Module 3
Whole Patient Assessment
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Abstract

Patient assessment in end-of-life care focuses on the relief of suffering. Suffering can be conceptualized as having physical, psychological (emotional), social (practical), and spiritual components. Patients suffer as persons with relationships to others, a past, and an anticipated future. Consequently, assessment must include all of these aspects of a patient’s condition and experience. A standard assessment should include the following areas: disease history, physical symptoms, psychological symptoms, decision-making capacity, information sharing, social circumstances, spiritual needs, practical needs, and anticipatory planning for death.

Key words

anticipatory planning, confidentiality, decision-making capacity, disease history, experience of illness, information sharing, interdisciplinary assessment, pastor, physical symptoms, practical needs, psychological symptoms, social worker, social circumstances, spiritual needs, suffering, whole patient

Objectives

The objectives of this module are to:

• identify 9 assessment areas
• know how to assess the areas of:
  - disease history
  - physical symptoms
  - psychological symptoms
  - decision-making capacity
  - information sharing
  - social circumstances
  - spiritual needs
  - practical needs
  - anticipatory planning for death

Clinical case on trigger tape

Mr Gonzales is a 67-year-old mechanic who immigrated to the United States from Mexico 10 years ago. His primary care physician is Dr O’Brien. Fourteen months ago, Mr Gonzales presented with microcytic anemia, which soon led to a diagnosis of adenocarcinoma of the colon, Duke stage C. Treatment included bowel resection and
adjuvant chemotherapy. During his treatment, Mr Gonzales was relatively asymptomatic. Recently, however, he has noted pain in his leg. Imaging studies revealed lesions in the liver and right femur. A bone biopsy confirmed the diagnosis of metastatic adenocarcinoma. It has been 3 weeks since Mr Gonzales learned the news of the cancer’s recurrence. The video shows a scene in which Dr O’Brien conducts a comprehensive assessment of Mr Gonzales.

Introduction

Patient assessment in end-of-life care differs from other clinical assessments in that its goal is to permit the relief of suffering. Effective implementation of management strategies to relieve suffering in end-of-life care must be based on a comprehensive assessment of the whole patient. Assessment must recognize that patients’ experience (and parents’ experience if the patient is a child) of illness is multidimensional. This module will focus on the essential elements of assessment for each major dimension of patient experience: disease history, physical symptoms, psychological symptoms, decision-making capacity, information sharing, social circumstances, spiritual needs, practical needs, and anticipatory planning for death.

Conducting a comprehensive patient assessment of suffering is important for physicians because the relief of suffering is as fundamental to the goals of medicine as cure or control of disease. Because the physician is the one who coordinates and directs care, it is important that the physician be able to assess each dimension of suffering. However, the physician is unlikely to elicit a complete assessment by working alone. Other members of the health care team (such as nurses, social workers, and chaplains) can conduct important components of this assessment. They bring unique skills to the task. They may learn important information that the patient or family may not have shared with the physician.

The assessment process can also be a therapeutic tool. Besides giving the physician information, the physician can discuss with the patient or proxy the meaning of the information and his or her assessment of the patient’s situation. This can help convey information to the patient regarding prognosis and the need for advance planning and personal preparation, particularly in the setting of overall deterioration. Of equal importance, it conveys compassion. It initiates the physician’s therapeutic role.

The role of the physician is to care for the whole patient, not just the disease. In listening to the history, acknowledging the patient’s experience, and analyzing the causes of suffering, the physician establishes this role in the eyes of the patient and family. By offering information and practical advice, teaching and friendship aspects of the role are conveyed. By introducing sources of support, the physician promotes the role of patient advocate. Members of the interdisciplinary team (such as nurses, social workers, chaplains, child life specialists, and others) along with the family will share the responsibilities of patient advocacy and implement the treatment plan. The physician need not, and should not, bear this responsibility alone.
Assessment overview

Whole patient assessment starts with the taking of a good history. Begin with a summary of the patient’s illness and treatment. Continue with an assessment of physical symptoms, then psychological matters. This strategy provides a convenient transition into assessing decision-making capacity. From there, assess the patient’s preferences for information sharing and decision making. The social and cultural aspects of the illness experience can then be readily assessed. Assessment of the spiritual aspects follows. Finally, the practical aspects of support and care services are important to assess, as are the patient’s and family’s anticipatory planning for death.

