1.3: Conceptual Frameworks Guiding Death & Dying

It's only when we truly know and understand that we have a limited time on earth—and that we have no way of knowing when our time is up—that we will begin to live each day to the fullest, as if it was the only one we had. -Elisabeth Kubler-Ross

Learning Objectives

- Define what a theory is and explain its relationship to patients with serious illnesses.
- Explain how nurses and clinicians can use theories for their care of patients.
- Describe the premise of quality of life and uncertainty in illness.
- Identify the five stages of grief.
- Describe what death awareness is and its relationship to end-of-life care.

People who are living with a serious or life-limiting illness have to deal with a lot in the course of their daily lives. Often, daily events such as preparing a meal or taking care of errands are burdens instead of normal parts of the day. The way that people understand and cope with their illness varies from person to person. Some people do well and some do not; it is a multi-factorial process. In nursing and healthcare in general, scholars have developed ways that can help clinicians to better understand how people react to their health and illness, which can help us understand why some people do better than others. These commonalities in the way that people behave can be explained by conceptual frameworks or theories. Sometimes called a model, a theory is an abstract generalization that aims to offer an explanation about the relationship between phenomena (Polit & Beck, 2014). A theory is usually a depiction of interrelated concepts in a manner meant to predict or explain a relationship among them.

Theories can be useful tools for nurses and clinicians because they can provide useful information about the patients we care for. People who live with serious illnesses have some common factors that can affect their lives and the way they
live with their illness. There have been several theories developed that have aimed to describe the ways people react to their illness and cope with the knowledge of their impending death. Nurses and clinicians should become familiar with these theories in order to better understand how their patients are dealing with these issues. Although each patient is an individual and may not behave entirely like what is described in a theory, it is useful for the nurse to be aware of how the majority of people deal with these issues. This will enable the nurse to better anticipate the needs and concerns of patients who are going through similar life events. In this chapter, we will begin by looking at a few theories that deal specifically with the quality of life and uncertainty in illness; often these two phenomena are very important for patients living with a serious illness. Then we will examine some specific theories that affect people whose illnesses progress to the terminal stage. These theories focus on various aspects of the death and dying process including stages of grief and death awareness.

Quality of Life Model

Quality of life (QOL) is a multi-dimensional concept that includes the physical, psychological, social and spiritual functioning of a person (U.S. Department of Health and Human Services, 2014). People who live with a serious illness often have various stressors that can affect one or several of these dimensions. Understanding a person’s quality of life can help nurses and clinicians plan appropriate care to meet the specific needs of that individual. Quality of life can differ from person to person, so perhaps an illness that affects one person’s psychological dimension might not affect another person with the same type of illness in the same way. Only individual patients can determine which aspects of their quality of life are affected. As nurses, we often witness things that we might perceive to be stressors or problems that need to be solved. We should never assume or be the judge of another person’s quality of life. What is important to one person, or to the nurse, may not be important to another. Even though the nurse may feel that their patient’s social quality of life is negatively affected, they need to ask the patient and not just assume.

Uncertainty in Illness

The concept of uncertainty in illness was developed by Merle Mishel in the early 1980’s and has been the focus of many scientific studies (Mishel, 1981). The role of uncertainty in a person’s experience with illness, hospitalization, and treatment was examined by Dr. Mishel and led to the development of this theory. The uncertainty that accompanies chronic illness has been identified as living with “continual uncertainty” (Mishel, 1990) and appraised as either “danger” or “opportunity.” In people living with a chronic illness, for example, exacerbations are often perceived as a “danger.” Willems, Hak, Visser, & Van Der Wal (2004) found that the majority of patients with congestive heart failure have thoughts about death only during their exacerbations. After recovery, these patients returned to another period of stability during which time the immediate “danger” that was once perceived was gone. In another study, patients with advanced heart failure viewed their future as unpredictable and uncertain (Dougherty, 2007). Their concerns about the future were related to fears surrounding the communication of health information from their providers. Some participants expressed fear and uncertainty about inquiring about information related to their prognosis and future.

People with chronic illnesses often wonder about what the future with their illness will be like. In a study by Curtis, Engelberg, Nielsen, Au, & Patrick (2004), 115 patients with severe pulmonary disease reported their need to receive better information about what to expect with illness progression and about what dying might be like. They were aware of the progressive nature of their illness; however, they had great uncertainty about what to expect with their future
functional status and how they might actually die. In contrast to the study in which heart failure patients only thought about death during exacerbations, patients with chronic pulmonary disease are often thinking about the next exacerbation and if it will be their last. In a study by Oliver (2001), patients reported fearing every exacerbation as the one that could end their lives. The concept of “fear” was reported in many studies that explored the perspectives of people living with chronic obstructive pulmonary disease (Seamark, Blake, & Seamark, 2004; Guthrie, Hill, & Muers, 2001; Habraken, Willems, De Kort, & Bindels, 2007). The uncertainty in prognosis and illness progression seems to go beyond just a life expectancy estimate for many people who live with serious chronic illnesses.

