients who are dying is to provide the best possible care for them and their families during the last phase of life through death. This is particularly important during the “imminent” phase. This is the phase that precedes the actual death, and is also the time when the patient typically loses consciousness. The care the nurse provides during this phase will affect the family’s memories of their loved one’s final days and hours on earth. It is vital that the nurse performs thorough assessments, rapid response to changes in status, rapid titration of medications, and timely discontinuation and introduction of interventions aimed to promote comfort.

There are many characteristics associated with the dying process which nurses who care for patients who are dying have grown accustomed to. The sights and sounds that can occur during that time, while normal for the nurse and clinician, can be extremely frightening and distressing for the family. One of the most important things that a nurse can do who is caring for patients nearing the end of life is to provide care for the family during this time and remember that although you may not remember what care you provided, the family will remember every second that took place during that time. If there are things that they witnessed that were distressful, that could negatively impact the perception of their loved one’s death. If their concerns were addressed and the patient was kept as comfortable as possible, that will positively impact the perception of their loved one’s death.

Phases of Dying

Actively dying

According to ELNEC (2010), there are two typical roads to death that can occur during the actively dying process: the usual road or the difficult road. The usual road is the best we can hope for when caring for persons at the end of life. It begins with sedation and lethargy and progresses to a comatose state and then death. The difficult road includes restlessness and confusion that often progresses to unpleasant hallucinations and delirium. Myoclonus and seizures can also accompany the difficult road.

Physical signs and symptoms associated with both roads can accompany the patient months, weeks, days or hours before death and vary from person to person. Refer to Figure 9.1 for a list of physical signs that the actively dying patient commonly exhibits.

- Pain
- Dyspnea
- Fatigue
- Cough
- Bowel Changes (Constipation/Diarrhea)
- Incontinence
Anorexia/Cachexia
Nausea & Vomiting
Depression/Anxiety
Seizures

Depending on the patient’s goals for care, various treatments are available to manage these conditions. Refer to Chapter 6 for a description of the best interventions used to manage the signs and symptoms patients are afflicted with during the end of life. The role of the nurse during the active dying phase is to support the patient and family by educating them on what they might expect to happen during this time, addressing their questions and concerns honestly, being an active listener, and providing emotional support and guidance.

Transitioning

Transitioning is a term used by clinicians to describe the period of time in between the actively dying phase and the imminent phase. In this phase, patients begin to withdraw from the physical world around them in preparation for their final journey. Some examples of this could include: decreased interest in activities of life, less frequent and shorter interactions with others, and acknowledgement of the presence of people and things that are not visible by clinicians and caregivers. This is referred to as “nearing death awareness” and often documented by clinicians as “hallucinations.” Possible explanations of this phenomenon from the medical community are as a result of hypoxia, acidosis, or alterations in metabolic processes. Patients will generally not exhibit any signs or symptoms of distress with this awareness, whereas patients whose dying is taking the difficult road might show signs of distress or agitation with their awareness.

During transitioning, it is important to keep the patient’s area as comfortable and peaceful as possible. Common lights and noises can contribute to restlessness and agitation; therefore it is advisable to keep lights soft, shades closed if possible, and external noises limited to a minimum.

Imminent

The term imminent is defined as “about to happen, forthcoming or near” (Merriam-Webster, 2012). The patient has transitioned into this last phase of the dying process and death can occur at any point now. Not all individuals will present with every sign or symptom, and the symptoms will occur in no particular order. During this phase, the body is in the process of shutting down. Multi-system organ failure often occurs and will result in some typical symptoms (Table 9.2).

<table>
<thead>
<tr>
<th>System</th>
<th>Symptom</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiological/ Circulatory</td>
<td>Cool and clammy skin</td>
</tr>
<tr>
<td></td>
<td>Mottled extremities</td>
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Table 9.2 Signs and Symptoms of Imminent Death
<table>
<thead>
<tr>
<th>System</th>
<th>Symptom</th>
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</thead>
<tbody>
<tr>
<td>Musculoskeletal</td>
<td>Rapid or irregular pulse</td>
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<tr>
<td></td>
<td>Inability to ambulate</td>
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<td></td>
<td>Inability to move/turn in bed</td>
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<tr>
<td></td>
<td>Increased lethargy</td>
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<tr>
<td></td>
<td>More difficulty to arouse</td>
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<tr>
<td>Neurological</td>
<td>Confusion</td>
</tr>
<tr>
<td></td>
<td>Restlessness</td>
</tr>
<tr>
<td></td>
<td>Increased respiratory rate</td>
</tr>
<tr>
<td>Respiratory</td>
<td>Periods of apnea or Cheyne-Stokes respiration pattern</td>
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<tr>
<td></td>
<td>Inability to cough or clear secretions</td>
</tr>
<tr>
<td>Urinary</td>
<td>Presence of increased secretions (&quot;death rattle&quot;)</td>
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<tr>
<td></td>
<td>Decreased and/or dark urine output</td>
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Often the change of care will focus as death becomes imminent (Berrie & Griffie, 2010). The assessment of vital signs will cease unless requested by the family, at which point the nurse would gently explain the overall rationale for measuring vital signs and whether this would provide any benefit for the patient. Out of all the stages of the dying process, this last phase is the one in which impending death becomes a reality for everyone involved. The family knows that their loved one will die; however, it is usually not as evident as it can be until death becomes imminent. During this phase, the patient becomes unresponsive to those around them and may appear to be sleeping. Sometimes the patient’s eyes will be partially open as they are resting. In hospice, we believe that the patient can still hear or sense the activity and loved ones around them and so we teach families to continue to talk to and gently touch their loved ones.

