

EPEEC

Education for Physicians on End-of-life Care

Participant's Handbook

Plenary 3

Elements and Models of End- of-life Care

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Abstract

The public expects the relief of human suffering to be a significant goal of the medical profession. Suffering can be conceptualized as a fragmentation of personhood, as a disturbed life story, as an opportunity, or as total pain. Patients don't suffer in isolation; patients and families must be considered together. Suffering is best relieved by using a team to approach the many elements involved in end-of-life care. The health care system that acknowledges those characteristics of the individual patient/family that cannot be changed and intervenes to influence those characteristics that can be changed will be able to deliver the best possible outcome. The phrase *palliative care* defines a model for the relief of suffering and the improvement of quality of life across the spectrum of illness. Hospice is currently the most widely available program for the delivery of palliative care at the end of life.

Key words

communities, continuum of care, culture, economic burdens, ethnicity, family and friends, fixed elements, framework, health care systems, hopes, hospice, institutional change, meaning, modifiable elements, outcomes, palliative care, personhood, physical symptoms, psychological, race, social, socioeconomic status, spiritual, standards, story, suffering, total pain

Objectives

The objectives of this plenary are to:

- describe conceptions of suffering
- describe the elements of end-of-life care
- define palliative care
- describe hospice and palliative care program standards

Introduction

Experiences toward the end of life are so closely associated in peoples' minds with suffering that it is hard to use one term without assuming the meaning of both. The aim of quality end-of-life care is, however, to avoid needless suffering in order to permit experiences that will have positive meaning. For this to happen, it is necessary for everyone involved to understand something about suffering, other elements of experience when facing the end of life, the types of intervention that can be helpful, and the resources and teamwork it takes to make these interventions available.

As Eric Cassell has written so persuasively, the public imagines that we as a medical profession study the issue of suffering in medical school. Indeed, they expect us to be

experts at the relief of suffering. As he pointed out in a remarkable paper published in 1982, the public would be shocked to learn that this subject doesn't get much attention in medical training. Conceptual frameworks, approaches for investigating and understanding suffering, and approaches for intervention to relieve suffering have been neglected in the training of physicians.

Organizing these concepts of suffering, connecting them with a framework for understanding the elements involved in end-of-life care, and with models for palliative care delivery systems, all in one coherent whole, is the task of this plenary session.

Conceptions of suffering

What does it mean to suffer? As a medical profession, and as part of a health care system, we must have a conceptual framework within which to work, study, and teach if we are to have a hope of relieving suffering. This is similar to other aspects of medicine—for each disease, each condition for which human beings seek assistance from the health care professions, there is a conceptual framework to investigate, understand, and intervene.

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. He pointed out that “bodies do not suffer, only persons do.” Persons are unique and do not experience a disease in the same way. Persons suffer when their 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 has built on the concept that personhood requires a past, present, and future by noting that human lives are, in a sense, stories. Our story is our sense of self, and as we face dying, our story comes to closure. In so doing our story transforms into our legacy. So often, when the patient comes to a physician, the emotional subtext of the patient's complaint can be heard as, “Doctor, my story is broken. Can you fix it?” Much suffering by patients facing the end of life can be understood in this perspective. The future looks different from before, and the present is consumed with new physical degeneration. The patient's private life is challenged by many new transitions, as is his or her usual role. The transcendent dimension may take on a new meaning.

Suffering is a challenge to meaning. Facing the end of life may challenge our usual sources of meaning. Loss of meaning is a form of suffering. Meaning usually must be found in new ways when death approaches. As you consider what you would list as the things that give you the most meaning and value in your life, think about how the prospect of disease might affect those. Byock has described the nature of opportunity brought by suffering and facing the end of life.

These same aspects apply to a child who is dying. In addition to the suffering of the child who is seriously ill, the parents and siblings suffer as they face the loss of this child, and their shared sense of the future.

However, the experience of illness and suffering is not unique to each individual. In listening to patients with advanced illness describe their needs and expectations for care, Cicely Saunders, founder of the modern hospice movement, conceptualized suffering as having 4 elements. She termed it “total pain” and identified the elements of physical, psychological (emotional), social (including practical), and spiritual pain. As you reflect on the things that you value most, and those that would be most important to you in the face of a life-threatening illness, most of them probably fit into these 4 categories.

