Assessment of Palliative Care Needs

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Medicine before the turn of the twentieth century focused primarily on the relief of symptoms as the disease followed its natural course toward recovery or death. Around 1900, the medical community began to look for the causes of disease in hopes of finding a cure [1], and symptoms were seen as clues to different illnesses. Technologic and pharmacologic discoveries of modern medicine allowed for new therapies and medicines to combat different diseases; however, there still remain countless illnesses that remain incurable. Millions of people around the world suffer from different disease-related symptoms that affect their lives, causing them to live in discomfort.

Looking back through history to medieval times, we are able to find the term “hospice,” which stems from the same linguistic root as “hospitality.” It refers to a place of rest and shelter for weary and ill pilgrims on a long journey. The modern hospice was introduced in 1967 by Dame Cicely Saunders as a specialized form of care focusing on the amelioration of symptoms and the promotion of the best possible quality of life [2].

Today, there are countless people on a long journey with serious illness who experience the burdens of their disease. Some are enrolled in hospice care, some are not, but all need relief of suffering; that is, they need palliative care. All patients enrolled in hospice programs receive palliative care. However, all palliative care may be provided outside of hospice programs as well.

To best accomplish relief for our patients, we need a team of health care providers to focus on the patient as a whole person, providing care in multiple spheres that affect the patient’s spiritual, psychologic, and physical being.

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thorough assessment of each patient is necessary to establish a patient-centered care plan to promote the best possible quality of life. This discussion details the whole-patient assessment used in palliative care while stressing the importance of an interdisciplinary team approach, illustrating the different domains of care, as well as care planning and delivery. Although the author’s experience comes from caring for patients in the United States, these principles can be applied in any setting and in any country.

**Comprehensive patient assessment**

Performing a comprehensive assessment for patients requires a thorough evaluation of several domains of the patient’s life. It is well documented that any one problem that a patient may be experiencing can be influenced profoundly by other aspects of patient suffering. Therefore, it is critical to examine all aspects of the patient’s life, illness, family, and environment to properly address the patient’s complaints and concerns. The term “total suffering” is used in palliative care to describe the sum total of a patient’s suffering, which includes spiritual, cultural, social, psychologic, and physical symptoms.

The interdependence of the various causes of suffering is illustrated in Fig. 1. Using pain as an example, unrelieved pain has the potential to cause suffering in all other domains of the patient’s life. Conversely, suffering in any other domain, whether it is of a spiritual nature, social conflict, cultural attitudes, depression, anxiety, or unrelieved physical symptoms, can contribute to the patient’s overall experience of pain. Therefore, it is essential that the successful palliation of pain “requires attention to some or all the other aspects of care and suffering and this,

![Fig. 1. Interdependence of the various causes of suffering. (A) Unrelieved pain may cause or aggravate problems related to any of the other aspects of suffering. (B) Unresolved problems relating to any other aspects of suffering may cause or aggravate pain. (From Woodruff R. Palliative medicine: symptomatic and supportive care for patients with advanced cancer. 4th edition. New York: Oxford University Press; 2004. p. 8; with permission.)](image-url)
of necessity, requires a multidisciplinary approach to assessment and treatment; failure to do this often results in unrelieved pain” [3].

**Multidisciplinary team approach**

Each patient who requires an evaluation by a palliative care team should undergo an extensive evaluation that encompasses multiple areas. These patients’ conditions are usually complex and often carry with them extensive medical histories, including treatment burdens and side effects from multiple interventions. In addition to the complex medical aspects of the patients’ disease, there may be other areas on which the care plan needs to be focused. As discussed below, the patient must be evaluated in the areas of disease history and management, physical symptoms, psychologic issues, social concerns, practical issues, and spirituality, to name a few. Medical education does not sufficiently or comprehensively address each of these domains of a patient’s life, so it is unlikely that a physician can elicit a complete assessment by working alone [4].

In addition to incompletely trained physicians, other disciplines bring unique perspectives and skills. Consequently, a comprehensive patient assessment must stem from a multidisciplinary team approach. Each team typically consists of at least a physician, nurse, social worker, chaplain, and home health aid but may involve many other participants, as is illustrated in Fig. 2.