Stages of Death

In 1969, Dr. Elisabeth Kuebler Ross wrote a book entitled On Death and Dying in which she outlined a conceptual framework for how individuals cope with the knowledge that they are dying (Kuebler-Ross, 1997). She proposed five stages of this process that included denial, anger, bargaining, depression, and acceptance. Not all people will go through each stage in sequence, and some may skip some stages altogether. It is important for nurses who care for patients who are dying to have an understanding about these stages in order to be able to properly care for and support themselves and their families.

Denial

Denial is the first stage because many individuals will initially react to being told that they may die by denying what they heard. People in this first stage will be in disbelief and think that their doctor has made some kind of mistake. Often patients will go to another doctor for a second opinion during this stage. Denial can be important for two reasons: it will initially be somewhat of a shock absorber enabling the person to seek clarification about the truth in what they were told. It can also provide patients with the needed time to become acquainted with the possibility that the information they heard is true which can enable them to internalize and begin to process that information.

Anger

Anger is the second stage and can be the most difficult for clinicians and caregivers to witness. In this stage, individuals have accepted that the news of impending death is true and they are naturally angry about it. They do not understand why they have to die, and they make this known to those around them. They may lash out at clinicians and loved ones alike because they are angry about their situation. Often, nothing that clinicians or family members do for them is right and they have negative things to say about other aspects of their life as well. Patients in this stage realize that they have lots of things in their life that they wanted to accomplish, but now they will not have the time.

Bargaining

The third stage is called bargaining, and it is a stage that is rarely visible to onlookers as it happens internally within the person who is dying. In this stage, individuals realize that they are past denying that they are dying and that they have been angry about it, with neither of the two causing any change in the outcome. Patients at this stage may bargain with a higher power to change their outcome and give them more time. Sometimes patients might bargain with their doctor to try to find any other option that might give them more time, but this bargaining is often accomplished internally between the dying patient and their higher power or God.
Depression

Depression is the fourth stage and is a natural part of learning that impending death is near. Patients might be saddened because they had things they wanted to accomplish, places they wanted to go, or people they wanted to see, and those things will now be cut short. In addition, patients may be experiencing decline in physical abilities, loss of function, and increased symptoms such as pain. Those are factors that can lead to depression even in people who are not dying, and are even more magnified in those who are dying.

Acceptance

The final stage is acceptance. This stage does not mean that the person is happy about their impending death, but rather that they have come to accept it and have found a sense of peace with it. The first four stages involved mostly negative emotions which have taken a toll on the patient. Time has progressed and patients can begin to move past the negative emotions and focus on the time they have left. During this stage, their hope for a cure is replaced by a hope that their final days will be peaceful and their death will be what they want it to be.

There are some important actions that nurses and clinicians can do during each of these stages to support the patient and their family. Table 3.1 outlines each stage and the associated actions that nurses can do to help.

Table 3.1 Nursing Interventions for the Stages of Dying

<table>
<thead>
<tr>
<th>Stage of Dying</th>
<th>Nursing Interventions</th>
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<tr>
<td>Denial</td>
<td>Actively listen to patients’ concerns and provide support as needed</td>
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<td></td>
<td>Be sensitive to patients’ thoughts and ideas even if medically unrealistic</td>
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<td>Patients need to feel like they are being understood and accepted</td>
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<td>Educate and support the family who may be on the receiving end of the patient’s anger</td>
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<td>Tell them that this is a normal part of the process and that the patient is angry at impending death and taking it out on those closest to them</td>
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<tr>
<td>Anger</td>
<td>Respond to the patient’s anger in an accepting but non-provoking manner and realize that the anger is not at the nurse but at the situation</td>
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<td>Approach the patient in a pleasant way without being overly cheerful; rather use the patient’s expressions to gauge your own expressions during interactions</td>
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<td>Since this stage often occurs internally, there may not be any particular action indicated on the part of the nurse</td>
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<tr>
<td>Bargaining</td>
<td>If the patient brings up the topic of God or spirituality, provide active listening and emotional support</td>
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<td>Pray with the patient if comfortable with doing so and if requested</td>
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Stage of Dying  Nursing Interventions

Depression

Avoid clichés; do not urge patients to “cheer up” or “look on the bright side”

Realize that nothing you do is going to take away their impending death and that your actions may be more meaningful to patients than your words

Educate the family about this stage and let them know that trying to cheer their loved one may not be helpful. Instead encourage the family to be supportive without trying to cheer the patient up

Patients may benefit from more non-verbal forms of communication such as quietly sitting with the patient, holding their hand, lightly stroking their back

Acceptance

Continue to anticipate the patients’ needs and address any concerns

Continue to provide emotional support to the patient and family

Death Awareness

In 1965, researchers Glaser & Strauss examined the context surrounding patients’ awareness of dying in the hospital setting. Using grounded theory methodology, they conducted interviews and participant observation on the interactions between patients and hospital staff. Their findings led them to describe the following four contexts of awareness of dying: closed awareness, suspicion awareness, mutual pretense awareness, and open awareness.