The broad perspective

All of these conceptions have 1 thing in common; they take a very broad perspective from which to view human existence. As health care providers, it is important that we have a comprehensive framework from which to work if we are to relieve suffering and enhance quality of life. Well-intentioned efforts that are too narrow in scope will miss the target. A narrow focus on physical pain can miss the patient who is depressed, or doesn't have the money for the pain medicines, or is afraid that the pain means that she is going to die. Yet, all of these aspects of human experience will influence the experience of pain. Similarly, a patient whose spiritual foundation is not challenged is less likely to complain about physical symptoms, while failure to address the spiritual dimension in a patient who is spiritually distressed may distort the physical dimension. As another example, a patient who feels abandoned by family, community, or medical professionals may express his or her suffering by emphasizing a physical complaint, or by giving up hope. While each aspect of human existence is an integral part of who we are, undue focus on any one aspect may be detrimental (eg, undue focus on a patient's social disconnection may distract a clinician from attending to physical needs).

Based on the conceptions of suffering discussed above and a commitment to the broad perspective of human existence, this plenary will consider the elements of the health care system that may be able to relieve suffering and enhance quality of life.

Elements of end-of-life experience

Elements in the broad conceptualization of end-of-life experience can be thought of in 4 categories: fixed elements, modifiable elements, interventions, and outcomes. Some of what the patient brings with himself or herself cannot change; in fact it would not be desirable to change some aspects. Knowing and accommodating these fixed characteristics, the clinician may then focus on a person's modifiable dimensions. Then the task is to identify the patient's expectations and needs, and deliver the appropriate care interventions, whether directly by the clinician or through other aspects of the system. Together these elements of need and care combine to determine the overall experience of the dying process—the outcomes by which the health care system and society must measure our performance.

Fixed characteristics of the patient

The most prominent fixed characteristic of a patient facing the end of life is his or her disease and its prognosis. Other fixed features have to do with the patient's background. Issues that arise as a person faces the end of his or her life, or as people face the loss of a loved one, are handled differently by people depending on their background and experience of life, ie, race, ethnicity, culture, religion, socioeconomic class, etc.

Some physicians may have competence in the care of patients with particular cultural backgrounds. Others may not. In any case, the individual patient's background must be learned. Through respectful inquiry, the physician can quickly learn about the patient's specific cultural issues.

Race

An individual's background can be broadly categorized into differences of race, ethnicity and culture, religion, and socioeconomic class. There are many ways in which these differences combine—race may not track culture, culture may not track religion, socioeconomic class may not track ethnicity, and so forth. Nonetheless, the categories provide a framework from which to work through the issues for an individual patient.

As examples, several studies have demonstrated race-related differences in preferences for life-prolonging intervention toward the end of life. Commentators have raised the possibility of mistrust across racial difference. In conducting advance care planning discussions or establishing goals for care, sensitivity to the possibility of mistrust may be helpful.

Ethnicity and culture

The impact of illness is handled differently in different ethnic and cultural groups. Culture has been shown to be a strong determinant in attitudes toward end-of-life decisions and care. A good deal of useful information is available on various cultural attitudes toward health, illness, and dying. However, it is important to remember that people are individuals and the best way to understand another person's culture is to listen carefully to his or her values and beliefs. Open, balanced communication is what is required to negotiate cultural differences.

Respect can be conveyed by erring on the formal side of normal interactions, at least to begin with. It is important to remember that our current-day norms in the US of informality are in the minority among cultural approaches. If questions 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. If there is a translator, you can also learn from him or her if someone is available and knowledgeable in the relevant group's context for living.

Further considerations are treated in various modules, including issues of information and truth telling, maintaining reasonable hope (see Module 7: Goals of Care), and involvement of translators (see Module 2: Communicating Bad News).

Modifiable dimensions

While the patient comes to the physician with an unchangeable diagnosis and a background that is set, there are often aspects of a patient's experience that are more modifiable than may be apparent initially. Physical symptoms, psychological and cognitive symptoms, social relationships and support, economic demands and caregiving needs, hopes and expectations, and spiritual, cultural, and existential beliefs can all change with time and effort.