The needs and experiences of each patient will establish what support is needed [5] to properly construct a care plan. For example, a patient who ex-

![Fig. 2. The various member specializations of the interdisciplinary team required for whole-patient assessment. MSW, Master of Social Work; OT, occupational therapy, PT, physical therapy.](image-url)
periences pain that is unrelieved with a conventional approach using opioids and other adjuvants is likely to experience some other form of suffering that aggravates their experience of pain. Therefore, it may be most appropriate for a chaplain to evaluate the patient’s spiritual concerns as a possible source of suffering, rather than increasing the dose of a medication. It is essential to determine the underlying cause or, in many cases, causes of the patient’s suffering to properly treat their complaints. “Relief of physical symptoms, emotional support, continuation of social roles and activities as much as possible, religion and religious rituals are important sources of support” [5].

**Domains of care**

*Medical and disease history*

Patients near the end of life are likely to have long medical histories that include multiple interventions. The illness’ effects and the treatment’s adverse effects often combine to create a complex history [4]. In addition, most of these patients also have multiple secondary diagnoses that confound their symptoms and care plan even further.

The first area of investigation should be that of the primary diagnosis for which the patient has been referred for evaluation. Is the diagnosis one of malignancy or a chronic and debilitating disease (ie, heart failure or chronic obstructive pulmonary disease)? Patients who have chronic, debilitating diseases traditionally have been treated by symptom management that focuses on acute exacerbations with interventions “directed at crisis management, rather than reducing baseline symptom levels” [6]. The treatment plan for the palliative team should be tailored to reduce baseline levels of suffering as well as to avoid and treat acute episodes.

It is also important to know when and how the condition was diagnosed. Most nonhematologic cancers require a tissue biopsy to confirm the diagnosis, whereas others require imaging and laboratory testing. It is helpful for the team to know how long the patient has been living with the diagnosis because the approach may differ between a patient who is newly diagnosed and experiencing the adjustment of having a terminal disease versus a patient who has had the time to adapt their lifestyle to deal with their diagnosis.

Often, the same symptoms that caused the patient to present for the initial evaluation that led to their diagnosis persist throughout the course of their illness. Therefore, it is helpful to know as much about the disease as possible, including its progression, so that a care plan can include what problems the patient may encounter further in their course.

Also of great importance is the history of treatment for the patient’s disease. It is helpful to know what has been done to try to treat the underlying disease and the response of each intervention. The physician should also consider whether every option has been considered and offered to the patient regarding the
treatment of their disease. The physician should be comfortable in knowing that the “previous treatments were appropriate based on their known effectiveness and the preferences of the patient” [4]. For example, if a new patient assessment reveals that a potentially curative treatment option has not been considered, it should be offered to the patient or proxy before admission to a hospice program [4]. It should also be noted what the patient’s desires are for further treatments and interventions. It is possible that, although an existing therapy may help the underlying disease, the patient may not want to consider further interventions.

In addition to the primary diagnosis, many patients have multiple secondary diagnoses, which may confound treatment options and care plans. There may be limitations to therapies owing to the patients’ inability to tolerate certain medications used to treat comorbidities. A thorough history of medications is also of great value because it may present barriers to treatment options while exposing some other avenues that have not yet been tried.

Obtaining a thorough disease-specific history of the patient’s primary diagnosis and of their secondary comorbidities is of vital importance to creating a comprehensive and effective care plan. Patients who are approaching the end of life are likely to experience acute exacerbations of their symptoms over time and also suffer a decline in their overall condition, which may limit certain interventions. The more prepared a team can be with regard to the patient’s past experiences and what they are likely to encounter during their disease course, the more effective a treatment plan that can be created.

**Physical symptoms**

As with any disease process, patients commonly identify with their physical complaints to determine the effectiveness of their care. If symptoms are well palliated, then patients will feel well and relatively free of disease. The experience of unremitting nausea or incapacitating pain, for example, is a constant reminder to the patient that he or she is ill and that exacerbations of these physical symptoms tend to convey progression of disease and a decline in condition.

