



Comfort

Comfort Goals

Instruction Material / Content

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Health Care Goals: Trajectory of Cure and Palliative Care

Making the choice. Talking about end of life is not easy in America. Our culture denies death as much as it values independence, achievement and affiliations. Generally we believe that dependence is to be avoided whenever possible. As a result of these values and beliefs, Americans tend not to talk about end-of-life care. National research findings indicate that:

- “25 % of Americans say they are not likely to talk about impending death with terminally ill parents.
- fewer than 25 % have put in writing how they want to be cared for at the end of life.
- 20 % admit they have not thought about how they want to be cared for at the end of life, while another 15 % say they have thought about their end-of-life care, but have not expressed their preferences.”¹

Such tendencies are consistent with the primary focus of the American health care system, providing acute care intending to cure illnesses and diseases. Abundant technological advances have emerged because of this focus and many procedures are available to treat illnesses and thereby extend life. This focus, however, has resulted in Americans living with chronic illness and has not drastically improved the quality of life years as discussed in the Impact modules.

The model or plan of care currently used in the United States focuses on aggressive treatment of the disease or illness at the time of diagnosis and along a treatment continuum until shortly before it becomes clear that death will occur. At this recognition, pain relief and palliative care become the treatments of choice.² This plan of care is insufficient to promote optimal proactive management of the symptoms that manifest in people with life limiting illnesses.

A new care model has been proposed by the World Health Organization (WHO) and is appropriate for people with life limiting illnesses. In this new model, disease (cancer, cardiac, pulmonary, hepatic, renal, etc.) treatment, pain relief, and palliative care all begin at diagnosis and are used concurrently with disease treatments up to death. This plan is especially important for the patient with illnesses associated with a short disease.²

The significance of the proposed WHO model is that attention to the patient’s quality of life is recognized from the time of diagnosis instead of aggressively attending to symptoms near death.

The WHO model shows that even though disease treatment, pain relief, and palliative care all begin at diagnosis, the disease treatments are more prominent near diagnosis, especially early in the disease trajectory. If the illness is diagnosed at an advanced stage or as the disease progresses, pain relief and palliative care increase in importance and curative therapies are used less aggressively. The significance of this proposed model is that attention to the patient’s quality of life is recognized from the time of diagnosis instead of aggressively attending to symptoms only when the patient is near death.

Relief of symptoms concurrent with disease treatment and only relief of symptoms when further disease treatment is undesired are cornerstones of effective palliative care. Many experts argue that patients would be more willing to accept hospice care if they did not have to fear loss of potential life-prolonging therapies. The WHO model does not force the choice between disease treatment and palliative comfort care, but argues for providing both in balance with the patient's needs and responses.

Because of the short time for intervention in some illnesses, there is a compelling need for nurses to implement the proposed WHO model, be proactive, aggressively manage symptoms, and attend to life closure and bereavement needs. In other illnesses with longer trajectories, there is urgent need for on-going, continuous care also focused on these needs.

On-going, continuous care. Findings from a national research study show that Americans want the kind of end-of-life care that hospice provides. “Americans say that the following services are most important for a terminally ill loved one:

- Someone to ensure that the patient's desires are honored
- Choice among types of services the patient can receive
- Pain control tailored to the patient's wishes
- Emotional support for the patient and family
- Opportunities for the patient to put his or her life in order
- Spiritual support for the patient and family
- End-of-life care provided without consideration of where the patient is living
- A team of professionals, such as physicians, nurses and counselors, to care for the patient
- Care to be provided in the patient's home or the home of a family member or loved one
- Continuity of caregivers, no matter where the patient is staying
- 75 % say that, if faced with care of a terminally ill patient, they would use an outside organization for support.”³

These findings show the need to publicize availability of hospice services and enhance individual and community levels of discussions about end-of-life care. It is important that Americans know that hospices and palliative care programs are available to provide the high quality care they want and need at the end-of-life transition.

Unfortunately, research findings indicate that “most Americans are completely unaware of hospice services.

- Nearly 80 % of Americans do not think of hospice as a choice for end-of-life care.
- Approximately 75 % do not know that hospice care can be provided at home.
- Fewer than 10 % know that hospices provide pain relief for the terminally ill.
- 90 % don't know that Medicare pays for hospice.”¹

An important role for health professionals is to educate patients and their families about the services available from hospices and palliative care programs. Additionally, health professionals can serve people facing the end-of-life transition by helping them to clarify their goals for acute, curative intent treatments and always provide palliative care for symptoms associated with their disease or illness. On-going, continuous care is a vital need and nurses are uniquely positioned to

assure that patients and families facing a life limiting illness get this need met. An appropriate starting point is to clarify preferences for end-of-life care.

