

END OF LIFE: PALLIATIVE VS. CURATIVE CARE

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PURPOSE OF THE COURSE:

Palliative care as a person approaches the end of life is a multifaceted, multidisciplinary responsibility for many healthcare professionals both in the community and within many of our healthcare facilities, including hospitals, long term care facilities and free standing hospice environments.

The purpose of this course is to provide the learner with some basic information about palliative care at the end of life, a service and aspect of care that has been recognized as one that requires indepth knowledge and skill in order for us to provide this service to our patients in the best way possible.

This course meets the Florida State requirements in reference to mandated End of Life Care content for nurses (RNs, LPNs, ARNPs) and others. Nurses and some other professionals can substitute this course for either AIDS/HIV or Domestic Violence for relicensure.

OBJECTIVES:

At the conclusion of this course, the learner will be able to:

1. Differentiate between curative and palliative care;
2. Discuss some palliative care concepts and principles including compassion, comfort, pain and other symptom management, patient and family involvement, the settings in which this care is provided, hospice and respite care, bereavement and psychological support at the end of life;
3. Apply palliative care concepts and principles into one's role and responsibility in the multidisciplinary team.

INTRODUCTION: The Need for End of Life Care and Related Education

"For those who live neither with religious consolations about death nor with a sense of death (or of anything else) as natural, death is the

obscene mystery, the ultimate affront, the thing that cannot be controlled. It can only be denied.” (Susan Sontag b. 1933, Columbia University Press, 1996).

As we all know, death is a natural, inevitable part of life. Everyone dies, but where and how humans die has changed throughout the course of human history. During the relatively recent past, many died at home amidst the presence of family members and other loved ones. They also died without the many medical interventions that are now available and accessible to those at the end of life, should the person elect to avail themselves to them. Ventilators, tube feedings, intravenous hydration, progressively more powerful medications, and other life saving and life sustaining interventions are examples of these recent newcomers to the healthcare scene.

About 2.4 million people die every year in America (Institute of Medicine, 2003). Life expectancy has increased and so also has the number of aging people in America. More Americans die every year than ever before.

Healthcare and healthcare providers must gain new perspectives and skills relating to the end of life and the challenges that revolve around this natural phase of life. This new perspective has become increasingly necessary because:

- care at the end of life has shifted from the home amidst family caregivers to a healthcare facility staffed with healthcare professionals;
- increasing numbers of people die every year;
- advanced technology and numerous life sustaining medications and treatments appear on the scene every day.

The rapidly expanding availability of life saving and sustaining medications and treatments offer many more options than were ever possible before. These options and alternatives offer false hope to some while they offer a cure to others. These advances also challenge the healthcare team with some ethical dilemmas. Should life-sustaining support be discontinued? Should tube feedings be given when the person is no longer able to eat?

End of life care, often referred to as the care of the dying, is defined as the care that an individual receives when death is expected within weeks or months due to the natural aging process, a terminal illness, an acute illness or accident or chronic illness.

Care at the end of life is now recognized as a subspecialty of care that requires a unique body of knowledge and specialized skills in the same manner that pediatrics, emergency medicine, and other subspecialties do. Research and education are steadily increasing; but, nonetheless, more research and education are needed to advance the end of life body of knowledge and to promote more highly refined evidenced based practice standards in this relatively new subspecialty.

The American Association of Colleges of Nursing has identified and delineated fifteen (15) end of life care competencies that can serve as guidance for all members of the multidisciplinary palliative care team. These competencies are:

1. Recognize dynamic changes in population demographics, health care economics, and service delivery that necessitate improved professional preparation for end-of-life care.
2. Promote the provision of comfort care to the dying as an active, desirable, and important skill, and an integral component of nursing care.
3. Communicate effectively and compassionately with the patient, family, and health care team members about end-of-life issues.
4. Recognize one's own attitudes, feelings, values, and expectations about death and the individual, cultural, and spiritual diversity existing in these beliefs and customs.
5. Demonstrate respect for the patient's views and wishes during end-of-life care.
6. Collaborate with interdisciplinary team members while implementing the nursing role in end-of-life care.
7. Use scientifically based standardized tools to assess symptoms (e.g., pain, dyspnea [breathlessness] constipation, anxiety, fatigue, nausea/vomiting, and altered cognition) experienced by patients at the end of life.
8. Use data from symptom assessment to plan and intervene in symptom management using state-of-the-art traditional and complementary approaches.
9. Evaluate the impact of traditional, complementary, and technological therapies on patient- centered outcomes.