There are many physical symptoms that terminally ill patients experience, including but not limited to pain, fatigue, insomnia, nausea and vomiting, breathlessness, anxiety, and depression. In addition, to completely assess the terminally ill patient, the overall level of function, sexual health, skin integrity, personal safety, and nutrition and hydration status must be assessed. “Physical assessment at the end of life differs from the standard patient assessment in that it is best organized by symptoms and functional activities, rather than by organ system or anatomy” [4].

**Pain**

Pain is the most common complaint of patients who have a terminal diagnosis and also the most feared complication of disease. It is especially prevalent in patients who have advanced stage cancer and AIDS, with up to 90% complaining of pain [4]. Pain may be a gateway to the assessment of other physical symptoms,
and, as it relates to total suffering, it may provide an avenue to explore the psychologic, social, and spiritual dimensions of one’s illness and symptoms [4].

The gold standard in assessing pain remains the patient’s subjective interpretation of his or her experience. The initial assessment includes the location, quality, severity, temporal profile, and the effect of medications. When determining the quality of pain, it is best to try to delineate if the problem is nociceptive or neuropathic or a mixture of the two. Assessing severity can be assisted by the use of a rating scale, such as a numerical, visual-analog, or a face scale. Although many different types of rating systems are available, it is important to choose one and use it consistently.

In relation to the patient’s overall quality of life, it is also important to know the impact that the pain has on function. It is useful to know what the patient’s perspectives are about their pain. Questions such as “What do you think is causing the pain?”; “What does the pain mean to you?”; and “Do you want something for the pain?” can help decipher how much impact pain has on a person’s quality of life and how to proceed in the plan of care.

**Other physical symptoms**

There are many additional physical symptoms that may contribute to a patient’s suffering. For each symptom, multiple causes must be considered to properly diagnose the cause and to construct a treatment strategy. It is possible that the patient’s symptoms may be caused by the primary illness, secondary illnesses, treatments and other medical therapies, or because of psychologic, social, or spiritual factors. Only a thorough investigation of the cause can enable the physician to devise an appropriate treatment strategy and ensure that the patient is as comfortable as possible, as quickly as possible.

Fatigue is one of the more common problems that patients experience. Lidstone and colleagues [7] have found that fatigue was present in 79% of patients at a large cancer center in London. Although cancer patients are more likely to experience fatigue than those with noncancer diagnoses, the complaint is not specific to the disease. Depression and anxiety are also highly prevalent and are the most underdiagnosed symptoms in patients facing the end of life [4]. Therefore, it is very important to inquire about symptoms of depression and suicidal ideation in these patients.

**Additional areas of physical assessment**

To completely assess a patient’s physical symptoms and function, it is important to include assessments of the level of function, including sexual function, and how it may have changed since the diagnosis. Also, the interdisciplinary team will want to investigate the patient’s safety to ensure that the patient is not in harm’s way. Nutritional and hydration status play a particularly important role in regard to what medications may be offered and how the patient may decline over time if he or she is not eating or drinking well. Last, it is beneficial in the assessment of all patients to know their skin integrity.
Patients who have decubiti are often malnourished, possibly poorly cared for, and more prone to pain and infection.

Psychologic issues

When patients are diagnosed with a terminal illness, they begin to ride an emotional roller coaster. The physician should ask how the patient is responding to the fact of being ill [4]. Many patients will experience feelings such as worry, tension, irritability, depression, and anger or even tranquility. It is helpful to identify the emotion, acknowledge it in an accepting way, and thereby normalize it for the patient [4].

Those people who are facing their own mortality usually also have many fears about what the future may hold. There are great concerns about the loss of control over their lives, their families, their independence, and even their bowel and bladder. They realize that even stable relationships may change with the news of being ill. Most patients also harbor fears of what types of symptoms they may encounter during their disease course and how they may contribute to their overall suffering. It is crucial to know what it is that the patient fears when preparing a long-term care plan that will address their concerns and provide a solution to any problem that may arise.