Pain and other physical discomfort

Patients may experience many physical symptoms as a result of their serious and life-threatening illness. Pain, although exceedingly important, is not the only one. Fatigue, drowsiness, insomnia, dyspnea, anorexia, and nausea are but a few of the common symptoms suffered by patients. For pain, and most of these symptoms, there are validated assessment tools and effective treatments.

While research is still necessary to improve our ability to manage symptoms effectively, the biggest need is timely application of knowledge that is already available. Clinician assessment of a full range of possible symptoms, use of assessment tools, appropriate interventions, and outcome measures are now incumbent on the medical profession.

Psychological and cognitive symptoms

Depression is widely underrecognized and undertreated in the general patient population and is an especially important problem in the dying patient. Too many clinicians rationalize helplessness and hopelessness in their patients with the thought that it is natural to be depressed when dying. On the contrary, depression is a frequently treatable complication of life-threatening illness. Feeling miserable is not an inevitable part of dying.

Clinicians should be vigilant and skilled in its treatment. Anxiety is another common form of emotional suffering. It is capable of exacerbating other forms of suffering and it is also treatable. Confusion, whether due to the illness or to treatment side effect, is also common and can range from minor degrees of disorientation to major and distressing hallucination. Mental suffering is as vexing as physical suffering. For some patients it is perhaps more so. Its recognition by the physician, assessment, and treatment are an integral part of end-of-life care.

Social relationships and support

Social relationships are usually challenged and changed by illness. A person's ability to stay in his or her job or go to school, to fulfill his or her prior role in the family, to keep

up friendships, and to be active in the community are all undermined. Social attitudes to illness may isolate a person, and the burdens of care may lead to stresses in intimate relationships. Fear as well as anticipatory bereavement can occur in both the patient and those around the patient, and can cause changes in the orientation of relationships. All these challenges arrive at a time when the patient and family need extra support. Effective social support will be much more likely with some professional assistance. The discipline of social work is that group of health care professionals who have gained experience in the study of family and social relationships and understand how to assess and intervene. Use them as colleagues in the service of the relief of social suffering. It is a sad situation that, in too many places, social work as a discipline has diminished to be little more than discharge planning and insurance verification. While there are many forces at work, one of them is the silence of physicians, in part because they have not learned the framework of care in which social work plays such an important part in the relief of human suffering. Insist on good social work where you work.

The discipline of Child Life is that group of health care professionals who are educated and trained in communication with children at a level appropriate for that child's developmental stage. They are able to help identify a child's fears and desires, and what they do and do not understand about their illness, or the illness of their loved one. Many health care systems and physicians do not have a good working knowledge of the contribution that child life specialists can make in communicating with and helping dying children, as well as the child siblings of a dying child. Insist on child life staff in the program where you work.

Economic demands and caregiving needs

The personal and economic burdens associated with a life-threatening illness can be enormous. About one third of families report a significant loss of income and savings when there is a member of the family who is sick. Usually the wife or mother or daughter of the patient provides the care. Many people have to leave their paid work to do so. Women and single people have to pay for help more often than others. Financial losses are also incurred by insufficient insurance coverage or delayed reimbursement for services. Recognition of, acknowledgment of, and assistance with these burdens, usually by involving social service support professionals, are critical. You don't have to do the work yourself—insist on the assistance of the health care colleagues who are available to you. Involve the community if you can.

Hopes and expectations

A patient's or family member's outlook is greatly affected by his or her expectations. A traditional inclination to sustain a patient's or family member's hope even at the price of deception has existed at various times in the history of the profession. Further, there has been an assumption in recent years that only cure can bring hope.

Yet, in numerous studies, the American public is quite clear that the vast majority expect the physician to tell them the truth. In fact, there is positive work to be done in facing dying, and there are developmental goals to be realistically hoped for in finishing and reviewing life's achievements and in reaching closure well. Through observation and study, we have learned that hope can be maintained, or strengthened, when we render a candid opinion to the patient of his or her prognosis. The task of the clinician is to assist the patient and family in discerning and achieving their own realistic goals. This skill can be learned, just like the skills of physical diagnosis or surgery. Think in terms of the final stage of development and closure; expect that a patient's hope can be maintained, even in the face of dying. This concept is perceived to be more difficult for pediatric or young adult patients when the person is dying far before the "normal" time. However, the concept that the truth is needed is especially true for parents facing the death of their child or for young adults if appropriate decisions are to be made.