Illness/treatment summary

The patient near the end of life will likely have a long medical history with multiple interventions. The illness’ effects and the treatment’s adverse effects often combine to create a complex history. In addition, there are often secondary concurrent illnesses. Be sure to record the treatment summary.

Consider whether you are satisfied that the previous treatments were appropriate based on their known effectiveness and the preferences of the patient. For example, an assessment of a new patient referred for hospice care may reveal that an appropriate curative treatment has not been considered. Such a treatment should be presented to the patient or proxy prior to enrollment in the hospice program.

It may be that efforts to control the underlying disease are appropriate even in advanced stages of illness. This is especially true with pediatric patients. Their parents may desire curative or life-prolonging therapy even in the face of poor prognosis.

Physical assessment

Physical assessment for a patient facing the end of life differs from a standard patient assessment in that it is best organized by symptoms and functional activities rather than by organ system or anatomy. After symptoms and physical impairments are assessed, a physical examination can be conducted. A physical examination confirms findings from the history and provides baseline clinical information. It also establishes a relationship that includes therapeutic touch. Occasionally it is helpful to conduct diagnostic tests. However, the results should clearly affect or help determine the therapeutic plan. Because there is a burden associated with diagnostic tests, keep these to a minimum if comfort is the goal.

Common Symptoms

It is common for patients to experience multiple symptoms during the last phase of life. The most common symptoms in this population are pain, weakness/fatigue, breathless-
ness, insomnia, weight loss, confusion, constipation, anxiety, nausea/vomiting, and depression. Ask about each one.

For every symptom, multiple potential causes should be considered. The symptom may be related to the primary illness. Alternatively, it may be due to the medical therapy for that condition, or it may be related to another medical condition. Psychological, social, and spiritual factors may play a strong role in the development of physical symptoms (see Plenary III: Elements and Models of End-of-life Care). There may be cultural components as well.

Each symptom should be thoroughly assessed (see Module 4: Pain Management, Module 6: Anxiety, Delirium, Depression, Module 10: Common Physical Symptoms, and Module 12: Last Hours of Living).

**Pain as a model for symptom assessment**

The assessment of pain can serve as a model for the full spectrum of other physical symptoms that patients may experience. In practice it often serves as a natural point of entry into other aspects of whole patient assessment. Pain is highly prevalent and often under treated. Frequently it is not assessed at all. Yet, once assessed, most physical pain can be well controlled. The assessment of pain may be a gateway to the assessment of other physical symptoms as well as the psychological, social, and spiritual dimensions of illness.

**Pain assessment**

Pain is present in up to 90% of patients with cancer and AIDS in advanced stages. Similar prevalence rates are reported in pediatric and geriatric patients.

Because symptoms are inherently subjective, patient self-report is the gold standard for assessment. There is no reliable way to assess what the patient is experiencing other than by asking the patient. The following characteristics need to be elicited and documented. These cardinal aspects of symptom assessment are listed below with questions that are likely to elicit the desired information. The effect of assessing pain in this way is both to gain a clearer understanding of diagnosis and to convey that the symptom is important to the physician. The implication of the answers to these questions as they relate to management is covered in Module 4: Pain Management.