Closely tied to the psychologic assessment are cognition and the capacity to make decisions. As patients progress through their disease course, they often suffer lapses in memory and cognition, and their overall ability to make decisions diminishes. A person may be globally incompetent and will need to rely on others to handle their affairs. These patients are unable to consent to any health care decision and must defer such decisions to a designated health care proxy [4]. Other patients may retain some decision-specific capacity, meaning that they have some compromised mental function without being globally incompetent. Their capacity to make decisions may be limited with respect to questions requiring careful analysis; however, decisions based on firmly held beliefs may still be authentic. Therefore, it is important to include the patient, as much as possible, in the decision-making processes. For example, a patient who does not know where he or she is and can no longer manage their own affairs, nonetheless, may have deep and meaningful insight into whether an amputation or intubation is acceptable [4].

It is of vital importance to determine whether a patient possesses decision-making capacity. The patient must understand that they are authorizing the decision and also that they are making accurate and rational inferences with the information given. They must demonstrate insight into the consequences of the decision; and finally, the patient must be free of any coercive influences that may sway his or her decision [4]. If a patient is able to fulfill all of the above requirements, then they have the ability to make decisions for themselves. We must always remember that it is the right of the patient to make their own decisions for their health care, even though they may not be decisions that we might choose for ourselves.
Patients who are faced with a terminal disease often are depressed by the fact of having to face their own mortality. They quickly face a series of losses that adversely affect their lifestyle and changes the way they live. Mazzocato and colleagues [8] performed a comprehensive assessment of patients in palliative care and found that “a majority of these patients were previously mentally healthy individuals but became psychologically vulnerable during the stress of the cancer and its treatment.” Because each person reacts to stress in a different way, it is useful to explore a patient’s coping skills, to assist him or her in coming to terms with the illness so that he or she can concentrate on other matters during this time.

Social issues

It is not only the patient’s experience of physical symptoms, emotions, and fears related to their illness that induces suffering but also the many social issues surrounding living with a terminal disease that create difficulty. Cultural diversity, changing interpersonal relationships, environmental constraints, privacy issues, and financial and legal concerns combine to complicate a patient’s life. Living with a terminal illness induces change in a person’s life, whether it is desired or not.

Every patient comes from a different background and upbringing. These differences make us a culturally diverse nation, and it is important to recognize that each person has different beliefs and values. Therefore, it is helpful to inquire about the patient’s cultural values so that we can create a plan that is consistent with their background. To ignore that or to possess a “lack of knowledge of other cultures may lead to policies, practices, and communication styles that screen out diverse groups or cause offense” [9].

Maintaining interpersonal relationships and an interactive social life is highly correlated with quality of life. If there is social isolation and a poor social life, the patient will likely perceive quality of life is poor [6]. A patient’s interpersonal relationships, whether with family, friends, or care providers, are strained under conditions of being ill and requiring others to do for them. It is important to provide the patient with a sense of purpose so that he or she does not feel that they are totally dependent on others for their survival. It is this need to care for others and to be needed, in addition to seeking and receiving support, that “stresses the reciprocity and counter dependence of relationships with beloved others, instead of being totally (physically) dependent” [5].

The family unit itself undergoes a great transformation during times of stress, such as a terminally ill family member. Either a family will band together and become stronger as a unit while caring for their loved one, or they may fall apart and not be able to handle the requirements of care. As Mazzocato and colleagues [8] discovered, although most patients had no or only mild signs of family disruption and impairment of social support in the past, under the stress of having a family member who is facing the end of life, “most of them need assistance at home and a small minority depend on disability allocations or are jobless [8].
The environment in which the patient lives is a large factor in determining needs and a plan of care. Issues such as stairs, ease of getting to the bathroom, the ability to call for help, and comfortable surroundings all contribute to overall quality of life and safety. Many patients desire to remain in their homes, despite difficulties that may arise as their condition declines. It is certainly their right to remain at home, and every effort should be made to accomplish this and to provide for maximal support and safety. An additional barrier that may be encountered is that of patient privacy. It is often a challenge to care for a patient while providing the maximum amount of privacy and dignity.