The specific focus of hope often changes over the course of the illness. In general, patients (and parents) can find fulfillment and closure in 4 ways. They can find meaning in understanding their achievements. A sense of readiness can come from having a chance to bring closure to their life. Comfort can be found in understanding that death is a natural part of the grand scheme of life, and in the hope of legacies left or connection with something that will live on after they are gone. For parents whose child is dying, comfort may be found in creating memories. The child's legacy can become the many lives affected by the child. Sometimes life's work can be completed within the span even of infancy. Security can be found in realizing the strength of their spiritual lives.

Spiritual, cultural, and existential beliefs

Chaplaincy is another important discipline that can support the patient, family, and physician in the relief of suffering. As with social work, most physicians have not been exposed to a framework for health care that properly includes this dimension and clinical specialty. The study and basis for clinical intervention in the spiritual dimension of illness and suffering is the primary work of chaplains. Some patients will do better without a pastor—if the physician simply frees them from their physical suffering so that they can get on with their own work. Other patients appreciate the pastor's support. Many clinicians have pastoral care professionals who can be included in a patient's team of care. Another approach is to involve the patient's own pastor. But be careful; involvement in a religious denomination does not necessarily enable a pastor to engage successfully in the relief of spiritual suffering any more than attendance in medical school gives you the ability to perform cardiothoracic surgery. Study, interest, practice, and facility are what make a good chaplain—as is true for a good surgeon. While medical professionals need not involve themselves directly in a patient's spiritual life, it is a critical aspect of life in advanced illness. Therefore, insist on competent chaplaincy in the settings where you work. Your patients deserve nothing less. Clinicians must be able to assess the importance of this sphere of life and help to engineer a plan that will address this unique aspect

of human experience when it is appropriate—it is much easier with skilled colleagues working with you.

Health system interventions

Technical interventions have been the main focus of much of medicine. In this larger perspective it is clear that technical intervention is just 1 of many elements in end-of-life care. Furthermore, it is not all provided by physicians and other professionals. Far from it. Family and friends provide much support, and the community is another important possible source of care. Institutions can provide many sources of care.

Family and friends

The “front line” of care has always been provided by family and friends for a great majority of patients. Even in an age when many patients die in an institution, this is still true. Currently, care is moving back into the home, which is where 9 out of 10 patients want to be, and health care delivery systems now favor this as well. Clinicians who understand and encourage helpful family involvement in patient care can bolster and be assisted by rather than feel interrupted by and undermine this important source of care. In addition, the clinician who is aware of the burdens of care, and can direct the caregiver to a source of support, will help foster quality of life for patients and families.

Communities

Some patients are involved in communities that can provide spiritual activities, support groups, and even volunteer nursing-aide care. Other members of the health care team may know about more resources than you do—ask them. These resources can be invaluable and the clinician should welcome them in whatever way best supports the patient. A few calls from yourself or a member of your team to the patient’s religious institution, school, workplace, or neighborhood community can put a network of care in place. One willing coordinator of community volunteers can provide transportation, help with shopping and home chores, or a few friendly visitors.

Professionals

The medical professional can uniquely guide and provide sources of care for suffering in all 4 elements of physical, psychological, social, and existential experience. The importance of interdisciplinary teams for this care cannot be overstated.

Technical interventions are the unique province of clinicians, and their importance is great. Clinicians should not lose track of the fact that some interventions do not involve adding on a treatment but rather withholding or withdrawing an unwanted or a no-longer-wanted intervention. In addition, clinicians must always recall the fact that empathic communication can itself be an intervention.

Societal institutions

Institutions in society powerfully determine peoples' activities and experiences as well as outcomes of those activities. This is no less true in end-of-life care. For instance, Medicare policies on hospice care determine who may receive what services in many cases.

Private institutions may also be influential in a patient's experience toward the end of life, whether these institutions are disease-based advocacy or support groups or community churches.

The nature of health care delivery systems greatly determines the possibilities for care, and this is taken up in the next major section.

Outcomes

Now, let's consider outcomes. There are both objective and subjective measures that are important in assessing the overall quality of care for dying patients and their families.

Objective measures

Objective measures include documentable portions of care such as physician's orders that evidence proper planning and care. Scales of symptom intensity should be used and can be correlated with treatment approaches to assess quality of care. Quality-of-life scales should be used as well. Global scales of suffering and of quality end-of-life care are being developed to provide clinically useful indicators as well as outcome measures. Scales for institutional processes of care are also under development.

