

EPEC™-O

Education In **P**alliative And **E**nd-Of-Life **C**are For **O**ncology

Self-Study Module 1:

Comprehensive Assessment

Module 1: Comprehensive Assessment

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Abstract

Comprehensive cancer care aims to treat both the underlying disease and the experience of living with cancer. Patients suffer as whole persons; they have relationships with others, a past, and an anticipated future. Suffering can be caused by the cancer itself and/or by treatment. Suffering can also be the result of predicaments imposed upon the patient and family by the disease process and therapy.

A **comprehensive assessment** is a critical step in providing quality cancer care and enables the health care team to address the patient's suffering while managing the underlying disease process. The initial comprehensive assessment identifies the fixed characteristics of the patient and any physical, psychological, social, spiritual, practical, end-of-life, or loss/grief issues that are a concern to the patient or family. The assessment interview(s) addresses issues of information sharing, decision -making, care planning, and delivery needs. In addition to monitoring changes in needs addressed in previous sessions, subsequent assessments must also include confirmation of the quality of care.

This very broad assessment is manageable if the functional inquiry starts with screening questions to highlight domains of issues. Then, based on the answers, the clinician can perform a more in-depth evaluation of specific areas of concern. While it may initially seem to be an overwhelming task, especially while attempting to keep within allotted visit schedules, a full evaluation can be completed over the course of several routine visits. Other members of the cancer care team can assist with multiple components of the detailed assessment.

Comprehensive assessments initiate the therapeutic relationship and recur throughout the course of the illness. The focus of the interview will shift as the needs of the patient change. Even a physician who is familiar with a patient should periodically conduct formal assessments of all domains of potential suffering from initial diagnosis until the end of the therapeutic relationship.

Introduction

Assessment, the process of evaluating a specific issue to gather data, is a core skill of all clinicians, particularly oncologists.

The patient's family includes those close in knowledge, care, and affection.

The public imagines that medical professionals study the issue of suffering in medical school (Ref. 1). Indeed, they expect us to be experts at the relief of suffering. The public

would be shocked to learn that this subject gets little attention in medical training, including the training of oncologists. **The goal of EPEC™-O is to provide the comprehensive cancer care team with the tools to integrate palliative care into the cancer (health) care plan.**

A comprehensive cancer assessment includes:

- Reviewing patient characteristics.
- Taking a complete disease and treatment history:
 - Reviewing the effect of medications
 - Noting any adverse events or allergies.
- Exploring the multiple issues that cause patients and families to suffer.
- Conducting a physical exam.
- Ordering laboratory and radiological investigations that are appropriate for the patient's situation and care goals.

The goal of comprehensive cancer care is to:

- Manage the underlying cancer and all of its associated comorbidities.
- Prevent and relieve suffering.
- Promote quality of living (and dying) for the patient and her/his family.

Using the information gathered in the comprehensive assessment, an individualized care plan is developed by the oncology team. The oncologist is the leader of the team and is responsible for the overall coordination and direction of the patient's care. It is important that he or she knows how to organize a comprehensive assessment into a framework to guide the evaluation of suffering and each step in the care process.

In a busy clinic, it is unlikely that an individual oncologist will perform complete comprehensive assessments. Other members of the cancer care team, including nurses, social workers, chaplains, and/or palliative care consultants, are the oncologist's partners in conducting important components of the detailed assessment.

Team members must collaborate, investing their efforts to integrate and coordinate the information collected by all for the benefit of the patient. Interdisciplinary team case conferences (e.g., tumor boards) provide an opportunity to:

- Synthesize data that have been collected into a cohesive whole.
- Discuss possible therapies.

When devising the plan of care, it is important to remember that the patient and family need to be involved in decision making and the plan should facilitate their participation.

A comprehensive assessment can be a therapeutic tool. Each assessment offers an opportunity for discussion with the patient and/or family about:

- The context of the patient's disease and prognosis.
- Issues that are causing suffering.
- The process of providing care.
- The need for advance planning and personal preparation, particularly when the oncologist anticipates that the patient will deteriorate in the not-too-distant future.

A careful functional inquiry coupled with active listening, during which the clinician reflects back his or her understanding of the conversation, can reassure the patient and family that they have been heard. Active listening minimizes the risk of misunderstanding between the patient and family and the care team. During the interview, team members have the opportunity to offer information, provide practical advice, and introduce sources of support. Paying attention to details and giving the patient and family an opportunity to be heard during a comprehensive assessment will give the patient and family a chance to build trust in the therapeutic relationship. When conducted in a sensitive, caring manner, the interview will convey the care provider's respect for the patient and family.

The subject of this module is the essential elements of assessment for each major dimension of the patient's experience with his or her illness and the health care system. Taking a complete disease and treatment history and conducting a full physical examination are essential parts of the comprehensive assessment. However, information about these skills is widely available elsewhere. This document, while respecting the importance of the medical history and physical exam, will focus on other factors necessary to provide patients with quality cancer care.

Module 1 - Video 1

Objectives

After studying this module, oncologists and other members of the cancer care team will be able to:

- Explain conceptions of suffering.

- Describe a framework to guide assessment of the multiple issues that frequently cause patients and families to suffer. This framework will be used to develop the patient's care plan.
- Use NEST, a validated screening tool, to facilitate an initial screening assessment.
- Carry out a detailed assessment of active issues.