- **Location:**
  - Where does it hurt most? Does it go anywhere?
  - How does your pain change over time?
  - How long have you had this pain?
  - Did it begin gradually or all of a sudden?
  - Does it come and go, or do you have it all the time?
- Quality:
  - What words might you use to describe the pain?
- Severity:
  - How bad is it on average? At its worst? Is it progressing or remaining stable?
- Modifying factors:
  - Does it feel better when you’re in a certain position?
  - Do you notice any change with [various activities]?
- Impact on function:
  - To what extent does the pain interfere with your normal activities?
  - What about your sleep?
  - Your ability to walk?
  - Your relationship with others?
- Effect of treatments:
  - What have you been doing for the pain?
  - Have you taken any medications?
  - How much relief does that provide?
- Patient perspectives:
  - What do you think is causing the pain?
  - What does the pain mean to you?
  - Would you like me to prescribe something?

Pain assessment in the non–cognitively intact person, such as an elderly patient with dementia, is challenging. Similar challenges are present in preverbal children. Behaviors such as grimacing, moaning, or crying may the only way to assess pain. Rely on experienced colleagues to help with assessment.

**Severity**

Symptom severity is an important aspect of assessment. Despite pain’s being subjective, patients can accurately and reproducibly indicate the severity of their symptom by using a scale. Scales for pain have been well validated as tools. They enhance the ability of the patient to communicate severity to health care professionals. They also enhance communication of severity between professionals. Numerical scales (0–10), visual analog scales, and faces scales (showing a sequence of faces in a row from happy to intermediate to sad) are all in use. The specific scale used is less important than using one in a consistent way over time. Some patients have trouble with the concept of rating pain on a numerical or
visual analog scale. Using a more concrete scale such as the Borg Faces Scale may be helpful, particularly with children.

Standardized pain assessment tools can help to assure that pain is adequately assessed. Many such instruments are available. The Brief Pain Inventory (Short Form) of the Pain Research Group, University of Wisconsin, Madison, is one example. A copy is included in the Appendix of this module.

A similar approach to that described for the systematic assessment of pain should be applied to the assessment of all other symptoms. When assessing a patient with multiple symptoms, it is extremely helpful to use a standardized form that can be used to track the symptoms over time. The Memorial Symptom Assessment Scale is an example that is included in the Appendix of this module.

**Function**

Assess both motor and sensory functions. Can the patient move around? Can the patient see or hear well enough? Is he or she safe? Can the patient complete activities of daily living? How are the physical aspects of relationships including sexual function?

**Psychological assessment**

Ask screening questions about cognition—are there times of confusion, hallucination? Ask about mood—anxiety, sadness. Depression and anxiety are among the most prevalent and most underdiagnosed symptoms in patients facing the end of life (see Module 6: Depression, Anxiety, Delirium).

Among the most important psychological issues are the meaning of the illness, emotional state, communication and support, and the existence of unresolved issues. The physician will want to assess the individual and determine whether the patient is coping adequately or whether referral should be recommended. Do not hesitate to ask screening questions about suicidal ideation. As a routine question among others, or indeed as an explicit and exploratory discussion, there is no evidence that it fosters thoughts of self-harm. Rather, it sets the groundwork for later discussions if they are needed, and it allows for self-expression, which can be therapeutic. See Module 5: Physician-Assisted Suicide.

**Emotional responses to illness**

There is always an emotional response to serious illness; it challenges a person’s sense of themselves and their role in life. Ask about how the patient is responding to the fact of being ill. Consider naming some common responses, such as anger, grief, instability, and tranquility. Some people move through stages of shock and struggle, and eventually reach resolution. Most people move between a range of emotions and not always in a predictable order. Emotions come in surprising waves and/or can be persistent. It helps to give the patient (or parent if the patient is a child) a sense that this is normal. One way to do this is to inquire about his or her emotions, and then actively listen to the patient’s re-
responses. It frequently helps the patient if the physician, or other health care giver, identifies the emotion, acknowledges it in an accepting way, and thereby normalizes it.

In the case of a dying child, the emotional responses of the parents and the siblings are particularly relevant, since they directly affect the child as caregivers. There needs to be attention from members of the psychosocial team to these adults and children at an age-appropriate level.