There are often financial concerns that patients have as they approach the end of their lives. The desire to leave a financial legacy is very strong. The thought of not being able to leave some financial security to loved ones can often become a major source of shame and even a desire to hasten death to relieve the financial burden on family members [4]. The cost of caring for a terminally ill patient can be quite high without the proper resources, because approximately “30% of families with a life-threateningly ill member spend a considerable portion or all of their life savings for the care of the patient. A similar percentage loses a major source of family income because of the illness” [4]. Therefore, it is important to consider financial aspects of care but also to address them with the patient and their families.

There are also legal matters that can confound a patient’s care. It is of utmost importance to determine who will be the durable power of attorney for health care if the patient cannot make decisions. The patient will also want to provide security for his or her loved ones. This may involve parental custody if there are small children involved or who will run the family business. “Patients take care of beloved ones by directing things that make (future) life as comfortable as possible for their beloved ones” [5].

Practical issues

As patients decline and their level of function diminishes, the ability to perform daily activities associated with normal life becomes more difficult. It is the inability to go out and do things that has the most impact on patients facing the end of life [6]. They require increasing assistance with their activities of daily living, such as bathing, dressing, feeding, cooking, and toileting. Even the care of one’s own pets can become burdensome, not to mention the difficulties of caring for a child. There are often concerns about transportation for food or to a doctor’s appointment, which must be addressed.

Even the most basic of human needs must be examined: Does the patient have suitable shelter? Is there food available and accessible? Is the electricity working? Is there heat? All of these issues are vital to anyone’s well being and necessary for survival.

There must also be a plan in place for any emergencies that may arise. A contact number for the hospice should be available to provide around-the-clock support. If there is an acute situation requiring an intervention, the patient should
already know who to call and where to be taken for care. It is good practice to troubleshoot and devise a plan of care to allow for the patient’s increasing symptoms such as pain, anxiety, or dyspnea. Having prepared the patient for the possibility of such events will establish a level of comfort that shows the patient that some of the more likely scenarios and how to deal with them have been anticipated, should they arise.

**Spiritual issues**

Spirituality is a universal component of illness and affects quality of life in profound ways. Someone who suffers spiritually will often experience an exacerbation of symptoms, whether it is pain, anxiety, nausea, and others. As terminally ill patients approach the end of their lives, they need time to reflect and come to terms with their illness and review their life’s events. We, as physicians, should “bear in mind the possibility that patients can experience significant spiritual growth and gain meaningful fulfillment during their last stage of life” [4].

Once patients have been diagnosed with a terminal disease, a wave of feelings wash over them, sending them into emotional turmoil, causing them to question the meaning of their life and the also of their disease. There is often a struggle in which the patient engages, and they may stir up “painful memories or shame about things past, may question the value or meaning of their life, the worth of relationships, and there may be guilt about failures and objectives not achieved” [3]. Spiritual or existential distress often stems from events related to the past, present, and future and may be closely tied to religion, as depicted in Box 1.

Patients approaching the end of life experience a loss of control in multiple spheres [4] and fear the consequences of such losses. As their disease state progresses, their original plans for life are trumped by illness. They may develop the inability to feed, bathe, or toilet, which is often associated with indignity and shame. Universally, patients will wonder what their disease progression will be and what will happen to them and their loved ones. They are curious about how and where they will die and what preparations they need to make (eg, advance care planning, estate planning, memorial services) for the end of their lives. Giving permission for patients to talk about these concerns often facilitates discussion and can be introduced in a general way by saying: “Many people in your situation think about dying. Is that something you are thinking about?” [4].