Conceptions of Suffering

What does it mean to suffer? Each of us has a personal sense of what brings meaning and value to our lives. Causes of suffering are also personal. You cannot relieve your patient's suffering unless you understand his or her perception of its cause.

As medical professionals, each of us must have a conceptual framework within which to work, study, and teach if we are to achieve our goal of relieving suffering. The concept of context is familiar in the world of medicine, where we have developed a conceptual framework to investigate, understand, and intervene in each disease we seek to treat.

In an attempt to understand suffering in a way that would permit further study and understanding and inform clinical care, Cassell outlined a conceptual framework for suffering. (Ref. 1) He observed that "Bodies do not suffer; only persons do." Each person is unique and experiences his or her disease in an individual way. Persons suffer when their being, or personhood, is threatened; elements of what it means to be a person include having a past, a present, an anticipated future, a private life, a role, and a transcendent dimension.

Brody built on the concept that personhood requires a past, present, and future by noting that human lives are, in a sense, stories. (Ref. 2) Our story is our sense of self. As we face a diagnosis of cancer, our story takes an unexpected turn. If death occurs, our story ends and becomes our legacy. Often, when a patient comes to a physician, the emotional subtext of the patient's complaint can be understood as, "Doctor, my story is broken. Can you fix it?" Much of our patients' suffering can be understood in this context. The future will be different than expected, and the present is consumed with new physical concerns. The patient's private life is challenged by unanticipated and unwelcome transitions.

Suffering challenges meaning. Often cancer patients develop new sources of meaning while coping with changes in their expected life plan. (Ref. 3) Some find that the spiritual or transcendent dimension of their lives changes. Children who have cancer experience the same challenges in meaning. Parents and siblings suffer as they face the illness of the child and adjust to the idea of a previously unanticipated future for the family. It is helpful to consider what provides meaning and value in your own life and think about how the prospect of cancer might affect this list.

Although each person suffers in an individual way, the experience of illness and suffering is not unique. In listening to patients with advanced cancer describe their needs and expectations for care, Cicely Saunders, founder of the modern hospice movement, conceptualized suffering as having four elements. (Ref. 4) She termed it total pain and identified the elements as:

- Physical
- Psychological (emotional)
- Social (including practical)
- Spiritual

K.M. is a woman in her 50s with adenocarcinoma of unknown origin, initially found in her lung and excised as a primary, and then presenting in her axillary nodes and behaving more like breast cancer. She returns for a routine visit, after surgery and chemotherapy, with an apparent remission. A medical student greets her and asks to take a comprehensive assessment prior to the attending physician's arrival.

Module 1 - Video 2

The broad perspective

All of these conceptions view human existence from a broad perspective. Well-intentioned efforts that are too narrow in scope will be ineffective.

- While pursuing a "cure" of the cancer, the health care team may fail to support emotional well-being of the patient and family.
- Undue focus on a patient's social disconnection may distract a clinician from attending to physical needs.
- A focus on physical pain can divert the health care team from recognizing that the patient is depressed, or doesn't have sufficient money for the pain medication, or is afraid that the pain means that he or she is going to die.
- Failure to address the spiritual dimension in a patient who is spiritually distressed may exacerbate his or her perception of physical pain. A patient whose spiritual foundation remains strong in the face of serious illness is less likely to experience physical symptoms.
- A patient who feels abandoned by family, community, or medical professionals may express suffering by emphasizing a physical complaint, or by giving up hope.

Patients benefit when caregivers avoid a disproportionate focus on a single aspect of the patient's needs. Many factors influence the patient's experience of pain. To relieve

suffering and enhance quality of life for our patients, we use a comprehensive framework to ensure that we consider all of the dimensions of patients' needs.

Dimensions of Illness, Bereavement, and Cancer Care

Addressing the suffering of the patient and family is most effective when guided by a framework that is based on the patient's experience of his or her illness and experience with the health care delivery system, as well as the family's experience with bereavement. The framework has three categories. Each is a part of the process of providing care and associated outcomes: (Ref. 5)

- Fixed characteristics
- Modifiable dimensions
- Health care interventions

Similar frameworks have been developed independently by several investigators. Each has based their framework on empirical findings from patients' perspectives, suggesting that the overall construct is valid. (Ref. 6) (Ref. 7)

Fixed characteristics

Issues arise as patients and families progress through the process of facing cancer. Goals of care and expectations about how therapeutic relationships are handled differ depending on the patients' and families' background and life experiences. Age, gender, race, ethnicity, culture, religion, and socioeconomic class are all factors in differing goals and expectations. As the United States becomes more ethnically diverse, physicians are increasingly likely to encounter patients whose world views and health beliefs differ from their own. Failure of the health care team to recognize and respond to these differences can impede communication and harm the therapeutic relationship. If oncologists and cancer care teams are to provide care "in a manner that is respectful of the patient's and family's personal, cultural, and religious values, beliefs, and practices..." it will be important to know basic information about the patient and her or his family from the outset. (Ref. 8)

Culture

Culture is a societal group's learned, repetitive, characteristic way of behaving, feeling, thinking, and being. Culture is transmitted from one generation to another through language, role modeling, and child enculturation.