**Fears**

Almost all patients have fears for the future as they face the end of life. Fears over loss of control, loss of dignity, loss of relationships, and physical suffering are all common. In tailoring a therapeutic relationship and a plan of care, it is critical to know what it is that the patient tends to fear.

**Unresolved issues**

Unresolved issues in personal matters and especially in relationships are a prominent part of the experience of patients at the end of life. You may discover that what stands between the patient and a comfortable frame of mind is an unresolved issue. Whether those issues have to do with settling old feuds, making or receiving last visits, or completing a lifetime project or piece of work, creating a plan of care that allows for that work is important.

These issues are rarely apparent to a physician unless questions directed to this area are asked. Examples might be:

- Is there something that you would like to do before you get too sick?
- Many people have old differences they would like to settle before they die. Is there anyone you want to be able to communicate with before you die?
- Many people have places or people they would like to visit. Do you?
- Some have a piece of work they would like to finish. Do you?
- In what ways has this illness affected you emotionally?
- Are you doing things that you enjoy?
- How has your mood been lately?
- How have you been coping with all of this?
- How have you handled stress in your life?
- Are you concerned about being a burden to others?
• Do you feel in control of your life right now?
• Have you thought about taking your child on one more trip before she dies?
• I think your child could manage a few half-days in school each week. Do you think that would help him?

**Decision making**

An aspect of assessment that follows naturally from a psychological assessment is that of decision-making capacity. It is fundamental for planning care. In order that decisions can be made with the patient’s, or parents’ if the patient is a young child, authentic understanding and agreement, it is important not only to follow the necessary steps for information giving (see Module 11: Withholding, Withdrawing Therapy), but also to be sure that the patient has the capacity to give meaningful consent.

**Capacity**

We can think of capacity in two ways—global and decision-specific.

Some patients are globally incompetent, ie, not competent in any area of functioning. They cannot handle their own affairs and must rely on others. Nor can they give meaningful consent to any particular health care decision. Under such circumstances, prior preferences, perhaps as expressed in advance care planning documents or conversations (see Module 1: Advance Care Planning), or expressed by proxies using substituted or best-interest judgments, must be considered.

However, among patients with advanced illness, it is quite common that the patient has some compromised mental function without being globally incompetent. Capacity may only be limited with respect to questions whose answers rely on careful analysis. Decisions based on firmly held beliefs may still be authentic. Consequently, it is generally helpful to include the patient as much as possible even when there is some mental compromise.

A patient who does not know where he or she is, and who can no longer manage his or her own affairs, may nonetheless have deep and meaningful insight into whether or not an amputation, intubation, or some other major medical intervention is acceptable. To afford that individual the full patient role in informed consent, the physician needs to determine whether the patient can:

• understand that he or she is authorizing the decision
• demonstrate that he or she is making accurate and rational inferences with the information given
• demonstrate insight into the consequences of the decision
• be free of coercive influences
For instance, if the patient has a near certain progression to sepsis and death in the absence of amputation, capacity to decide must be in doubt if the patient says that amputation is unnecessary for survival. In like fashion, if the patient agrees with the amputation but seems to think this is someone else’s operation or that the decision is not his or hers to make, capacity must be in doubt. If, on the other hand, the patient holds the view that death is better than amputation at this stage, a decision not to operate might be understood to reflect rational use of the information. If a patient is declining life-prolonging intervention in circumstances that include a strong sense of family burden or professional abandonment, such a decision may be unduly influenced by others’ agendas and should be carefully revisited in order to reduce and separate out conflicting interests from those of the patient.

If capacity is absent for the decision at hand, involve the proxy and share the decision making in the usual fashion, with the proxy speaking in the patient’s role.

**Goals of care**

Whether you are working directly with the patient or with the patient’s surrogate, assess what are the goals for care. If a patient has made the transition away from hope of cure to a focus on quality of life, it is important to relate goals of care to matters of personal meaning. Ask the patient what he or she thinks are the most important things to accomplish now. A range of possible goals should be explored, from aggressive comfort care to prolonging life until a certain meaningful event (see Module 7: Goals of Care).