10. Assess and treat multiple dimensions, including physical, psychological, social and spiritual needs, to improve quality at the end of life.
11. Assist the patient, family, colleagues, and one's self to cope with suffering, grief, loss, and bereavement in end-of-life care.
12. Apply legal and ethical principles in the analysis of complex issues in end-of-life care, recognizing the influence of personal values, professional codes, and patient preferences.
13. Identify barriers and facilitators to patients' and caregivers' effective use of resources.
14. Demonstrate skill at implementing a plan for improved end-of-life care within a dynamic and complex health care delivery system.
15. Apply knowledge gained from palliative care research to end-of-life education and care. (American Association of Colleges of Nursing, 2004)

Other leaders in end of life and palliative care practice include:

- The National Consensus Project which has developed *Clinical Practice Guidelines for Quality Palliative Care* (2004); and
- The Institute of Medicine which has published an extensive report entitled "Describing Death in America: What We Need to Know" (2003).

This Institute of Medicine report emphasizes that, "Care for those approaching death is an integral and important part of health care. Everyone dies, and those at this stage of life deserve attention that is as thorough, active, and conscientious as that granted to those for whom cure or longer life is a realistic goal." (Institute of Medicine, 2003).

Other necessary end of life care elements identified by the Institute of Medicine as crucial to the provision of high quality care include:

- respect and consideration of the patient's and family members' unique needs, including those relating to their values and culture;
- strong clinical and interpersonal skills;

- an organizational culture that strives to correct system flaws and problems that impede quality care at the end of life;
- education of healthcare providers and consumers about care at the end of life;
- additional end of life care research, particularly in four problematic areas, including needless pain; economical, organization and/or legal barriers in respect to end of life care; how best to educate physicians and other healthcare providers about the end of life and end of life care; and the building of an evidence based practice methodology with a proven record for consistent positive outcomes (Institute of Medicine, 2003).

In summary, seven areas for improvement relating to end of life care include the need for:

1. skilled, reliable and supportive care;
2. healthcare workers to relieve pain and suffering using existing knowledge;
3. collaborative efforts by policy makers, consumers, healthcare organizations and healthcare providers to revise financing to facilitate quality end of life care, eliminate legal and policy barriers to effective pain management and to develop effective end of life care practices;
4. the education of healthcare professionals in end of life care knowledge and skills;
5. palliative care to be recognized as a specialty with a defined knowledge base;
6. national research to broaden and strengthen end of life care knowledge; and
7. public discussion and exploration about the options available at the end of life and the experience of dying (Institute of Medicine, 2003).

National Consensus Project which has developed *Clinical Practice Guidelines for Quality Palliative Care* identifies and addresses eight (8) domains of quality palliative care. The domains and some areas that are focused upon are below.

1. *Structure and Processes*

This domain underscores the need for a multidisciplinary team to assess and provide care to both the patient and the family member(s) at the end of life. This care should be based on the unique needs, values and goals of the patient and family. Community resources should be available and accessible in order to provide the client with the best possible quality and continuity of care, as based on these needs, values and goals. This domain also emphasizes the need to educate members of the palliative care team about this subspecialty of care and to provide them with the emotional support so they can continue to cope with the stressors associated with this kind of care.

2. Physical Aspects of Care

Effective pain management and symptom management are addressed in this domain.