Since the way in which people perceive palliative care can be significantly influenced by their cultural values and beliefs, cultural competence among physicians is essential. (Ref. 9) Cultural competence is viewed as a continuum, and many professional

organizations have developed guidelines for cultural competency training and cross-cultural caregiving practice. (Ref. 10) One of the most widely used conceptual schema was first developed for mental health practice and has wide applicability. It focuses on an organization's overall cultural competence. (Ref. 11)

Organizations may be perceived as progressing from negligence to inclusion, as follows:

- **Cultural destructiveness** reflects behaviors that are harmful to certain cultural groups.
- **Cultural incapacity** occurs when there is not sufficient capacity to help members of diverse cultural groups.
- **Cultural blindness** assumes that what works for members of the dominant culture will work for everyone.
- **Cultural precompetence** recognizes that limitations exist and seeks improvement in working with diverse cultural groups.
- **Cultural competence** entails accepting and respecting cultural differences and assessing and seeking to expand the knowledge base to ensure an inclusive relationship centered on patients.
- **Cultural proficiency** entails promoting genuine cross-cultural initiatives in the relationship.

Resources for promoting cultural competence and proficiency are included in the Health Professional Resources section of this module.

Culture has been shown to be a strong determinant in attitudes toward health, illness, and dying. However, it is important to remember that people are individuals with attitudes arrayed along a continuum. Careful listening facilitates understanding. Remember that an individual's values must be understood in the context of a particular culture but not all members of a culture have identical beliefs and practices. Through respectful inquiry, oncologists and members of the cancer care team can learn about each patient's background and specific cultural issues.

It is a good practice to convey respect by conducting the interview using formal conversational norms. For example, our current custom in the United States of addressing people by first names is considered disrespectful in many cultures. Although we must ask our patients questions, if they are respectfully posed, they will rarely be offensive.

It is always best to use interpreters when language barriers exist; using family members is fraught with difficulty. An interpreter or translator may also be able to supply information about the relevant group's cultural context.

Cultural considerations are explored further in several modules. Information, truth telling, and involvement of translators are issues covered in EPEC™-O Module 7: Communicating Effectively and EPEC™-O Module 8: Clarifying Diagnosis and Prognosis. Maintaining reasonable hope is addressed in EPEC™-O Module 9: Negotiating Goals of Care.

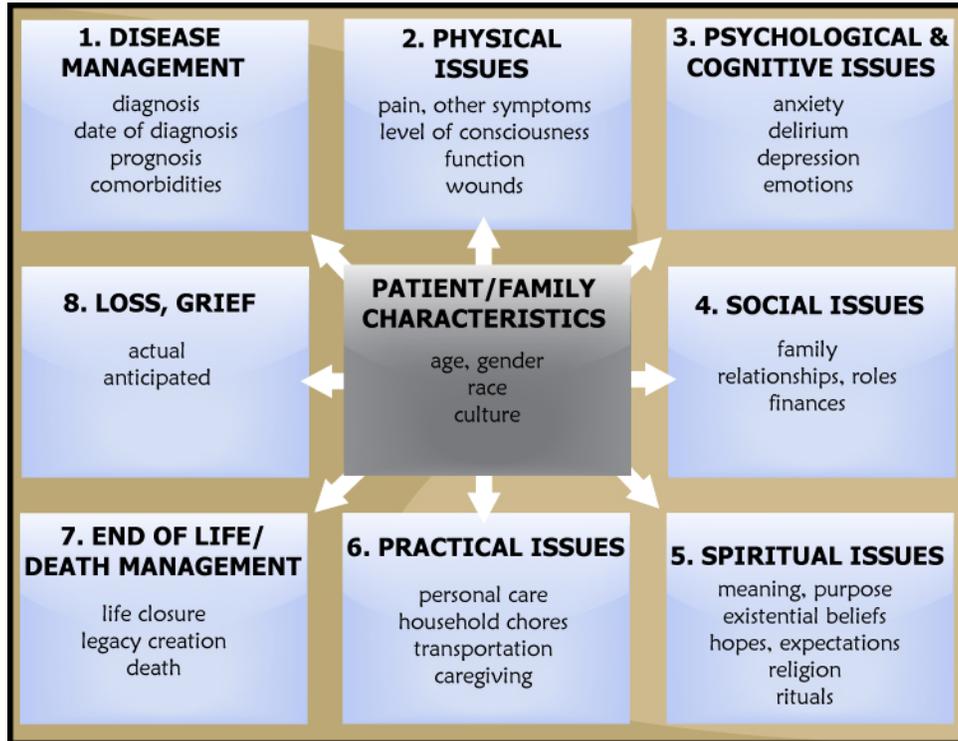
Modifiable dimensions

In addition to the cancer, there are often other aspects of a patient's experience of illness and bereavement that can be modified. The following issues can all be changed with time and effort, and if left untreated may have a negative impact on the modifiability of the patient's cancer:

- Physical symptoms
- Practical and caregiving needs
- Economic challenges
- Psychological issues and social relationships
- Spiritual and existential beliefs
- Hopes and expectations
- Preparedness for death and the grief that comes with real and anticipated losses

These issues have been divided into eight core domains that are used to guide a functional inquiry. (See Figure 1 for an overview and Appendix 1 for a more detailed listing of these issues.)