Every human being possesses spirituality, and it is unique to that individual. It “encompasses the purpose and meaning of an individual’s experience and involves relationships with, and perceptions of, people and all other things and events” [3]. It is rooted in family and cultural traditions as well as religious practices and is modified by one’s life experiences. Spirituality is “the basis for an individual’s attitudes, values, beliefs and actions” [3]. A patient’s spiritual care should begin with the patient being accepted as they are, in a nonjudgmental way, and not to allow the caregiver’s beliefs or values to enter into discussions unless requested by the patient.
Religion differs from spirituality in that it “is the relationship between an individual and God, characterized by belief in, reverence for and desire to please that God” [3]. Regardless of what one’s religious beliefs may be, we should always reserve the utmost respect for an individual’s religious beliefs and traditions. It is helpful to inquire about a patient’s religious practices, including prayer, diet, and hygiene, and the way a person chooses to practice their beliefs should always be respected. It is erroneous to assume that all persons of the same religious faith practice their beliefs the same way; therefore, one’s religious needs are based on an individual evaluation, not by their religious affiliation. If we

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**Box 1. Spiritual and existential distress**

*Relating to the past*

Value and meaning of a person’s life  
Worth of relationships  
Value of previous achievements  
Painful memories or shame  
Guilt about failures, unfulfilled aspirations

*Relating to the present*

Disruption of personal integrity  
Physical, psychologic, and social change  
Increased dependency  
Meaning of a person’s life  
Meaning of suffering

*Relating to the future*

Impending separation  
Hopelessness  
Meaninglessness  
Concerns about death

*Relating to religion*

Disease as a punishment  
Existence of after-life

show a lack of respect to an individual’s religious belief system, then we may be creating an avenue for spiritual suffering and possibly cause problems between the patient and staff [3]. Specific questions pertaining to religion are often best dealt with by an expert in that religion, such as a rabbi, priest, minister, Imam, etc. Although there are many religious resources available in the community, many religious leaders have never had any specific training in end of life care; therefore, it may be helpful for the hospice chaplain to assist them in that regard.

Complete spiritual care encompasses grief and the impact of loss. Patients facing the end of life are constantly experiencing losses, whether because of worsening physical limitations, the loss of independence, financial security, or relationships. Grief begins from the day the patient is first told of their terminal diagnosis, as they anticipate the eventual losses they will experience, including death, referred to as “anticipatory grief.” Unfortunately, some patients do not have a cohesive support network and exhibit impaired coping strategies such as protected avoidance and denial [10]. Actual grief occurs once the loss has taken place and is often associated with emotional distress characterized by crying, loss of concentration, sadness, anger, despair, anxiety, and guilt. Physical manifestations may also be present that include, but are not limited to, numbness, restlessness, tension, tremors, sleep disturbances, weight loss, and fatigue and also by different aches and pains [10], which add to one’s experience of total suffering. Occasionally, one’s inability to cope with the losses can lead to a complex grief reaction, which may manifest itself by alcohol or drug use, inhibited or delayed grief, psychotic disorders, or psychiatric changes such as depression or anxiety.

Some guidelines to remember spiritual assessment include the recognition that spiritual suffering is a universal component of illness and can have a profound effect on quality of life. Spiritual pain should always be suspected in patients facing a terminal illness, and a comfortable atmosphere must be created in which the patient is allowed to express him or herself. The physician should be careful not to allow personal beliefs and values to influence or contradict those of the patient [4]. Physicians may ask questions regarding spiritual pain and suffering by using open-ended questions such as those in Box 2.

Information sharing

A large part of the patient assessment is the communication of information. Foremost, it is important to maintain patient confidentiality to keep the patient’s health information private. An effective strategy to establish a patient’s understanding of their illness is to find out what he or she already know about the diagnosis. This will give the physician a good sense of the patient’s level of understanding and the interpretation of information given previously. It creates an opportunity either to confirm what the patient already knows or to correct some misinterpretations or miscommunication that may have occurred. The physician should be sure always to talk in lay terms that the patient will understand and avoid medical jargon, which may lead to further confusion.
It is vital to determine what information the patient wants to know and how it should be delivered. Some patients will want to know every possible detail of their disease, whereas others may not want to know anything. Also, some patients may want to be straight to the point, whereas others may need a little lead-in to prepare them for bad news.