Clarifying Values and Priorities: Patient, Family, Healthcare Providers

Health professionals provide active, desirable, and important comfort care to the dying. In order to provide quality comfort care to the dying, health professionals elicit, document, display, and assist in implementation of the patient's wishes for end of life care. This comfort care service is not assisted suicide or euthanasia.

Health professionals can use many techniques to assist patients and families to begin the dialogue about their preferences for end-of-life care. One technique for facilitating the discussion is available on the web at <http://www.agingwithdignity.org/5wishes.pdf> where one can view the Five Wishes. The Five Wishes and the Five Wishes Video can also be obtained by visiting the following web site: <http://www.agingwithdignity.org/order.html>.

Another technique is available to help patients and families sort out their priorities or specify their wishes. Discussions about priorities are important in order that others can speak for a person when the person is not able to speak for him/herself as discussed in the Ethics module. People differ tremendously in their priorities and goals. These differences can be very individual or sometimes related to a person's faith, ethnic heritage, education or other cultural characteristics. The only way to know a person's values and goals is to ask the person or facilitate values clarification or goals setting discussions among the person, family and health professionals.

Norlander and McSteen⁴ provide a systematic plan by which to engage the patient and family about comfort goals at the end of life. The assessment guide and typical questions are presented on the following web site. <http://www.nursingcenter.com/ce/article.cfm?id=4853CF66-AA15-11D4-83E0-00508B605149>, accessed July 9, 2001.

It is not uncommon for health professionals to differ amongst themselves in their priorities, values and goals. Hence, it is important for discussions to occur amongst health professionals and for the care they provide to stay focused on the patient's priorities. For example, Table 1 shows some of the variability in goals among a patient, family and their nurse caregiver.

Table 1. Care Goals from the Perspectives of the Patient, Family and Nurse.

Patient Goals	Family Goals	Nursing Goals for Patient and Family
Being comfortable	Keeping patient at home	Relieving symptoms
Staying at home	Keeping patient comfortable	Maintaining daily activities
Being independent	Keeping the family together	Completing unfinished business
Increasing strength	Learning to care for the patient	Addressing spiritual issues
Keeping the family together		Determining patient and family members choice for site of death (home, hospital, nursing home)
Fighting the illness		Providing amount of help needed and desired
		Exploring issues and feelings
		Making decisions
		Planning for changes, emergencies, death

Adapted from: (p. 62)⁵

Cassell and Foley ⁶ published an emerging consensus among medical specialties regarding the core principles guiding end-of-life care (Table 2). These core principles have been adopted or adapted and adopted by many of the medical specialty organizations.

Table 2. Core Principles for End-of-Life Care.

Clinical policy of care at the end of life and the professional practice it guides should:

1. Respect the dignity of both patient and caregivers;
2. Be sensitive to and respectful of the patient's and family's wishes;
3. Use the most appropriate measures that are consistent with patient choices;
4. Encompass alleviation of pain and other physical symptoms;
5. Assess and manage psychological, social, and spiritual/religious problems;
6. Offer continuity (the patient should be able to continue to be cared for, if so desired, by his/her primary care and specialist providers);
7. Provide access to any therapy which may realistically be expected to improve the patient's quality of life, including alternative or nontraditional treatments;
8. Provide access to palliative care and hospice care;
9. Respect the right to refuse treatment;
10. Respect the physician's professional responsibility to discontinue some treatments when appropriate, with consideration for both patient and family preferences;
11. Promote clinical and evidence-based research on providing care at the end of life.

Source: ⁶, used with permission.

The American Medical Association (AMA) contends that since people in the last phase of life seek peace and dignity, they should be able to expect these eight elements of care from physicians, health care institutions, and the community:⁷

- The opportunity to discuss and plan for end-of-life care;
- Trustworthy assurance that physical and mental suffering will be carefully attended to and comfort measures intently secured;
- Trustworthy assurance that preferences for withholding or withdrawing life-sustaining intervention will be honored;
- Trustworthy assurance that there will be no abandonment by physicians;
- Trustworthy assurance that dignity will be a priority;
- Trustworthy assurance that burden to family and others will be minimized;
- Attention to the personal goals of the dying person; and
- Trustworthy assurance that care providers will assist the bereaved through early stages of mourning and adjustment.