Figure 1: Domains of Issues During Illness and Bereavement

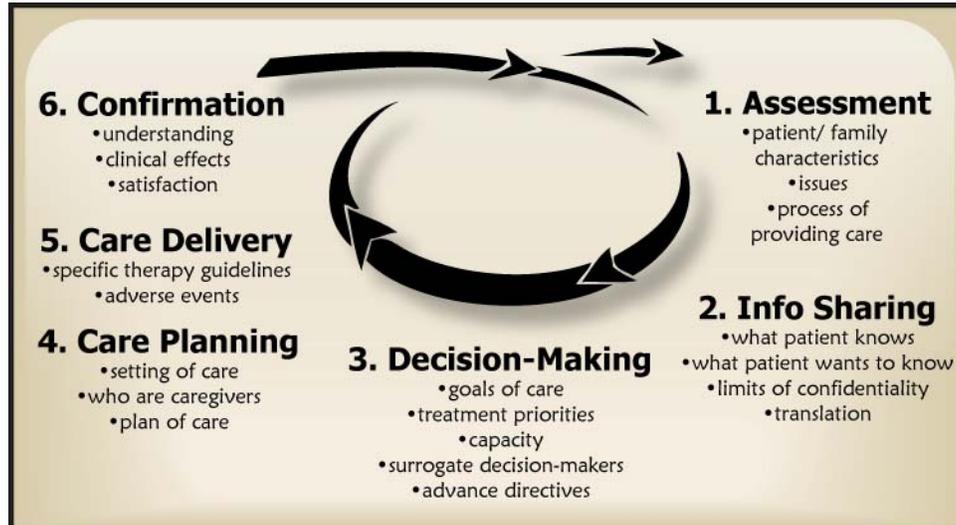


Module 1 - Video 3

Health system interventions

Technical interventions have been the main focus of much of cancer care. Viewed from the perspective of comprehensive cancer care, it is clear that the delivery of technical interventions is just one of six steps in the process of providing high-quality cancer care. (See Figure 2 for an overview and Appendix 2 for a more detailed listing of steps that can be used to guide a functional inquiry.)

Figure 2: Essential Steps in the Process of Providing Care



Efficient Assessment

The dimensions of illness, bereavement, and cancer care provide a simple but complete framework to guide assessment. Routine use of this framework will ensure that the oncologist and other members of the cancer care team do not overlook issues of concern to the patient and family.

During the initial portion of your first assessment of a new patient, find out some basic facts about the person and how to relate to her or him in a respectful fashion. This can be accomplished with a simple inquiry about how the patient would like to be addressed or greeted. For some, a first name is comfortable or even comforting, but for others it is disrespectful. In some cultures a handshake is affirming, in others touching the opposite gender is forbidden.

To make the assessment process more efficient, divide it into two phases—an initial screening to identify issues of concern followed by a detailed evaluation of all active issues.

Initial screening

During the initial screening, start by asking open-ended questions about the patient, including her or his overall health and understanding of the situation. Then ask a series of validated screening questions that assess each of the major dimensions of the issues that frequently cause suffering. One such validated screening tool is NEST. (Ref. 12) Others, such as RAI-PC, are also available. (Ref. 13)

Once a need is detected, more specific evaluation questions can follow. As demonstrated in the trigger tape, a whole-person assessment can be completed comfortably within the usual 15-minute office visit if the physician is practiced in its use.

Screening with NEST

NEST utilizes a series of questions selected for their sensitivity to detect needs that are of concern to the patient. These have been grouped into four dimensions to generate the mnemonic NEST:

- **N**Needs in the social domain
- **E**xistential matters
- **S**ymptom management needs
- **T**herapeutic relationship matters

For a deft approach to sensitive concerns, ask the NEST questions in reverse order. Start by orienting yourself to the patient's cultural context. Leave inquiry into financial matters to the end. Memorize the screening questions from each area. With practice, they will flow smoothly in a conversational manner.

Table 1: NEST screening questions

NEST groupings (reversed)	Screening questions	Domains
To inquire about Therapeutic relationships:	1. How much do you feel your doctors and nurses understand you and relate to you with respect?	Patient/family characteristics
	2. How clear is the information from the medical team about what to expect regarding your illness?	Information sharing
	3. How much do you feel that the medical care you are getting fits with your goals?	Decision-making
To inquire about Symptoms:	4. How much do you suffer from physical symptoms such as pain, shortness of breath, fatigue, bowel or urination problems?	Physical
	5. In your mind, how often do you feel confused or anxious or depressed?	Psychological
To inquire about Existential matters:	6. How much does religious belief or your spiritual life contribute to your sense of well-being?	Spiritual
	7. How much does this illness seem distressingly senseless and meaningless?	Spiritual
	8. Do you have some matters you would like to resolve with people close to you?	Spiritual
	9. Since your illness, how much do you live life with a special sense of purpose?	Spiritual
To inquire	10. How much trouble do you have getting access	Practical