The interaction between the patient and their family during the imminent phase is very individual. Some families are distant and uncomfortable being near their loved one during this phase. No one wants to see their loved one in that state; it hurts to watch, and can be too painful for some to cope with. Even though the family may know death is imminent, it will not feel real until they are actually seeing it. Other families may be very involved with the patient during this phase: lying in bed with their loved one, talking to them, and being present in the moment. Neither scenario is wrong, and the nurse caring for patients at the end of life needs to always remember that. The nurse should support the patient and family, reserve judgment, and not make assumptions about the reasons behind the family’s behavior. The nurses' role is not to be the authority on how the family should act, but to provide comfort and quality of life for the patient and empathetic support to the family.
There are often several nursing interventions and activities for the nurse to perform during the imminent phase. Most of which are related to the communication, coordination and continual assessment and response to changes in patient’s status. When the death is imminent, the family must be informed that death is near. As mentioned before, sometimes this is shocking to the family, despite knowing that their loved one is dying. This has to be communicated to the family in a sensitive and calm manner. Each nurse will have their own way to exchange this information, but it is very important that the family be told that death can occur at any time so that they can prepare. There may be family in the area or out of town that would like to come and see the patient and who is waiting until the patient gets closer to death. It is important to educate families during the dying process that the final phase may progress very quickly as a way to encourage loved ones to come sooner rather than later.

The imminent phase is also the time when some families may want clergy or pastoral care present. Depending on their religious affiliation, some patients and families may want sacraments or special blessings performed before death occurs. It is important to tell the family that the process leading to death has begun, and that if they would like clergy present they should begin that process now. The nurse can assist families with obtaining pastoral care if the family does not have their own. The coordination of spiritual support may be extremely important to the family at this time and the nurse should be sure to evaluate for this as part of their assessment.

The Death

There are two ways that death can be classified: clinical death and biological death. Clinical death comes first and is when a person’s heart stops beating. Circulation of the blood and respiration also stops once there is a cessation of heart beat. It is during this time that individuals can be revived by way of CPR. Oxygen can be given, the blood can be kept circulated and the heart beat could be potentially restored. Most patients who are at the end of life opt for a do-not-resuscitate order, and therefore CPR is rarely given. Research has found that CPR is ineffective at restoring heartbeat in patients who are living with terminal illness (ELNEC, 2010). There is a 4 to 6 minute window in which patients can be revived with CPR. Without CPR, in approximately 4-6 minutes after clinical death (the cessation of heart beat), brain cells will begin to die from lack of oxygen. This is called biological death and is called the point of no return, meaning that once the brain dies, CPR will not be able to bring that person back. It is at this time that the cells in other organs, such as kidneys or eyes, will also begin to die. Several hours after biological death occurs, rigor mortis occurs. Rigor mortis is defined as the temporary rigidity of muscles occurring after death (Merriam Webster, 2014). It results from the loss of adenosine triphosphate (ATP) which makes muscles become stiff with the loss of energy flow (Bate-Smith & Bendall, 1947). Rigor mortis will begin to set in several hours following death and be at its peak 12-18 hours following death. Rigor mortis will disappear 48 hours following death.

CPR is not typically performed with patients who are expected to die and those who have a DNR, DNAR, or AND. Witnessing a patient’s death without the resuscitation process can be difficult for the nurse or clinician, as we have been trained to do everything possible not to cause or contribute to a patient’s death. In end-of-life care, the death is the expected outcome of the care we provide, and as nurses we want to ensure that the patient has as “good” a death as possible and that they have died in the manner they wished. But it is very difficult to stand by and observe a death in progress—everyone silent with eyes fixed on the patient’s chest. As mentioned before, respirations can become quite erratic, very shallow with extended periods of apnea in between breaths. The moment will come in which the patient’s chest will not rise again. This time period can seem like an eternity for both the family and the nurse. Take extreme caution when determining whether or not the last breath has been taken. Extended periods of apnea close to death can...
last up to a minute or more. Be certain that death has occurred before proceeding to assess for signs of life. Typically the patient's mandible will drop and almost a sudden pallor will appear. The pulse in the carotid artery may still be palpable, although very faint and thready, until the heart catches up with the absent respirations. This may take a minute or two. Be sure to listen for a heartbeat with a stethoscope for a full minute. In hospice this is performed for two reasons: to ensure that the patient has died, and also to provide the family with the extra peace of mind knowing that their loved one is really gone. Never fail to assess for signs of life, including heartbeat, respirations, and pupil status by checking the patient's pupils with a light for fixation and dilation. The nurse should make sure that the patient is covered with a light sheet up to below the shoulders. It is atypical for the deceased patient to be completely covered including face and head, so refrain from doing so unless otherwise directed by the family.

Following the death of a patient, the nurse should offer their condolences to the family and extend assistance with contacting any other family members or individuals the family requests. Depending on the location of the death, the nurse would contact the medical examiner to notify them of the death, as well as the physician and other clinicians who were involved with the patient. The nurse can also contact the funeral home for the family as requested. In home care, the nurse would ask the family if it was alright to remove any tubes or catheters from the patient, and if they would like to assist in bathing/preparing the patient for transport to the funeral home. The nurse would assist the family in removing any jewelry or other items from the patient. Be sure to maintain the highest dignity and respect for the deceased patient during this post-mortem care.

**What You Should Know**

- Dying is a multi-faceted process that is uniquely individual to each person.
- The most common signs and symptoms before death include: increased pulse/respiratory rate, Cheyne-Stokes respirations, cool/mottled skin, and decreased urine output.
- It is important to provide support for the patient and family throughout the entire dying process.
- Be sure to communicate to the family when a patient's death becomes imminent so that other family members and/or clergy can be called.

**References**