**Advance care planning**

A small step from assessing goals for care is planning ahead for future care. Depending on the stamina of the patient and his or her expectations, this assessment may be left for a subsequent visit. Wherever possible, however, start the discussion at the initial assessment. Pick a couple of likely scenarios, given the patient’s current illness, and ask what would be the goals for care in such a circumstance. Then ask about a few key treatment decisions. Offer a worksheet or document to help talk through the issues and to record the preferences for future care (see Module 1: Advance Care Planning).

**Communication assessment**

Whether a person is a “talker” or a “silent type,” communication happens and it matters. Most people do better if there is someone to share difficulties with. It is useful to identify who this person is for the patient. It may be family, but it may not. One of the most challenging aspects of end-of-life care is when the patient is alone. Then, the physician and members of the health care team become critical components of support.

Accurate information generally leads to the best outcomes. Misunderstandings over information are usually problematic. As part of routine interaction with the patient, ask if
the patient understands what is being said and if he or she has answers to all his or her medical questions.

There are different personal and family styles of information sharing. Ask the patient whether he or she wants a lot of information or not so much. Ask how he or she wants to involve family and friends in information about the illness.

Be particularly attuned for difficulties if the patient is keeping his or her diagnosis a secret, or if the family is doing the same in reverse. In such cases, it can be helpful to ask the informed party if you can check with the uninformed party to see how much information they would like to have. Sometimes it helps to organize a family meeting where the physician can help “tell” the information and ensure that all hear the same information at the same time. Social workers can be particularly helpful in this regard. This is the only aspect of confidentiality that is quite often different from other aspects of patient care (see Plenary II: Legal Issues).

If language is a barrier, try to find a professional translator (see Module 2: Communicating Bad News).

**Social assessment**

Illness impacts the social aspects of life. Conversely, social circumstances impact illness. The discipline of social work should be appropriately integrated into the treatment team to assist the patient, family, and physician. However, outside of hospice and a few other programs, patients with serious illness do not receive comprehensive social assessment by a qualified social worker as a routine part of medical care. Therefore, while the physician cannot perform the work of a social worker, the physician should be able to make an initial assessment of the patient’s social needs. The following areas of a person’s social environment are relevant to the evaluation of suffering in the social dimension: caregivers for the patient, domestic needs of the patient, community support available to the patient, and financial resources available to the patient. The need for practical support, which may be an important element of the physical assessment, is also addressed here.

**Community**

Some cultures have a more positive attitude toward care of the dying than others, but in general in the United States, there is little care offered routinely to the dying.

A tiny percentage of life-threateningly ill patients get practical assistance from their community. However, services may be available and should be sought wherever possible. Again, social workers may know much more than the physician about a community’s resources. Many religious communities from all denominations not only have a tradition of care, but also have service systems. There are disease-based advocacy groups that offer practical advice in some cases. Other local resources such as library reading services, may also be available. In particular, physicians who take the trouble to contact, or ask a
member of the team to contact, possible sources of support from the worksite, school, or
neighborhood communities may find that there is a network of care that springs up.

**Financial**

About 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. The result may be significant economic
hardship.

Patients often receive medical bills that they do not understand and cannot pay. Some
may be reimbursed slowly, but patients who have prided themselves in keeping up with
the bills may feel shame.

A major source of shame and even desire to hasten death stems from the financial burden
on family members. The desire to leave a financial legacy is strong. Savings for the
grandchildren or for education may be spent on medical care, much to the misery of the
family and the patient. Ask about this aspect.

**Spiritual assessment**

Each person has a spiritual or transcendent dimension to his or her life. Physicians often
hesitate to inquire into this universal dimension of human experience, yet studies suggest
patients welcome the inquiry. Spiritual life is understood by some in terms of religious
feeling, and by others in terms of personal meaning in a larger context. We mean here to
cover either interpretation of the term. Find the interpretation most fitting to the patient;
but in either case there is no need to emphasize a mysterious aspect to this part of a per-
son’s experience. It is a universal and important part of each individual’s life.

