1.5: Initiating Conversations about Goals of Care

Remind yourself that if you think you already understand how someone feels or what they are trying to say, it is a delusion. Remember a time when you were sure you were right and then discovered one little fact that changed everything. There is always more to learn. -Douglas Stone

Learning Objectives

- Define goals of care in the context of advanced illness.
- Identify various measures used by clinicians for prognostication.
- Describe how clinicians use the benefits and burdens of treatment to assist patients in determination of their goals of care.
- Identify strategies associated with the initiation of end of life conversations.
- Explain various factors associated with patients preferences for care.

Individuals come equipped with their own attitudes and beliefs about the things in life that are important to them. These include beliefs about who they are, what gives them meaning, what they value, and what they hold to be true. These priorities are what make people individuals, although many people likely hold similar things in high regard. These can include family and friends, good health, and general well-being and happiness. When a person becomes seriously ill, the various stressors associated with their illness can take a toll on their overall priorities in life. Most people have an idea of what they want out of life and the things that they can accept and not accept regarding their personal well-being. When a person is diagnosed with a serious, life-threatening illness, they will have to consider what goals they hope to achieve related to their illness and what priorities they place on their current and future care. Many patients, however, do not realize the magnitude of their illness and/or the options they have for care. The role of the nurse or clinician is to educate patients and families about their illness and options for care based on their goals and preferences. Nurses need to ask patients what it is that they hope for and want within the context of their illness. It should never be assumed that nurses
know what is best for their patient. Each person has their own set of values and ideals that may or may not change in the course of living with a serious illness. Many patients do not know what to ask and it is up to the clinician to help elicit these kinds of conversations with patients, always being sure to meet patients where they are in terms of dealing with their individual illness process. This chapter will focus on providing the student nurse or clinician with ways to initiate and facilitate effective conversations with patients regarding their goals and preferences for care.

What are Goals of Care?

Goals of care are the outcomes that patients place the highest value on and would hope to achieve in regard to their illness. They are what the patient wishes for in terms of their illness. What is it that the patient would like to see happen with their illness, if there is no chance for reversal or total cure? What are the things they value as the most important in their lives? Would they rather focus on maintaining the quality of their life even if it means that the quantity of their life (or time they left) would be decreased? Do they want to continue to use all medical treatments necessary to increase their lifespan even if it will make them very sick? Having a patient ponder these questions will help them formulate and clarify their goals of care as they near the end of life. Often patients have not thought about what their goals of care are as they may have just been recently diagnosed with their illness or may have been too sick to consider what they might want. It is vitally important for the clinician to assist patients in formulating a plan for their care based on their values and preferences. Often this is done in conjunction with the family, who may or may not have their own goals for the patients’ care; this can pose a challenge if there are significant differences between the two. In order for a patient to determine what their individual goals of care are, they have to know the severity of their illness, which includes their overall prognosis and life expectancy based on their terminal illness.

Prognostication

ELNEC defines prognostication as the estimation of the future course and survival of an illness (ELNEC, 2010). Prognostication can provide the terminally ill patient with information regarding the usual course of their type of illness, including the most sought after question, “How much time will I have left to live?” Accurate prognostication of patients with advanced illnesses has been a challenging element in the ability to provide quality options for care at the end of life (Willems, Hak, Visser & Van der Wal, 2004). Even the most highly skilled physicians cannot pinpoint the timing of a patient’s expected passing, and a patient’s reaction to a prognosis is similarly unknown. A patient may want to know the timeline of their disease’s progression, and yet may not believe it. On the other hand countless patients believe firmly that no one on this earth can tell how long they have left and the only one who knows for certain is God. Yet many patients do want to be told how much time they have left; in fact, they expect to be told. Lowey and colleagues conducted a study examining the perspectives of patients with advanced illnesses and asked patients whether they wanted to be told if their illness got to the point where it was considered to be life threatening. Overwhelmingly, all participants in that study expected that their doctor would tell them when their illness became that severe. Most wanted to be told so they could re-evaluate their goals of care and plan for their future (Lowey, Norton, Quinn, & Quill, 2013).