In summarizing its role in caring for patients at the end of life, the AMA referred to the AMA/Robert Wood Johnson Compassionate Competent Care Initiative, whose goal is to ensure that practicing physicians are equipped with the knowledge and skills to provide the best possible care for dying patients. The initiative seeks to educate physicians throughout the country in the practicalities of discussing and completing advance care planning and in the goals and interdisciplinary clinical skills of palliative care. The program also seeks to promote endorsement of these skills by the leadership and general culture of medicine.

Source: ⁶, used with permission.

The American Nurses Association position related to end of life decisions was last updated in 1998. The brief document refers to the 1994, position on "Assisted Suicide" which asserts that nurses should not participate in assisted suicide, stating such acts violate the Code for Nurses with Interpretive Statements⁸ and the ethical traditions of the profession. ANA's position statement acknowledges that there are many ethically justified end-of-life decisions and states that "nurses, individually and collectively, have an obligation to provide comprehensive and compassionate end-of-life care which includes the promotion of comfort and the relief of pain, and at times, foregoing life-sustaining treatments."⁹

Reconciling the priorities is the first step to providing patient-family centered nursing care. Conflicting goal or mutually exclusive goals are particularly challenging, but essential for effective end-of-life care. Negotiation and conflict resolution skills are needed in some situations. Effective end-of-life care is facilitated by a calm presence focused and centered on comfort and dignity for the person facing the end-of-life transition.

Nurses need to recognize and respond to changing goals over the trajectory of the dying process. Setting goals begins with the initial assessment and is ongoing with each visit. The patient's and family members' responses to the physical and emotional challenges of the dying process are variable and require continual reassessment, active listening, guiding and coaching about

potential threats to comfort and how to prepare in advance for maintaining comfort. For example, a patient who has unfinished business and is not ready to die may change his/her stance and opt for aggressive resuscitative measures until the life closure activities have been completed. Nursing goals are continually adjusted to center care on the patient's and family's priorities.

Patient and Family Centered End-of-life Care

Health professionals enact several roles as they provide comfort care. Coaching the patient and family to cope with crises is an important role for nurses. When symptoms are not well controlled, crisis often occurs and must be managed within the context of family dynamics. Patient-centered and family-centered care in which the health professional makes an implicit promise to provide active comfort-care and implements care on that promise are important cornerstones for effective end-of-life care.

Facilitating wishes. Nurses play a vital role as they elicit, document, display, and assist in implementation of the patient's wishes for end of life care. A technique is available to help patients and families sort out their preferences for treatments and other comfort. Discussions about preferences also are important to enable others to speak for a person when the person is not able to speak for him/herself as discussed in the Ethics module. People differ tremendously in their preferences sometimes by virtue of their faith, ethnic heritage, education or other cultural characteristics. The only way to know what a person wishes is to ask the person or facilitate the discussion among the person, family and health professionals. It is not uncommon for health professionals to differ amongst themselves in their own personal preferences. Hence, it is important for discussions to occur amongst health professionals and for the care they provide to stay focused on the patient's wishes. In doing so, the health professional demonstrates value for the patient's views while implementing his/her wishes for end-of-life care.

Tending to the needs of the health care provider. Health professionals are most effective in providing comfort care to dying persons and their families when the professional recognizes his/her own attitudes, feelings, and expectations about comfort. As well the health professional must recognize and implement care respecting the individual, cultural, and spiritual diversity that exists in the beliefs and customs of dying people and their families. Such care demonstrates value for the patient's views while implementing his/her wishes for end of life care. Such comfort care also assists the patient and family in coping with the suffering, grief and loss at the end-of-life.

Caring for dying persons and their families can be a strain for the professional caregiver. Observing unrelieved suffering is particularly difficult, and one coping strategy is to ignore the pain. Such a coping strategy is less effective than employing aggressive pain management strategies. Nearly all pain can be relieved and a great deal of suffering can be ameliorated with aggressive, multidisciplinary care planning and intervention. Coaching the patient and family to focus on living each day rather than on the losses is one effective strategy to alter suffering. Dealing with one's own grief also is important, as described in the Grief module.

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