Satisfaction

Subjective experience remains one of the most important outcomes in the end. Although surveys of satisfaction often show poor correlation with other indicators of quality care, it remains an important concept and a tangible outcome measure. In the end it is the subjective experience of dying, caring, and bereavement that are critical. Much of the fear, trepidation, and distrust of contemporary health care comes from direct experiences with a beloved family member or friend. We have the ability to alter this perception.

Models for care

We have defined suffering and built a conceptual framework for its relief and for the enhancement of quality of life. Nevertheless, health care institutions are critically important to our system of care. It is now widely recognized that cognitive information such as that covered in this EPEC curriculum is necessary, but not sufficient, to deliver good end-of-life care to our patients. Pernicious and sometimes perverse systems of care have developed that reinforce the status quo. Our current systems of health care were not conceived within a comprehensive framework for relieving suffering. As different studies

have demonstrated, current systems may, in fact, promote suffering, particularly for those who are near the end of life.

Consequently, clinicians must often be creative in meeting the broad needs of their dying patients. Because physicians remain a key advocate for patients and their families within the health care system, you may be an agent for change within the health care systems in which you work. Urge yourself and your colleagues to insist on these elements for your patients. It is what you will want for yourself and your family when you need care.

An approach is developed in Plenary 4: Next Steps for fostering health care systems that work well for dying patients. To prepare for this, it is important to understand the concept of hospice and palliative care.

Hospice

In the 19th century, hospice was a term to describe places where the dying could be cared for. They were generally run by religious orders. In a remarkable development from listening to first 1 patient, then many patients, Cicely Saunders founded St Christopher's Hospice south of London, England, as a new kind of hospice. It is a place where a team of professionals in a single institution pursues the medical, emotional, social, and spiritual care of patients and families. Most importantly, it is an academic hospice, where education and research are pursued simultaneously with patient care. What we now generally term *palliative care* has grown out of, and includes, hospice care.

In the short 30 years since the founding of St Christopher's, what has been called the hospice movement developed on the fringes of institutional medicine. The response from institutional medicine was perhaps understandable—no conventional system likes to be challenged by a “movement” that is critical of the mainstream. Nevertheless, in the US, it has developed widely, primarily as programs of care for patients at home. The Health Care Financing Administration (HCFA) reported in 1994 that there were 1682 Medicare-certified US hospices serving nearly 20% of patients dying in the US. Many more have sprung up since then. The fruits of this movement are receiving considerable and well-deserved recognition.

In the United States, the single word *hospice* is used to describe 4 different concepts. Hospice can be a site of care for the dying, such as a free-standing facility or a dedicated unit within a hospital or nursing home. It can be an organization that provides care in a variety of settings but usually focused on the patient's home. The term is also used to describe an approach to care that is integrated into all manner of care sites and practices, including intensive care units if necessary. In this sense it is synonymous with palliative care. Finally, it is used to describe a benefit available to Medicare beneficiaries and subject to the rules and regulations promulgated by HCFA to govern that federal program.

Unfortunately, the use of a single term for all of these meanings has led to some confusion. For many patients, the term still means a place to go to die. For many physicians, the term *hospice* means a poorly understood community-based program into

which a patient disappears after the physician signs a form certifying a prognosis of less than 6 months. These persist even though the majority of patients enrolled in hospice programs live in their own homes until they die, because that is where they want to die. Surveys of the American public indicate that, if they knew they had a life-threatening illness, more than 80% want to die at home.

It is incumbent upon all physicians to understand the concepts, as well as the details, so that their patients get the best possible care. Just as physicians work with their local hospitals, nursing homes, and other sites where health care is delivered, so physicians need to understand and work with their local hospice agencies so that the best possible care is administered.

Palliative care

To move beyond the confusion, the stigmatization, and the restrictions that have evolved as unintended consequences of the Medicare hospice benefit, the concept of palliative care has started to evolve as a response to the continued deficits in caring for patients and families. Various groups have defined palliative care in diverse but related ways. Each of the proposed definitions has in common the focus on relieving suffering and improving quality of life. All of the definitions stress 2 important features: the multifaceted, multi-dimensional nature of the experience of living with an acknowledged time-limiting illness, and the priority of working as a team to achieve the relief of suffering and facilitate the enhancement of life. The importance of supporting the family and patient as a unit is clear. An issue that continues to be debated has been whether the term *palliative care* should refer to a discrete period at the end of life, or whether it is a concept that is relevant whenever suffering accompanies illness.