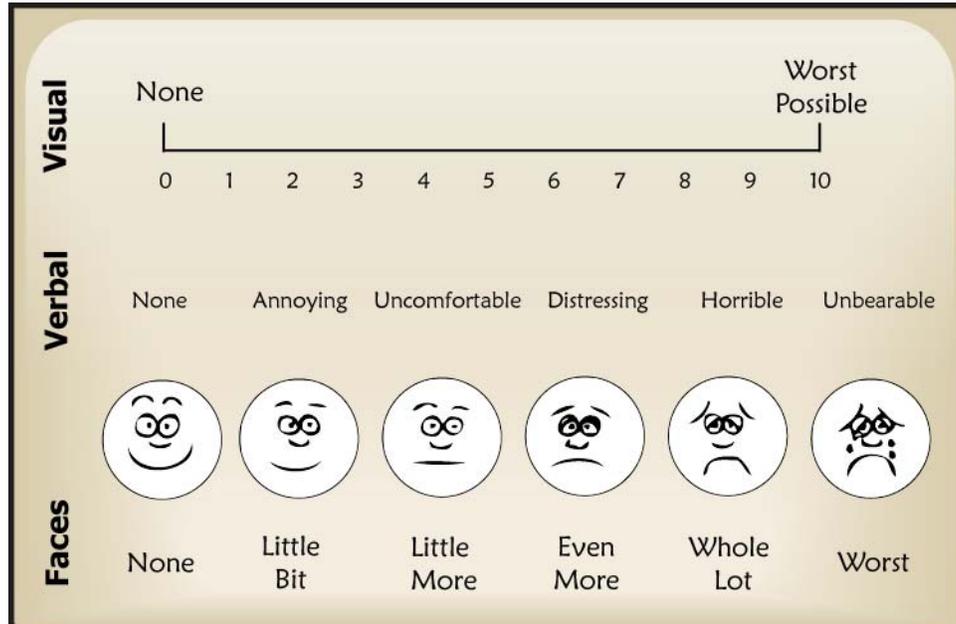
NEST groupings (reversed)	Screening questions	Domains
about social Needs:	to the medical care you need?	
	11. How much help do you need with caregiving—things like getting meals or getting to the doctor?	Practical
	12. How often is there someone to confide in or feel close to?	Social
	13. How much of a financial hardship is your illness for you or your family?	Social

Detailed assessment

If the response to any of these questions suggests that there is a concern, use more specific questions to explore the details. Depending on the extent, severity, urgency, and priority of needs, evaluation may proceed directly or be postponed for another visit.

Detailed strategies for assessing issues that patients and families living with cancer confront are included in numerous EPEC™-O modules. Issues that arise as a result of the care process are also integrated into the Modules. Whenever possible, use one of the scales shown in Figure 3 to quantify the severity of the symptom.

Figure 3: Severity Assessment Scales



The Faces scale is adapted from the Wong-Baker FACES Pain Rating Scale. (Ref. 14) Additional nonvalidated questions that may be useful to assess content areas not included in other EPEC™-O modules are included in Appendix 3.

If there seems to be no issue within a given dimension, that area can probably be considered free of need and not evaluated further.

As part of the detailed assessment, don't forget to ask about past experiences with medications, adverse events, and allergies.

Careful documentation of your findings is an important part of the functional inquiry.

Physical Examination and Tests

After your functional inquiry, conduct a physical examination. Depending on whether the encounter is for an initial comprehensive assessment or a focused evaluation, delay the physical exam until the full verbal portion of the comprehensive assessment has been completed. A physical examination not only adds to the history and provides baseline clinical information but also establishes a relationship that includes therapeutic touch.

Occasionally, laboratory and radiological investigations are helpful. Before ordering any tests, decide with the patient and family how the result will change the plan of care, or if the results will not influence the care plan. In a few instances, it will be valuable to know

if there is disease stability or progression even when no therapeutic intervention is planned.

Summary

Patients and families have a multidimensional experience of their illness and the process used to provide them with care. To effectively manage all of the issues that cause patients and families suffering, oncologists and other members of the cancer care team must first be able to identify these issues.

A framework to guide functional inquiry can be used to efficiently conduct a comprehensive assessment (see Figures 1 and Figure 2 and Appendix 1 and Appendix 2). To ascertain whether frequently occurring dimensions of the cancer experience are concerns, start by asking 13 screening questions from NEST. Then conduct a more comprehensive inquiry for each of the issues where concerns or needs are identified. Detailed assessment strategies, including sample questions to ask, findings to look for on physical examination, and possible laboratory and radiological investigations, are available in each of the EPEC™-O modules. Additional nonvalidated questions that may be helpful for topics not included elsewhere in EPEC™-O are in Appendix 3.

A whole-patient assessment sets the stage for the comprehensive cancer care team to address all of the patient's and family's sources of suffering. Use it periodically to screen for issues that require a detailed reassessment. Based on your findings and the patient's goals of care, revise the care plan appropriately.

By comparing serial assessments, members of the cancer care team will be able to determine the outcomes of their therapeutic interventions.

Key Take-Home Points

1. Patients' suffering has a context; consider patients and families together.
2. Bodies do not suffer; only persons do. Personhood means having a past, present, and future. Suffering is a challenge to meaning, and loss of meaning is a form of suffering.
3. Elements in the broad conceptualization of comprehensive cancer care can be thought of in three categories:
 - Fixed elements
 - Modifiable elements
 - Health care interventions and their associated outcomes

4. The greatest need in changing the system of care is timely application of knowledge that is already available.
5. Conceptual frameworks, approaches for investigating and understanding suffering, and approaches for interventions to relieve suffering have been neglected in the training of physicians.
6. Whenever possible, quantify the severity of an issue.
7. Minimize the burden of laboratory and radiological investigations; order tests only when the results will have a specific use.

