2.2: Management of Emotional and Spiritual Distress

The pain of the mind is worse than the pain of the body. -Publilius Syrus

Learning Objectives

- Explore the meaning of hope in the context of death and dying.
- Describe loss and emotional suffering in the patient who is dying.
- Identify common causes of, and interventions for, spiritual distress in patients nearing the end of life.

While much of the focus of end-of-life care is on the assessment and management of physical pain and symptoms, emotional and spiritual distress can also be experienced by patients who are dying. Yet this type of pain is less frequently discussed and in turn, less apt to be evaluated by the nurse or clinician. Chapter 12 is exclusively focused on grief and bereavement which is more related to the bereaved family following the death of their loved ones. Patients who are nearing the end of life also feel loss and grief, but in a different sense than their family. The purpose of this chapter is to discuss the various emotional and spiritual pain and distress experienced by dying patients and how nurses and clinicians can help support them during their final journey.

Hope in the Context of Death and Dying

Hope can be an important factor for patients who are nearing the end of life because it is what gives people the determination and will to go on (LaPorte Matzo, 2001). People might not be aware that patients who are dying continue to have hope; however, that hope might be very different from what they may have hoped for in the past. When a patient first becomes sick and diagnosed with a serious illness, they might hope to be completely cured. As that patient’s illness progresses to a point in which it is considered terminal, the patient’s hope may change. Instead of hoping for a cure, the patient now may hope for more time or less pain. Whatever they hope for, it is important that the nurse support the
patient in their hopes, even if not quite realistic in light of their illness (LaPorte Matzo, 2001). Hope has been found to be a positive and “powerful force against despair” and “can help patients and families journey through difficult times leading up to death” (Zerwekh, 2006).

The concept of hope was described in a study of patients with cancer while deciding about resuscitation status. Twelve out of 23 patients discussed the nature of hope in regard to both present and future decisions. Hope was a way for dying patients to connect to others (Elliott & Olver, 2007). Another study found high levels of hope with the majority of patients, 70% of whom were classified as having very advanced disease (Felder, 2004). Variability in responses was found in another study that explored the relationship of hope and the need for prognostic information in patients with COPD and cancer. Some patients thought that knowing prognostic information might impact their hope and have negative psychological consequences such as increased anxiety (Curtis, Engelberg, Young, Vig, Reinke, & Wenrich et al., 2008). Patients’ hope was not differentiated by type of diagnosis.

Nurses can help to foster and promote hope in patients by encouraging them to live in the present and focus less on the future (Zerwekh, 2006). This can help assist the patient to evolve their original hope for a cure into hope for other things, such as hoping to have well-managed symptoms, hoping to feel well enough to spend quality time with family and friends, and hoping to accomplish any goals they have before their death. Ersek (2001) outlined 6 nursing interventions that could foster hope (Table 7.1).

Table 7.1 Nursing Interventions to Promote Hope

- Keep symptoms well managed.
- Encourage involvement in positive experiences that transcend their current situation.
- Foster spiritual processes and find meaning.
- Promote reconciliation and connections with others.
- Assist patient in setting realistic goals.
- Focus the patient’s attention on the short-term future.

Loss and Emotional Suffering

Loss is defined as the “absence of a possession or future possession” (ELNEC, 2010) and occurs when something or someone is missing (Zerwekh, 2006). Loss can refer to a person, relationship, thing, or situation, and can occur well before a patient dies. The patient and family can have feelings of loss as they anticipate the impending losses that will occur or the death itself (ELNEC, 2010). Grief is the emotional response to a loss, which will be discussed in the context of the family in Chapter 12. Patients can have a series of losses related to their illness, well before they get close to the end of life. In a study that examined the perspectives of patients with end stage heart failure or COPD, patients reported having multiple losses throughout their illness trajectory (Lowey, Norton, Quinn, & Quill, 2013). Some of these included the loss of functional abilities and independence as their illness worsened, and most feared the losses that were to come. This anticipatory loss can greatly impact emotional status and precipitate suffering in patients. Patients who live with advanced illnesses often feel trapped in many ways by their illness. As mentioned with the study above, patients...
feel as if they are losing themselves and their abilities a little bit at a time, and that can take a terrible toll on their emotions. If left unmanaged, this can cause a great deal of suffering.

Suffering is defined as "a state of severe distress associated with events that threaten the intactness of a person" (Cassell, 1991). Suffering can impact a person's body, mind, or spirit and is greatly compounded with the presence of pain. It can be acute or chronic, and a patient living with serious illness can experience either kind or both together (Zerwekh, 2006). The Hospice and Palliative Nurses Association defines existential distress or suffering as "suffering that is not relieved by treatment of psychological symptoms or that occurs in the absence of physical symptoms" (Hospice and Palliative Nurses Association, 2012). Existential suffering is related to who we are as individuals and can threaten a patient's sense of identity. In a recent article that explored existential suffering a typology of 8 factors were found to be related to this kind of distress. These include: death anxiety, loss and change, freedom of choice, dignity of the self, fundamental aloneness, altered quality of relationships, meaning, and mystery (Kissane, 2012). The last factor, mystery, relates to the mystery about what happens to people after they die. This question is even considered by the most faithful of people and is a normal response of being a human being. In essence, not being entirely certain where a person will go after they die can cause a great deal of stress and anxiety, which contributes to suffering. This factor is closely related to a particular kind of suffering that originates from spiritual distress, which we will discuss next.

### Spiritual Distress

Spirituality has been defined as “more of a journey and religion may be the transport to help us in our journey” (Narayansamy, 2004). Patients who are dying often think about their own spirituality. For some, it is a time to become more in touch with one's spirituality, and for others it is a time for their spirituality to become even stronger. Still, there are patients who do not want to discuss spiritual issues and are often angry at their situation and angry at any higher powers which they feel responsible for their impending death. As a nurse who cares for patients nearing the end of their lives, spirituality is something that needs to be taken into consideration. It can be just as important for a patient as their unmanaged pain or dyspnea and needs to be treated as a priority by nurses. Often nurses are uncomfortable with asking about or talking with patients about spiritual issues, particularly if the nurse is not a religious or spiritual person. As mentioned before, a person can be spiritual without being part of a formal or organized religion. In hospice and palliative care nursing, issues related to spirituality and religion are frequently encountered, and most nurses are comfortable addressing these with their patients. There are many instances in which hospice nurses work closely with chaplains and clergy in the care planning of patients. It is also not uncommon for hospice nurses to pray with their patients. The extent to which a nurse prays with patients is largely dependent on the comfort level of the nurse with an expression of religiosity in the form of prayer.

The nurse should assess the patient’s emotional and spiritual needs and concerns during each interaction or visit. There are several formal instruments available to measure hope and hopelessness and the nurse should check with their facility to see which ones are available for use. It is also helpful for the nurse to ask the patient whether they would like to have a chaplain or minister come to talk with them. Sometimes patients will want to talk with someone but are either not comfortable about it or are not aware of who to ask about it.

### References