Closed awareness

Closed awareness occurs when clinicians fail to disclose prognostic information to the patient. The patient is kept in the dark about their poor prognosis and impending death. Health care clinicians are careful not to say anything to the patient that would make him or her aware that that their death was near. Patients often begin to suspect that they are not being told everything, particularly if the nurses and doctors appear secretive in their conversations. This may lead to the patient to move to the next context of awareness.

Suspicion awareness

The patient has suspicions about his overall prognosis and health status in this context and begins to realize that he is not being told this important information. This might lead the patient trying to find out the truth by asking various staff members direct or indirect questions that could provide information about their suspicions. Often patients will try to trick the staff member into telling them something. For example the patient may tell the nurse that the doctor said that their illness is very serious, in efforts to either prove or disprove their suspicions.
Mutual pretense awareness

In this context, both the patient and the clinician are aware that the other party knows of the poor prognosis or impending death. Instead of acknowledging it openly, both parties pretend that it is not true and continue to act as though everything was normal. This arrangement acts as a coping mechanism for the patient, who might not be ready to openly discuss the poor prognosis.

Open awareness

In open awareness, both the patient and health care clinician are aware of the poor prognosis or impending death and openly acknowledge it. This context allows both parties to openly talk about the prognosis, which could be beneficial to the patient in coping and acceptance of his situation. This context is also better for the staff member as they do not have to be careful not to get caught speaking about prognosis as in closed awareness, nor do they have to lie to the patient if they ask outright about their condition.

Recent Research on Death Awareness

There is a growing body of literature on prognosis and death awareness for both the patient and their family. In 280 patients with advanced cancer, there were no significant differences in reports of peacefulness between patients who were and those who were not aware that they were terminally ill, however the families of patients who were aware reported higher quality deaths than those who were not (Ray, Block, Friedlander, Zhang, Maciejewski, & Prigerson, 2006). In this sample, only 49 out of the 280 patients reported being aware of their terminal condition, which means the majority of patients were unaware.

People with exacerbating remitting trajectories have been found to be even less aware of possible death than those with cancer. In a study that compared the needs of patients with lung cancer and COPD, three-fourths of those with lung cancer knew that they might die and had been given more accurate prognostic information (Edmonds, Karlsen, Khan, & Addington-Hall, 2001). Only 8% of patients with COPD were told they might die by their physician versus 30% of patients with cancer. In another study that retrospectively explored the perspectives of family members of those who died with COPD, over half the participants reported not being aware their loved one might die, 78% of whom would have wanted to know that information (Elkington, White, Addington-Hall, Higgs, & Edmonds, 2005).

A commonality that was found in studies that examined death awareness in patients was their open acknowledgement of future death. Interestingly, participants reported their deaths would result from their increasing age, not from their serious illness (Agard, et al., 2004; Gott et al., 2008; Murray, Boyd, Kendall, Worth, Benton, & Clausen, 2002; Rogers et al., 2000). It is uncertain whether this suggests that people do not understand the likelihood of death from chronic life limiting illnesses, such as heart failure for instance, because of poor communication about the illness or because they do not believe what they have been told.

Readiness to Die

The need to better understand the experience of patients confronted with impending death was examined by Copp
She sought to explore this experience particularly from the nursing perspective and exploring the nurse-patient relationship within the context of patients living with impending death. Copp found that patients who knew they were going to die at an uncertain time made many references to a separation between their body and their self, as though they were separate entities. This split in between oneself and one’s body was examined closely to better understand the individuals’ readiness to die. The readiness to die theory was based on four patterns or modes that individuals could be going through at any given time that relate to the degree of readiness of their body and their self to death. Dying persons could only be in one mode at a time but could change between modes as their illness progressed and as they came to terms with their mortality. These four modes are organized by:

- Person ready, body not ready
- Person ready, body ready
- Person not ready, body ready
- Person not ready, body not ready

It is quite possible that death could occur within each of the four defined modes; however, as clinicians we could only hope that the majority of our patients would be within the “person ready, body ready” mode. In this mode, both the patient’s body and the patient’s internal self are aligned as being ready. Copp’s theory provides a different way to think about how patients who know they are going to die might be processing that information.

**What You Should Know**

- Theories, such as the Quality of Life Model and Uncertainty in Illness theory can help nurses understand commonalities in the illness experience of their patients.
- Patients can go through 5 stages of dying including: denial, anger, bargaining, depression and acceptance.
- An open awareness of dying often has the best outcomes for both the patient and clinician.

**References**