Individuals who report a strong spiritual life sometimes report a greater sense of purpose
and a greater sense of having come to terms with dying than others, as well as better
communication and relationships. The physician should bear in mind the possibility that
patients can experience significant spiritual growth and gain meaningful fulfillment
during their last stage of life. The physician should know how spiritual this patient has
tended to be in the past, how inclined toward spiritual life he or she now is, whether or
not he or she would like, or has, a pastor to visit, and whether there are religious rituals
that are important.
Meaning of illness

Patients facing a life-threatening illness are often thinking about questions that they do not articulate easily or freely. It often requires someone, such as the physician, to give permission. Questions such as:

- What will happen to me?
- How will the illness proceed?
- What will happen to my child?

are nearly universally experienced. Patients frequently will be thinking about death and dying, with questions such as:

- How will I die?
- Where will I die (home, nursing home, ICU, hospice etc)?
- What do I need to do (estate planning, life review, advance care planning etc)?
- How will my child die? Where will my child die?

The physician may give permission for people to talk about these things by introducing the subject in a general way by saying:

- Many people in your situation think about dying. Is that something you are thinking about?

As patients face these questions, they also have to adjust to major changes and losses. In their personal world, they will likely be thinking:

- Who will care for the people I love who depend on me?
- Who will care for me?
- Will I be a burden?
- Will they still love/respect me?
- What about my job?

Parents of a dying child will be thinking:

- How can I go on without my child?
- How can I let my child die?

Another major issue tends to be loss of control. Plans are trumped by the illness. Independent people who have never considered being otherwise now face dependence. People face, or fear, loss of control in multiple spheres. Loss of body control, including the ability to feed, bathe, and toilet oneself, is certainly a frequent concern. These losses of control are associated in many people’s mind with indignity and shame.
**Spiritual activities**

While it is helpful to know the religion and religious denomination a person affiliates with, the degree to which religion is important must be evaluated separately. Ask how often the patient has gone to services in the past and whether he or she would like to do so now. Ask if there are particular prayers or scriptural resources that mean a lot to the patient that he or she may need help with. Some patients engage in spiritual activities that are outside of organized religion. The level of activity in these pursuits is also relevant.

Occasionally, physicians feel comfortable praying with a patient. Many patients would like their physician to do so. This is not a necessary part of the patient-physician relationship. However, it can be helpful if the physician is comfortable allowing the patient to express religious feeling. The physician should be sure that the best available resources have been made available to the patient for his or her spiritual care.

**Pastors**

Training in end-of-life care for pastors is not more developed than for physicians. That is to say, many pastors working in the community did not receive any specific training in end-of-life care. However, end-of-life care is a part of most religious groups’ framework. Some patients will do better with their own pastor from their existing community, as part of the treatment team. Chaplains working in health care institutions, however, may have much more training related to the spiritual care of people who are very ill. They may be able to assist the patient and his or her local pastor.

**Rituals**

Ask if the patient wants special prayers, declarations, rituals, or last actions. Someone should be sure that special prayers or actions and last prayers or declarations are carried out as the patient and family would like them to be.

**Spiritual crises**

Many aspects of advanced illness are not commonly appreciated to be fundamentally spiritual. Yet, the search for meaning and purpose in life is a spiritual quest. Likewise, the perceived loss of connection to a community or to a way of life may challenge the sense of meaning and purpose. Sometimes feelings of guilt or unworthiness may be manifestations of spiritual suffering. If they remain unrecognized, an appropriate plan for relief cannot be instituted.

Other aspects may be more conventionally noted to be spiritual. Patients may question their faith or express a desire for forgiveness and reconciliation. Many patients may feel abandoned by God.