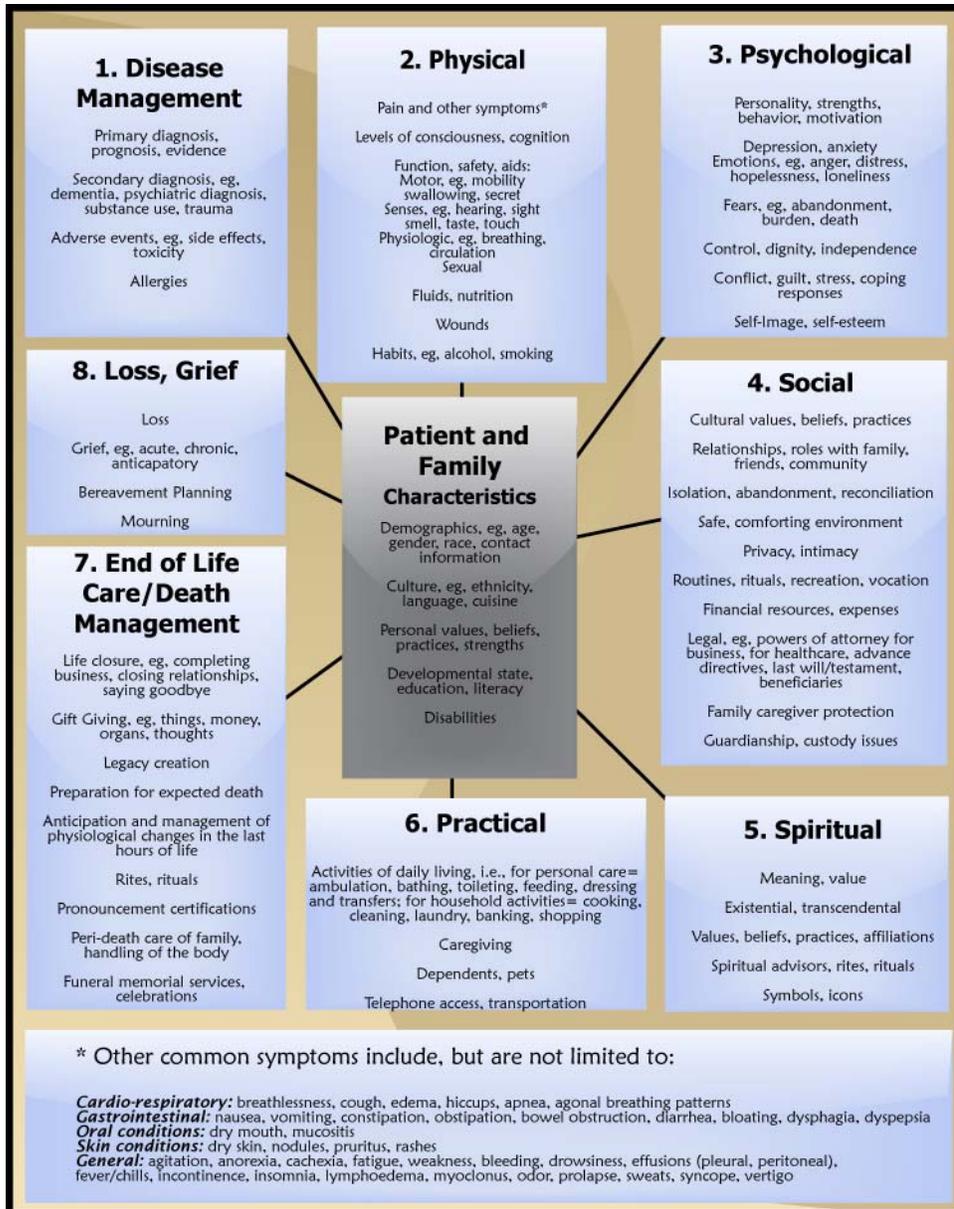
Pearls

1. Make a partnership with your patient and the family caregiver; draw them into the interdisciplinary team and foster their active participation in the plan of care.

Appendix 1: Domains and Issues of Illness and Bereavement

Patients and families face multiple issues during illness and bereavement that cause suffering. These issues can be grouped into eight domains. The most common issues are listed below.

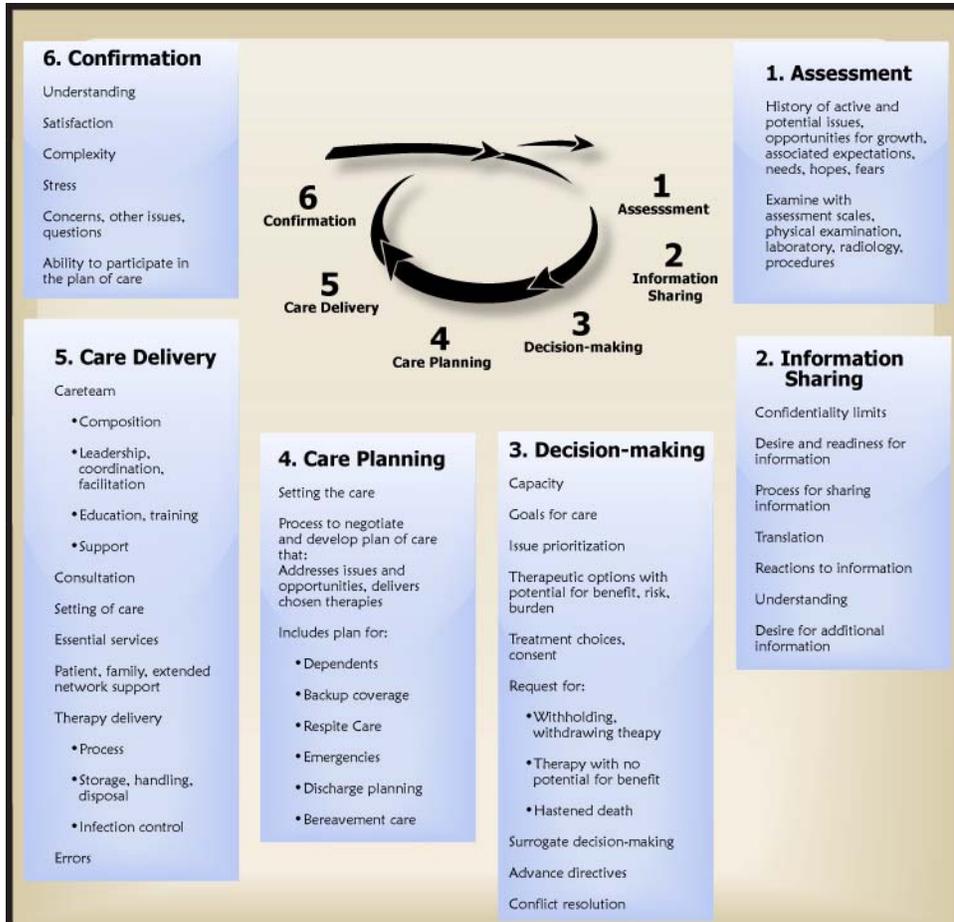
Figure 4: Domains and Issues of Illness and Bereavement