Whenever information is shared with a patient, we must ensure their understanding of the information given. It is often helpful for the patient to have someone with them who may be more objective, able to ask questions, or even take notes if necessary. In their study of the health care needs assessment of lung cancer patients, Krishnasamy and colleagues [11] found that only 58% of patients and 45% of lay carers stated that they had been told that the underlying illness was cancer or lung cancer. This finding reinforces the fact that when someone receives bad news, they are often overcome by emotion and have difficulty concentrating and processing information.

It is imperative to create a relaxed environment to allow for the patient or their loved ones to ask questions. There may be many boundaries contributing to the patient’s abilities to ask questions during a health care encounter, such as “patients’ coping styles, physician attitudes and patient and professionals’ health care beliefs” [11]. The degree of understanding that a patient and caregivers have about the disease and clarification of services that the hospice and palliative care team will provide will have a profound effect on the patient’s expectations and satisfaction [6].

When a patient is not able to process information or does not have decision-making capacity because of disease, the information will need to be presented to a substitute decision maker and other caregivers. This is seen typically in the

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**Box 2. Guidelines for spiritual assessment**

- Are you a spiritual person?
- What role does religion play in your life?
- Have you thought about what will happen after you die?
- What are the things that matter most to you?
- How have you tried to make sense of what’s happening to you?
- If you were to die suddenly, are there important things you feel would be left undone?
- As you look back on your life, what has given your life the most meaning?
- What are some of the things that give you a sense of hope?

population aged 80 years and older who often suffer from dementing illnesses. In discussions concerning goals of care for these patients, Evers and colleagues [12] have found that there was significantly less communication between the patient and the team, with a reciprocally larger amount of communication between the patient’s family and the team. This signifies an important point in the communication chain because if lay carers do not have adequate information and instruction, they may “experience feelings of anxiety, loss of control and perceptions of inability to care for and support patients” [11]. Often, it is useful to elicit the help of a social worker to facilitate the information sharing, usually through family meetings. As is evident, precise information presented in a simple fashion generally leads to the best outcomes, whereas misunderstandings can usually become problematic [4].

Goals of care

Each patient will have different expectations and goals they wish to achieve with the time they have remaining. It is important to ask “what they think are the most important things to accomplish now” [4]. Some patients will want to endure to certain milestones, such as birthdays, weddings, graduations, or anniversaries. Others may find that the most important thing is taking a long awaited trip or finishing a hobby or project that they have been working on.

A patient’s goals of care will help the team establish the aggressiveness of care. Whatever the patient’s goals, the team will need to work together to help meet them. For example, a social worker may be able to facilitate in helping a patient travel to another part of the country by establishing relations with another hospice to look after a patient while they are in that area, in addition to providing all the necessary provisions to help ensure the patient has a safe trip. It will require a team effort to meet an individual’s goals.

Care planning

Care environment

Each patient should be asked where he or she would like care to take place. Many want to remain at home with the help of home hospice; however, some patients believe that they are too much of a burden to their families and want to be somewhere else. Whether it is in the home or another facility, such as a nursing home, board and care, or an inpatient hospice unit, there will be challenges unique to each setting.

Patients who choose to remain in the home often have barriers to their care. The home itself may present physical limitations to the patient, such as ascending and descending stairs, getting to the bathroom, or preparing meals. Caregivers must be in place to provide support and safety. Many times there must be 24-hour supervision for the patient, and if the family and support network cannot provide
that degree of care, then an outside resource must be contacted to ensure quality care and safety.

The physical location of the home also plays an important role. As Buehler and Lee [13] note in their investigation of home-care resources for rural families with cancer, the more remote a rural family, the fewer resources that are available. The geographic location of the patient is likely going to affect access to specialist services and other resources “resulting in greater involvement of family members in caregiving” [14]. These patients will need more assistance from community resources as well as intensive hospice support.