There are some general guidelines for spiritual assessment: remember, it is a universal component of illness and affects quality of life in profound ways. The physician will fre-
quently want assistance in managing spiritual suffering, but may play a critical role in identifying it.

Suspect spiritual pain in a patient who is facing a life-threatening illness. Establish a conducive atmosphere and express interest in the area. Listen for broader meanings in patients’ descriptions of their situation and how they are feeling. Finally, be aware of the physician’s own beliefs and biases toward religion and the spiritual dimension.

Physicians might ask about spiritual pain and spiritual issues by using questions like these:

- 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?

**Practical assessment**

It is hard to overestimate the importance of practical help. Ask about who is available to help. Ask about domestic needs, including how the patient manages with chores of day-to-day living—cooking, cleaning, shopping, banking, and paying the bills.

**Caregiver**

Most patients have or need someone to be a primary caregiver from their family and circle of friends. This is true even in a health care institution. When at home, the responsibility can be a full-time and demanding task.

Studies show that most caregivers in the home are wives or daughters. In the case of dying children, caregivers are usually the parents. Consequently, widows and single people may be more isolated and may have to rely on paid or volunteer community help to meet their needs if they are to stay at home.

The relationship between the patient and the caregiver is important. Some patients, and some caregivers, find the relationship difficult and it can leave a lasting negative impact on them. Others do not want to have their families caring for them, no matter how loving or willing. Likewise, some family members are unwilling to care for an ill relative. To intervene positively, both the patient and the caregivers must be assessed.
Many find that even with a willing family caregiver at home, there are unmet needs. Ask how well the patient (or parent if the patient is a child) feels his or her needs are being met. There may be need for care on holidays or a need for supplementary help. There may be a need for respite care.

**Domestic needs**

As illness progresses, difficulty getting between the health care site and home is common. Ask about transportation needs. Difficulty obtaining food and/or cooking is also common. Keeping the lighting and heating paid for can be a challenge. It is reasonable to ask about such basic issues as food, heat, and light, and whether those needs are being met.

**Family**

Many people have family. That family may be composed of dependent children or elders. They may be infirm. Pets may be as important as other members of the family. When these people face dying, the family has to be cared for in a different way and often by a different person. Ask about family and what arrangements have been made.

**Anticipatory planning for death**

Patients and family members grieve over loss of function, and they grieve in anticipation of loss. Figuring out what grief is normal and what is complex or exaggerated and in need of intervention is an important part of assessment.

Planning ahead can be a very helpful coping mechanism for present and future losses. Patients can usually readily relate their hopes for life closure, gift giving, leaving a legacy. In the case of a dying child, parents can think about plans for honoring their child’s memory. The child may participate, depending on age. Plans for how to accommodate these needs are important. Ask if the patient has, or would like to make, plans for rites, rituals, funerals, memorial services, and even celebrations (see Module 1: Advance Care Planning, and Module 12: Last Hours of Living).

**Summary**

Patients’ experience of illness is multidimensional, and effective management strategies in end-of-life care require a comprehensive assessment of the whole patient. Essential elements of assessment include disease history, physical symptoms, psychological symptoms, decision-making capacity, information sharing, social, spiritual, practical, and anticipatory planning for death.
Key take-home points

1. End-of-life care must be based on a comprehensive assessment of the whole patient.
2. The assessment process can be a therapeutic tool.

Illness/treatment summary

3. Know whether previous treatments correspond to the treatments available and desired by the patient for his or her underlying illness(es).

Physical issues

Assess symptoms, function, safety, hydration, and nutritional status.

4. Physical symptoms may be related to the primary illness, current or past medical therapy, or another medical condition.
5. Psychological, social, and spiritual factors may play a strong role in the expression of physical symptoms.
6. Pain often serves as a natural point of entry into other aspects of assessment.
7. Patient self-report is the gold standard for assessment.
8. To understand pain requires an understanding of its location, quality, severity, modifying factors, impact on function, the effect of treatments, and the patient’s perspectives.
9. Include an assessment of function, safety, hydration, and nutrition.