As much as patients want to know prognostic information, it can be a challenge on the part of physicians to give accurate information. Christakis (1998) suggested many factors that are highly subjective and variable which relate to proper prognostication by physicians. The lack of consensus in defining “the end of life” was suggested to play a role in the difficulty with prognostication (Lamont, 2005). Prognostic uncertainty is the inability to determine and provide an
accurate prognosis and it occurs with many illnesses that are chronic in nature, such as heart failure. This is due to the chronic exacerbating illness trajectory, in which a patient will have an exacerbation and then get better. This makes it more difficult for physicians to determine when the patient is nearing the end of life. One study found that even 3 days before the death of patients with heart failure, the median physician-predicted 6-month survival was 54% (Levenson, McCarthy, Lynn, Davis, & Phillips, 2000). More often than not, physicians tend to overestimate prognosis, particularly for patients with chronic end-stage diseases. In a sample of 468 patients with both cancer and non-malignant disease, only 20% of 343 physicians gave accurate (within 33% of survival) prognostic predictions (Christakis & Lamont, 2000). Since the risk of sudden death in people with heart failure is 6 to 9 times greater than in the general population (Lloyd-Jones, Adams, Carnethon, De Simone, Ferguson, & Flegal, et al., 2009), physicians have an even greater uncertainty regarding prognostication.

Despite being told prognostic information, many patients and family members have been found to overestimate or disbelieve what they are told. A large number of family caregivers did not believe or agree with the life expectancy estimation communicated to them by their physician in a study by Cherlin, Fried, Prigerson, Schulman-Green, Johnson-Hurzeler, & Bradley (2005). Even patients with an advanced illness seemed to underestimate the seriousness of their disease, with 36% of 103 cancer patients reporting their disease as being “stable or in remission” (Sapir, Catane, Kaufman, Isacson, Segal, Wein et al., 2000). Another study found patients with heart failure reported that understanding prognosis and life expectancy information was not helpful in their coping or planning for care at the end of life (Dougherty, Pyper, Au, Levy & Sullivan, 2007). Just as prognostic information is unique to each individual, the manner with which people take in that information varies. On the other hand, family caregivers of terminally ill patients had different preferences regarding the need to be informed about the incurable nature of their loved ones’ illnesses (Cherlin et al., 2005). In retrospect, some families wished they would have known the seriousness of the illness which ultimately lead to their loved one’s death, while this was not important to others. Family members in another study also valued honest communication from the physician in a way that did not destroy all of their hope (Wenrich, Curtis, Shannon, Carline, Ambrozy, & Ramsey, 2001).

The majority of studies in this area focused on mortality as the endpoint of prognostic information. There was great variability in the literature among people with advanced illnesses about the need to know prognostic information. In a study by Gott and colleagues (2008), some of the patients with advanced cardiac disease were aware of their poor prognosis, but did not want to have conversations about explicit prognostic information regarding mortality. Another study found mixed views about the desire to know the prognosis among 20 patients with end stage heart failure (Horne & Payne, 2004). In a study by Rogers, Addington-Hall, Abery, McCoy, Bulpitt, & Coats et al. (2000), participants actually wanted and sought out prognostic information from the research interviewer regarding their illness. Although some patients do not want to know when they will die, many want to be informed about what it will be like for them as their illness progresses. The sense of uncertainty about what the future holds in general seemed to be a greater concern in patients living with advanced illnesses. It is unknown whether a sense of what the future holds as it relates to quality of life might have a greater effect on what options people choose as they near the end of life.

There are several predictors that physicians can use to help them be able to provide patients with an accurate prognosis. There are various instruments and tools available including the Karnofsky scale score (Karnofsky & Burchenal, 1949) which evaluates a patient’s functional status on a scale of 0 to 100. A score of 100 indicates optimal performance status and a score of 0 indicates death. Patients with a score of 50 or below require considerable medical care. Patients’ clinical signs and symptoms can also be used to estimate prognosis. Severe dyspnea at rest, dysphagia
(inability to swallow), profoundly decreased appetite, decreased hydration status, and marked weight loss have been associated with decreased survival time among cancer patients (ELNEC, 2010). Abnormal laboratory values can also provide information to help assist the physician in estimating survival time. The literature also suggests that physicians ask themselves whether or not they would be surprised if their patient died within the next 6 months. If the answer is no, then that can also be used in conjunction with the clinical data to assist with prognostication.