Approximately 43% of patients who reach age 65 spend time in a nursing home, with a mortality rate of approximately 25% per year [15]. A patient who receives care in a nursing home setting will likely benefit greatly from hospice services. Reynolds and colleagues [15] note that hospice serves only 5.6% of nursing home residents at the end of life. It is imperative that patients residing in nursing homes receive intensive interdisciplinary team support because many have “high rates of untreated pain and their treatment preferences may not be considered in end of life decisions” [15]. The older palliative care patients are more likely to succumb to diseases that are chronic in nature, marked by lengthy periods of decline and functional impairment [12]. The most common causes of death in nursing home patients are pneumonia (19%), coronary artery disease and congestive heart failure (19%), cancer (17%), and stroke (10%) [15].

Reynolds and colleagues [15] also illustrated that there were many unmet needs of patients that caregivers identified, most commonly emotional and spiritual needs (30%), personal cleanliness (23%), and undertreatment of pain (19%). The plan of care should focus on the patient’s goals and wishes while palliating any symptoms the patient may experience.

Regardless of the environment where the care takes place, there needs to be a comprehensive plan established to allow for fluctuations in symptoms and changes in condition. The team must plan for anticipated events such as sudden changes in symptoms, caregiver breakdown, family emergencies, and bereavement issues. Arrangements should also be made for the patient’s final rites, rituals, funeral or memorial services, and celebrations of the patient’s life while the patient is still able to provide input into what their wishes are. A bereavement counselor should also be notified so that they can work with the deceased patient’s family and loved ones.

**Care delivery**

Once a care plan has been created, targeting the patient’s physical symptoms, psychosocial, spiritual, and practical matters, the interdisciplinary team must work together to achieve the goals of care. It will require the use of an entire team to meet the needs of just one individual. Many patients have close relationships with their physicians, and as Lidstone and colleagues [7] illustrate in their article about concerns of cancer outpatients, the skills offered by the palliative care team
“should complement those offered by the oncologists, and a collaborative approach is essential to achieving optimal management” [7].

Perhaps the most important member of the team is the patient. Everyone has the right to be a partner in his or her own care, and preserving the patient’s autonomy is important to the success of the care plan. The patient should always feel that he or she is in charge of care and is an active participant in the decision-making process. Another key element to the success of the care plan is the support of the caregivers. They may be family, such as husbands, wives, partners, children, or other more distant relatives or friends, neighbors, or even private hire personnel. Caring for a terminally ill patient is a very demanding task and as much support as possible should be offered. Providing the lay carer (and patient) with all the essential information of what they might experience and what to expect as the disease progresses can help establish a certain comfort level pertaining to the patient’s care.

As the disease progresses, it not only takes a toll on the patient but causes untoward effects on the caregiver as well. Krishnasamy and colleagues [11] found that the lay carers who play a significant part in the care infrastructure “have been shown to experience considerable physical and psychologic needs in relation to their caregiving role” [11]. The caregiver suffers largely psychologic difficulties, with a desire to hide feelings and protect the patient from further stress. Caregivers are often fearful about the future or finances, feel sad, low, anxious, restless, or angry or experience a loss of concentration [11]. Therefore, the interdisciplinary team needs to focus on the patient and family as one unit.

**Confirmation**

The final step in the assessment of the palliative care patient is one of confirmation. We must establish that the patient and all those involved in their care have a complete understanding of palliative care and the hospice philosophy, the disease process, and the treatment plan. Sufficient time should be provided for questions to be asked so that any misunderstandings may be corrected. It is also very important to ensure that the treatment plan is consistent with the patient’s goals of care, while maintaining patient autonomy as an active participant. Last, we must ensure that all are satisfied with the care plan to minimize anxiety of caring for a patient near the end of his or her life.

**Summary**

Caring for a patient at the end of his or her life requires a thorough understanding of the patient’s disease as well as a detailed investigation of all domains of the patient’s being. The patient’s goals of care should be revealed, and the interdisciplinary team must work together to provide the patient with maximal care, to ensure the best quality of life possible. We must devise a comprehensive
and flexible plan so that any anticipated issues may be quickly resolved. As Sir William Osler stated, our goal as physicians is “to cure sometimes, to relieve often, to comfort always.”

References