The Institute of Medicine defines palliative care in this fashion:

“Palliative care seeks to prevent, relieve, reduce or soothe the symptoms of disease or disorder without effecting a cure.... Palliative care in this broad sense is not restricted to those who are dying or those enrolled in hospice programs.... It attends closely to the emotional, spiritual, and practical needs and goals of patients and those close to them.”

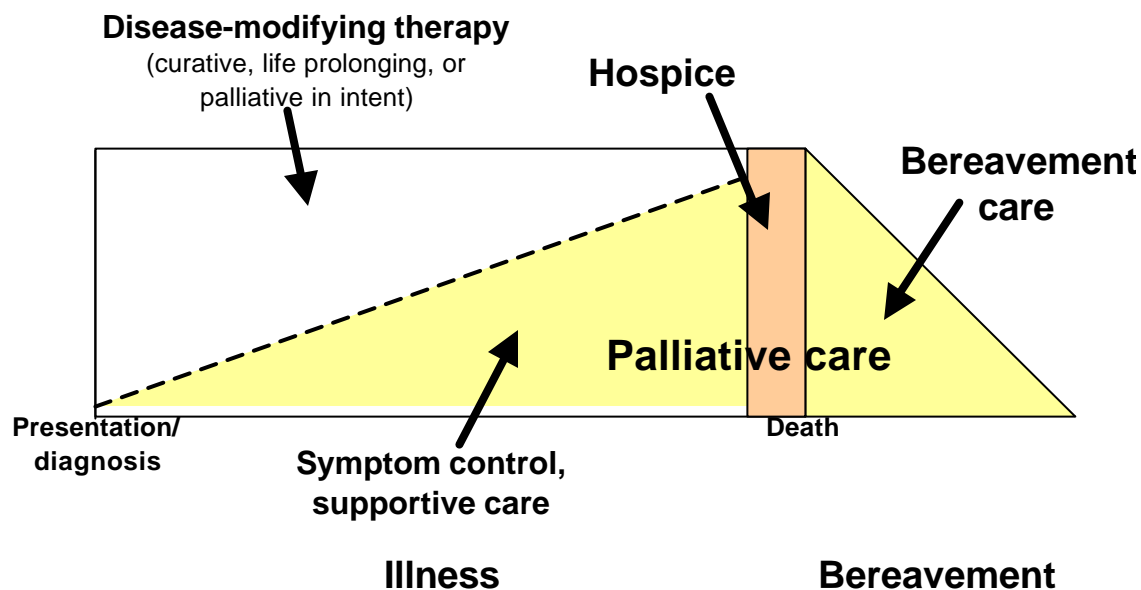
The World Health Organization (WHO) defines palliative care as:

“The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with anti-cancer treatment.”

It goes on to expand and explain with these 6 points:

- affirms life and regards dying as a normal process
- neither hastens nor postpones death
- provides relief from pain and other distressing symptoms
- integrates the psychological and spiritual aspects of care, fostering opportunities to grow
- offers an interdisciplinary team to help patients live as actively as possible until death
- offers a support system for the family during the patient's illness and their own bereavement

Continuum of care



Some have depicted a continuum of care graphically, showing how disease-modifying therapy with curative, life-prolonging, or palliative intent wanes as the illness progresses toward the end of a person's life, tapering to nonexistence as active dying begins in the last hours of life. Comfort-oriented symptom control and supportive care increase over time, maximizing as dying culminates in death. Often people receive this care through a hospice program. Anticipatory grief over many different losses begins before death. Bereavement continues for some time after death. Palliative care provides for all 3 phases for the family as well as for the patient.

Standards for hospice and palliative care

The hospice industry in the US is regulated by standards and guidelines promulgated by HCFA and measured and regulated by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO). These standards may also be applied to palliative care.

Access

Hospice agencies cannot always provide care to all comers, but the obligation to care for the dying is such that turning patients away is intolerably difficult for many of them. The best hospices have tended to expand rather than limit access. Oregon is currently aiming for universal access to hospice care. Medicare benefits are not panoramic and should be well understood if you are to provide the best benefits available to patients who need them.