Appendix 2: Process of Providing Care

During each therapeutic encounter, the process for providing care involves six essential steps that guide the interaction between caregivers and the patient and family. While these steps do not need to occur in any specific order, each must be completed during each encounter. The most common steps are listed below.

Figure 5: Process of Providing Care



Appendix 3: Additional Detailed Assessment Questions

In addition to the detailed assessments included in each of the modules of EPEC™-O, cancer care teams may find the following nonvalidated questions useful during a detailed assessment.

Physical issues

Assess both motor and sensory functions.

- What is the patient's performance status?
- Can the patient move around?
- Can the patient see or hear well enough?
- Is he or she safe?
- How are the physical aspects of relationships, including sexual function?

Psychological issues

- How is the patient responding to the fact of being ill?

Consider naming some common responses, such as anger, grief, instability, and tranquility.

Social issues

Ask about family and what arrangements have been made to accommodate changes necessitated or caused by the cancer.

Spiritual issues

Individual form of spirituality

How does the patient's spirituality offer a sense of well-being and coping resources to him or her?

- "When you are looking for spiritual comfort, what do you do?"

If the patient seems hesitant, you can add:

- "Some people listen to music; others pray or do something else. What helps you?"

To find out if there is a community component to the patient's spiritual life, simply ask:

- "Do you have a community with which you share your spiritual side?" Or "What role does religion play in your life?"

Existential distress

To what extent does the cancer seem senseless and meaningless? Does the patient accept his or her diagnosis, prognosis, and the impact of that on personally important relationships? Be alert to the possibility of a spiritual crisis.

To gain insight into a patient's spiritual orientation, a preamble can be helpful: "This illness seems to be especially distressing now." Then go on to ask a direct question such as:

- "Do you sometimes feel abandoned or judged?"
- "How do you understand the meaning of your illness?"
- "How much distress is it causing?"
- "Is it impacting any of your important relationships?"

Purpose

Does the patient have a sense of purpose in life that is fitting with his or her prognosis and limitations imposed by the illness?

- "How have you made sense of what is happening to you?"
- "Do you feel that you have a sense of purpose in life that you can pursue, even with [having had] cancer?"

A key question, whether for survivors or the terminally ill, may be:

- "Do you feel settled in regards to your diagnosis and prognosis?"

Unresolved issues

- "Is there something that you would like to do before you get too sick?"
- "As you look back, what has given your life the most meaning?"

For those who are aware they have a poor prognosis, examples might be:

- "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 a family vacation while you are still able?"
- "If you were to die suddenly, are there important things you feel would be left undone?"

What helps?

- "Do you have a community that can help?"
- "Would it be helpful to bring in a team member with a suitable pastoral counseling background?"

Practical issues

Ask about the patient's ability to complete his or her activities that support daily living.

- "Are you able to complete all your own ambulating, bathing, toileting, feeding, dressing, and transfers?"
- "Are you able to complete all your own cooking, cleaning, laundry, banking, and shopping?"
- "Do you have any need for assistance with transportation?"

Loss, grief

- "How well do you feel you have adjusted to this [illness/loss/prospect]?"

Information sharing

- "How do you want to handle important health information?"
- "What will allow for clear understanding and the best decisions?"

Decision making

- "What are the goals for your care that brought you here today?"
- "What are the things you most want to accomplish?"

Appendix 4: Reprinted Documents

Brief Pain Inventory (Short Form), reprinted by permission of the Pain Research Group. Copyright 1997. Available at <http://www.mdanderson.org/pdf/bpisf.pdf>. Accessed April 11, 2005.

Memorial Symptom Assessment Scale, reprinted by permission of the Memorial Sloan Kettering Cancer Center, New York, NY, USA. Available at <http://www.mywhatever.com/cifwriter/content/41/pe1262.html>. Accessed April 11, 2005.

Edmonton Symptom Assessment System (ESAS). Available at <http://www.palliative.org/PC/ClinicalInfo/AssessmentTools/AssessmentToolsIDX.html>. Accessed April 11, 2005.

References

Module 1: Comprehensive Assessment

- 1 Cassel EJ. The nature of suffering and the goals of medicine. *N Engl J Med.* 1982;306:639-645. PMID: 7057823.