Psychological issues

Assess emotion, cognition, mood, coping responses, fears, and unresolved issues.

10. There is always an emotional response to serious illness.
11. Always screen for anxiety, depression, and delirium. When necessary, conduct a more in-depth assessment using validated tools.
13. Almost all patients have fears about the future as they face the end of their lives. These may include fears of loss of control, loss of dignity, loss of relationships, being a burden, and physical suffering as they imagine the disintegration of their world and their ability to function.
14. Unresolved issues in personal matters, especially in relationships, are a prominent part of the experience of patients at the end of life.
Decision-making issues
Assess capacity, goals of care, advance care directives, and proxy decision makers.

15. Does the patient have capacity to give meaningful consent?
16. Differentiate between global incompetence and decision-specific capacity.
17. Know the criteria for decision-specific capacity.
18. Know the patient’s goals of care, advance care directives, and who the proxy decision maker is.

Communication, information sharing
Establish the process for information sharing and limits for confidentiality.

19. Know how much information the patient wants to know and how to best communicate that information.
20. Know how much information the patient would like to share, and with whom. Know the patient’s limits for confidentiality.

Social issues
Assess the environment, family and community resources, financial, and legal issues.

21. Everyone needs a safe and accessible environment in which to live, especially at the end of life.
22. Cultural attitudes toward death and care of the dying vary widely.
23. Life-threatening illness can lead to social isolation and abandonment.
24. Know the community groups that may be able to help.
25. About 30% of families spend a considerable portion, if not all, of their life savings caring for a loved one.
26. A similar percentage of families lose a major source of income due to the illness.
27. Being a real or perceived financial burden on others is a major source of shame and desire for hastened death.

Spiritual issues
Assess the meaning of illness, present spiritual/religious activities, desired prayers, rites, and rituals.

28. Each person has a spiritual or transcendent dimension to his or her life.
29. Our sense of meaning and value is the cornerstone to our desire to continue to live.
30. Illness will have different meaning for each patient and family.
31. Understand the role of religion in the person’s life and the resources his or her religious affiliations may bring.

32. Do not assume that the chaplaincy skills of a pastor encompass end-of-life care; be open to searching for the right pastor.

33. Know the prayers, rites, and rituals the patient and family wish to honor and carry out.

34. Spiritual crises may present in many different ways.

**Practical issues**

Assess caregiving, domestic needs, and care of dependents.

35. Know who the primary caregiver(s) will be, how skilled they are, and how comfortable the patient is with them in this role.

36. Unmet domestic needs may be a source of considerable patient distress.

37. Know how dependents will receive the ongoing care they need.

**Loss**

Assess the impact of anticipated and actual losses.

38. Patients and family members are likely to experience many different losses over the course of a life-threatening illness, and as a result of the patient’s death.

39. Grief and other emotional responses to loss vary widely, depending on the meaning and value placed on the loss, and the person’s ability to adapt to the resulting change.

**Anticipatory planning for death**

Assess the preparedness and planning for life closure and death.

40. Assess the patient’s and family’s stage in each of the tasks of life closure and how prepared each person is to engage in a continuing process to plan for death.

**Pearls**

1. Do not talk too much. Use silence to stimulate the patient to talk.

2. Pain is a model for the assessment of other symptoms.

3. Believe the patient.

4. Routinely assess severity by using a validated tool.

5. Most people also grieve in anticipation of loss.
Potential pitfalls

1. Tacitly agreeing to avoid subjects; patients often do not tell the physician everything.
2. Failing to reassure patients who fear that the truth will make the physician angry.
3. Avoiding the emotional responses.

Resources


Appendix

Appendix: reprinted documents

Brief Pain Inventory (Short Form), reprinted by permission of the Pain Research Group. Copyright 1997.

Memorial Symptom Assessment Scale, reprinted by permission of the Memorial Sloan Kettering Cancer Center, New York, New York, USA.