**Benefits and Burdens of Treatment**

Now that you have a basic understanding about what illness trajectories are and their relationship to hospice, we will discuss an important indicator of how clinicians can assist patients with deciding whether or not to continue disease driven treatments or opt for a more palliative form of care. The benefits of treatment are the positive aspects that the patient should receive in regard to that treatment option. These can include: total cure of illness, reducing the progression of illness, reducing the negative effects of another treatment on the illness, providing relief of symptoms associated with the illness, and increasing quantity of life and/or increasing quality of life. These benefits are mainly positive things that would result from undergoing the treatment option. The burdens of treatment can then be classified as the negative aspects of undergoing the treatment, which can include: progression of illness despite having the treatment, worsening of symptoms or development of additional/new symptoms while on the treatment, reduction in crucial and protective lab values such as red blood cells, white blood cells and platelets, and the burden physically, psychologically or emotionally that may result from engaging in the treatment.

Although there are usually some negative effects associated with most medical treatments, these should not outweigh the positive effects. This is how clinicians can weigh the benefits of treatment against the burdens. For example, a nurse has a patient with advanced cancer who undergoes a clinical trial that may or may not extend their life. The patient has undergone all other conventional treatment options and this clinical trial is the last option available to them. Although the short and long term effects are questionable with this treatment option, it may help to extend their life. If that is the goal of care for this patient, then this option may be ideal. Another example might be a patient who undergoes grueling chemotherapy which produces very negative side effects. The patient’s next scan shows that the cancer has spread despite having the treatments and has reduced blood counts to a dangerous level. It is at this point that the burden of the treatment is outweighing any benefit that the treatment may have. The clinician can determine individual patient’s benefits and burdens of treatment and can use that criteria as a way to assist patients with looking at prognosis and formulating their goals of care. Additionally, reviewing the benefits and burdens of treatment periodically may be required with illness progression as the patient may have to re-evaluate their original goals of care and make changes based on how their illness is progressing.

**Initiating the Conversation**

Despite having a good understanding about a patient’s particular illness trajectory and available treatment options, there will come a point in which a conversation needs to occur between the health care clinician, the patient, and the family. These conversations are inherently the most difficult kind that occurs between clinicians and patients, as most of the information exchanged in the conversation is based on negative news. Often the conversation is to inform the patient that their illness is progressing despite current treatment options and/or all curative type of treatment options have been exhausted. Quill (2000) discussed the differences between urgent and routine indications for initiating an end of life care adaptation.
conversation. Patients whose death was imminent, who talked about wanting to die, or who inquired about palliative care or hospice were identified as urgent indications for initiating a conversation about end-of-life care. In comparison, basic discussions about prognosis and treatment options were considered to be more routine indicators (Quill, 2000).

There is a large body of literature about communication between the patient and provider, particularly related to end of life discussions (Cherlin et al., 2005; Tulsky, 2005a; Tulsky, 2005b; Casarett & Quill, 2007). Often these conversations have been delayed until the patient’s illness has become very advanced and the patient may be very close to the end of life. The difficulty in determination of prognosis and a delay in initiating the conversation can be challenging factors that have been found to contribute to hospice delays (Casarett & Quill, 2007). However, a growing body of literature suggests delays in hospice care for patients at the end of life is a result of poor communication about prognosis and options for care at the end of life between patients and physicians. Although 70% of cardiac patients described having a good relationship with their physicians, only 2 out of 80 patients reported having a discussion related to end of life (Formiga, Chivite, Ortega, Casas, Ramon, & Pujol, 2004). Casarett, Crowley, & Hirschman (2004) found that 75% of decedents received information about hospice care as an option at the end of life from a hospice care provider rather than their physician. The differences on the topics viewed as important between patients and physicians could have a role in these communication issues. Patients reported focusing more on outcomes of care rather than on treatments, whereas the physicians’ focus was more on treatment preferences, particularly life sustaining interventions (Rosenfeld, Wenger, & Kagawa-Singer, 2000). Sapir et al. (2000) examined the expectations of patients with cancer regarding their oncology care providers and found 85% of patients to be satisfied about the information they received about their disease, with 90% reporting satisfaction with the manner in which that information was communicated. The majority of participants (98%) expected their oncologist to be skilled in diagnostic modalities, with 90-95% expecting providers to be considerate and tactful.