The question of suffering and its relation to organic illness has rarely been addressed in the medical literature. This article offers a description of the nature and causes of suffering in patients undergoing medical treatment. A distinction based on clinical observations is made between suffering and physical distress. Suffering is experienced by persons, not merely by bodies, and has its source in challenges that threaten the intactness of the person as a complex social and psychological entity. Suffering can include but is by no means limited to physical pain. The relief of suffering and the cure of disease must be seen as twin obligations of a medical profession that is truly dedicated to the care of the sick. Physicians' failure to understand the nature of suffering can result in medical intervention that (though technically adequate) not only fails to relieve suffering but becomes a source of suffering itself.

- 2 Brody H. *Stories of Sickness.* New York, NY: Yale University Press; 1987.
- 3 Byock I. The nature of suffering and the nature of opportunity and the end-of-life. *Clin Geriatr Med.* 1996;12:237-252. PMID: 8799345.

Encountering a patient who is suffering in the midst of terminal illness is an all-too-common occurrence for clinicians who care for the elderly. This article explores the personal experience of suffering in the context of life-limiting illness. The concept of personhood is used to illuminate the nature of suffering. Clinical observation documents that some persons experience a subjectively heightened sense of well-being as they die. The concept of personhood and the model of lifelong human development are applied to the explanation of this apparent paradox, enabling an understanding of the nature of opportunity at the end-of-life.

- 4 Saunders C. Terminal patient care. *Geriatrics.* 1966;21:70-74.
- 5 Emanuel EJ, Emanuel LL. The promise of a good death. *Lancet.* 1998;351(Suppl II):21-29.
- 6 Singer P, et al. Quality end-of-life care: Patients' perspectives. *JAMA.* 1999;281(2):163-168.

- 7 Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end-of-life by patients, family, physicians, and other care providers. *JAMA*. 2000; 284:2476.
- 8 von Gunten CF, Ferris FD, Portenoy RK, Glajchen M, eds. *CAPC Manual: How to Establish a Palliative Care Program*. New York: Center to Advance Palliative Care; 2001. Available at <http://www.cpsonline.info/capcmanual/content/elements/values.html>. Accessed March 28, 2005.
- 9 Kagawa-Singer M. Cultural diversity in death and dying. *Gerontol Geriatr Educ*. 1994;15:103-108.
- 10 Kagawa-Singer M, Blackhall LJ. Negotiating cross-cultural issues at the end-of-life: "You got to go where he lives." *JAMA*. 2001;286:2993-3001; full text.

Studies have shown cultural differences in attitudes toward truth telling, life-prolonging technology, and decision-making styles at the end-of-life. Skilled use of cross-cultural understanding and communication techniques increases the likelihood that both the process and outcomes of care are satisfactory for all involved.

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Self-Assessment

Module 1: Comprehensive Assessment

1. Mr. Bennett is a 43-year-old man status post resection of a kidney for hypernephroma that extended through Gerota's fascia. He has a postoperative pain syndrome that suggests the formation of a neuroma with neuropathic pain. Although he is an airline pilot, he has been unable to work for the past year. He might be expected to be suffering in which sphere?

- a). emotional
 - b). practical
 - c). spiritual
 - d). all of the above
 - e). none of the above
-

2. Mr. Wright is seen in the office for follow-up of his Stage IIIA nonsmall-cell lung cancer and diabetes mellitus. During the interview, which comment most suggests psychological distress?

- a). "My leg hurts right here."
 - b). "I'm so worried about my wife."
 - c). "I don't know how I'll get to my appointment."
 - d). "Why did I get this disease?"
-

3. Mrs. DeGuilio is an 84-year-old woman with neuropathic pain affecting hands, feet, and knees after combination chemotherapy for Stage III ovarian cancer. Today she notes increased swelling and pain in her knees. An important question in pain assessment is:

- a). Have you noticed a fever?
 - b). How does it affect your life?
 - c). Have you lost weight?
 - d). How are you feeling overall?
-

4. Mrs. Patton is a 54-year-old woman with advanced myelodysplastic syndrome and is bedbound with increasing fatigue. What question by Mrs. Patton most suggests spiritual suffering?
- a). "Why is this happening to me?"
 - b). "How will I pay for my care?"
 - c). "What is likely to happen next?"
 - d). "Will I suffocate?"
-

Self-Assessment Answers

Question 1. The correct answer is: d)

This question is aimed at understanding the conceptual framework for suffering. He is likely to be suffering not just in the physical sphere (pain), but in emotional, social (practical), and spiritual spheres.

Question 2. The correct answer is: b)

This question is aimed at understanding the meaning of patients' questions in the context of assessing suffering. Worry falls in the psychological distress dimension. Although there is overlap, the other possible answers are focused on the physical (pain), practical (transportation), and spiritual (questions beginning with "Why").

Question 3. The correct answer is: b)

This question is concerned with pain assessment. The effect of pain on a patient's life is an important component. The other questions may be part of the overall assessment of the patient, but don't relate to the pain assessment.

Question 4. The correct answer is: a)

Assessing spiritual suffering is important. Questions that begin with "Why" are often related to the spiritual dimension. They need to be recognized for what they are—simple answers or biologically based answers (e.g., your muscles are weak) will miss the mark. The other possible answers relate to social (financial and practical) and physical (prognosis and symptom management) issues.