Informed choices

Delivery of care should meet the patient and family expectations as much as possible. Relevant expectations include having access to services, being informed and in control of treatments to relieve pain and other physical symptoms, and psychological, social, and spiritual support. Patients will be treated with the family as a unit of care, participate in choice of settings, choose among options for interventions including referrals for intervention, have adequate information sharing and confidentiality from other parties, and have absence of discrimination. Bereavement and grief support for survivors will continue even after the death.

Symptom management and support

Symptom management, mental and spiritual health, and social support often require different kinds of programs that were not anticipated when the Medicare hospice legislation was written in 1982. Many hospices have worked with their communities, hospitals, and physicians to develop programs that stand outside the Medicare-regulated hospice delivery model in order to meet the needs of patients and families. These have included palliative care units, bridge programs, and the like.

Grief and bereavement support

Support of the patient with anticipatory grief or grief over lost function, and support of the family for some time after bereavement are also important functions in end-of-life care.

Transfer options, continuity of care

Sometimes patients, with their families and physicians, decide that medical interventions that require hospitalization in an acute care facility are needed; transfer from home or a hospice facility is necessary. This is possible without jeopardizing the patient's place in hospice. As far as possible, continuity of providers between settings should be available.

Research and evaluation

Hospice care is a mature enough field that there is a responsibility for systematic evaluation, research, and education of incoming professionals in the same way that we are introduced to the rest of the spectrum of health care. Numerous committees, commissions, professional associations, and agencies are working with the nation's medical schools and graduate and postgraduate programs to be sure that physicians are well educated in their role in palliative care, as well as the way in which they can use hospice to promote best end-of-life care for their patients. Physicians are urged to support those developments, as well as the initiatives to critically study best practices so that the entire system may improve.

It is now up to us in the medical mainstream to make use of hospice as a routine part of medical care in the US. Hospice should no longer be viewed as an alternative to standard care; rather it represents an important resource in the completion of good medical care. This EPEC project is but one example of the widespread move to integrate the principles developed in hospice into mainstream medicine in order to provide its benefits to all dying patients. The challenge is to do this without losing the quality and safe personal touch of smaller systems of care. I urge each of you here to work within your own health care communities to be sure that the hospice agencies help you to take the best care of your patients and their families. If you are satisfied, let them know. If you are dissatisfied, work with them until it is right. If there is no hospice agency serving your area, then work with your community until there is one.

Summary

This plenary has attempted to place in a coherent picture a variety of conceptions of suffering, a framework of elements in end-of-life care, and a set of models and standards for the delivery of quality end-of-life care. Conceptions of suffering include fragmentation of personhood, stressed personal stories, opportunities for growth, and total pain. Elements of care can be divided into those that are fixed, which include the patient's racial, ethnic, cultural, and socioeconomic background, as well as the diagnosis and prognosis. Elements that can be modified include the symptoms suffered in the physical, mental, social, and spiritual realms. Interventions are not limited to professionals and health care delivery sites, but include those that can be mobilized by family, community, and others, and include social institutions or programs such as Medicare policy. Outcomes must be measured if systems are to be improved and measures are becoming available. Defini-

tions and models of palliative and hospice care were provided, together with suggestions for setting standards for end-of-life programs.

Key take-home points

1. Patients' suffering has a context; patients and families must be considered together.
2. Palliative care defines a model for the relief of suffering and the improvement of quality of life across the spectrum of illness. What we now generally term palliative care has grown out of, and includes, hospice care.
3. Bodies do not suffer, only persons do. Personhood means having a past, present, and future. Suffering is a challenge to meaning. Loss of meaning is a form of suffering.
4. Elements in the broad conceptualization of end-of-life experience can be thought of in 4 categories: fixed elements, modifiable elements, interventions, and outcomes.
5. The biggest need in changing the system of care is timely application of knowledge that is already available.
6. Hospice should be a routine part of medical care in the US. It is not an alternative to standard care; rather, it represents an important resource in the completion of good medical care.
7. Conceptual frameworks, approaches for investigating and understanding suffering, and approaches for intervention to relieve suffering have been neglected in the training of physicians.

Resources

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