Strategies for Effective Communication

The first step in effectively communicating with patients who are nearing the end of life is to determine how much information they want to be told. Many times patients will want to know the truth regarding prognosis but prefer not to hear the sensitive details. In order to effectively communicate with patients, the clinician should seek clarification about this before the conversation takes place. In exploring the preferences of patients with cancer and pulmonary disease about the communication of truthful information, Deschepper and colleagues found that patients prefer gradual information that is “dosed” to each individual person (Deschepper, Bernheim, Vander-Stichele, Van den Block, Michiels, & Van Der Kelen et al., 2008). Acknowledging and normalizing the uncertainty in the course of illness for patients with exacerbating remitting illnesses such as heart failure can strengthen the communication process between providers and patients (Goodlin, Quill, & Arnold, 2008). The preservation of hope has been identified from both patients and providers within the context of communication of health information. Kutner, Steiner, Corbett, Jahnigen, & Barton (1999) found that although 100% of terminally ill participants wanted their physicians to communicate information in an honest manner, 91% of them also wanted their physicians to be optimistic. Physicians of patients with end stage COPD reported intentionally withholding bad news as a way to foster hope in the patients they felt needed it (Curtis, Engelberg, Nielsen, Au, & Patrick, 2004). Previous studies have found that patients with cancer generally wanted to know information about their illness, even if it was considered to be “bad news.” They also expected honesty and sensitivity from their provider during the communication process.
Patient Preferences for End-of-life care

Patient decision making about treatment preferences, particularly related to life-sustaining treatments and resuscitation, has been examined with various sub-groups of people with advanced illnesses. The treatment preferences of middle-aged and older adults with advanced cancer were examined by Rose, O’Toole, Dawson, Lawrence, Gurley, Thomas, et al. (2004). The positive correlation between what patients wanted and preferred in regard to treatments compared with the care they actually received was only found to be strong with the older adult group. Treatment burden, type of outcome, and likelihood of outcome were found to influence decision making in end of life treatment preferences of patients with advanced illnesses (Fried & Bradley, 2003). Patients were more apt to accept burdensome treatment with the likelihood of good outcomes; however, they would be willing to accept more burdensome treatment with poorer outcomes as their illness worsened. This suggests that their health status influenced the values of the burden and benefits of the treatment; however, these values and perceptions seemed to change over time as they became more ill. So patients themselves can weigh the benefits and burdens of their treatment and use those to make health related decisions about their care.

Type of diagnosis was not found to be associated with treatment preferences in another study, but decreased functional status was positively associated with decreased preference for a high burden treatment (Fried, Van Ness, Byers, Towle, O’Leary, & Dubin, 2007). Bambauer & Gillick (2007) examined treatment preferences for care at the end of life with 86 patients receiving palliative care consultation and found the vast majority to prefer maximizing comfort (54%) and maintaining function (27%), with only 19% preferring to prolong life. The majority (56%) of this sample were patients with non-cancer illnesses, 23% of which were diagnosed with heart disease.

Patients with heart failure (83%) were found to receive more life-sustaining treatments, such as cardiopulmonary resuscitation, mechanical ventilation, vasopressors, and admission to critical care units, than patients with cancer (43%) (Tanvetyanon & Leighton, 2003). Forty percent of elderly cardiac patients hospitalized during an exacerbation said they did not want to have CPR to sustain life, and 50% preferred to receive care at home if there was no hope for recovery from the exacerbation (Formiga et al., 2004). The majority of patients with advanced heart failure wanted life-prolonging treatments withdrawn or withheld when appropriate; however, the appropriate time was not defined (Willems et al, 2004). Seventy-six percent of heart failure patients with do-not-resuscitate (DNR) orders still received some type of life-sustaining treatment before death compared with those without any DNR orders. Cardiopulmonary resuscitation (CPR) was the only intervention that was significantly less frequent for patients with a DNR order. Interestingly, although the prevalence of DNR orders were similar between cancer and heart failure patients in this sample, patients with heart failure received DNR orders much later during their hospital admission than patients with cancer.

What You Should Know

• Before any good plan for end-of-life care can be developed, nurses need to assess the patients’ goals of care.
• Difficulties with prognostication can contribute to late referrals for palliative care or hospice.
• Previous research has supported patients’ preferences to be told prognostic information, even if it is bad, in order to be able to make informed care decisions at the end of life.
References


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