3. Psychological and Psychiatric Aspects of Care

Pre-existing psychiatric and developmental issues have to continue to be addressed in addition to the psychological effects of the end of life on the patient and family members.

Depression, anxiety, delirium, stress, cognitive impairment, anticipatory grieving, coping mechanisms and bereavement are specifically mentioned as palliative care needs in this domain.

The goals of this palliative care domain aim to enhance emotional growth, to promote adjustment and healing, and to facilitate the completion of unfinished business.

4. Social Aspects of Care

The social aspects of end of life palliative care include those related to interpersonal relationships and practical everyday needs. Sexuality, intimacy, finances, transportation, caregiver availability, etc. are addressed.

5. Spiritual, Religious and Existential Aspects of Care

Religious, spiritual and existential needs must be assessed and supported throughout the end of life phase for both the patient and the family members.

6. Cultural Aspects of Care

Quality care at the end of life requires that we address patients' cultural preferences and characteristics, including those related

to decision-making, disclosure, truth telling, rituals and language.

7. Care of the Imminently Dying Patient

Care for the patient and family is intense and multifaceted when death is imminent. The patient often needs special attention in terms of hygiene and symptom management. The family often needs education about the signs and symptoms of imminent death.

8. Ethical and Legal Issues

Some of ethical dilemmas and issues at the end of life include those revolving around the cessation of fluids and nutrition, DNR orders, and the use of sedation when the respiratory system may become compromised as the result of it.

Some of the legal issues associated with the end of life are wills, guardianship, self-determination, advance directives, surrogate decision-making, confidentiality and honoring the patient's known wishes (National Consensus Project, 2004).

PALLIATIVE CARE VS. CURATIVE CARE

Curative care has as its focus the curing of an underlying disease and the provision of medical treatments to prolong and/or sustain life. Palliative care focuses on the provision of wholistic, compassionate supportive, rather than curative care, aimed at symptom management and the provision of the highest possible quality of life for the person, their family and significant others. Palliative care is often referred to as "supportive care" and "comfort care" but it involves much more than those two aspects of care. It is not a signal to provide no care. Palliative care is just as rigorous and involving as curative care.

END OF LIFE PALLIATIVE CARE CONCEPTS AND PRINCIPLES

All humans, especially those at the end of life, have the basic innate right to make decisions and choose among options when they are competent to do so. Our patients have a right to know about their medical status and the alternative treatment options that are available to them. They can then make a knowledgeable decision about what they want and what they do not want at the end of life.

Some at the end of life choose curative care. Others may choose palliative care. Some choose to avail themselves of a multitude of vigorous, invasive and even painful treatments and diagnostic

procedures. These choices indicate that the individual has opted for a curative methodology. Some of the treatments used in this curative care methodology include tube feedings, aggressive medication regimens, parenteral nutrition, intravenous hydration, mechanical ventilation, and sometimes very extensive surgical procedures, all aimed to sustain life.

On the other hand, some patients prefer and choose to avail themselves of a multitude of supportive, palliative options. They may choose the cessation of life sustaining interventions like renal dialysis, mechanical ventilation, and tube feedings. They may refuse surgical procedures other than some that simply relieve pain and increase their quality of life. They choose, instead, to have their physical, psychological, social, and spiritual needs met in a different way through the caring help of a competent, compassionate, multidisciplinary team that focuses on symptom management and control, the avoidance of needless suffering, and a holistic approach that supportively meets their unique needs. They choose these kinds of interventions and palliative care, rather than curative interventions.

THE MULTIDISCIPLINARY PALLIATIVE CARE TEAM

Palliative care, hospice and respite care are specialized philosophies of care rather than a physical environment or place. They are treatment modalities that transcend brick and mortar. Palliative care, hospice, and respite care are provided in a variety of settings, such as private homes, hospitals, nursing homes, assisted living facilities and other settings, such as a community hospice care facility.

Palliative care hospice teams generally consist of the following team members:

- the patient's own physician and/or a specially trained hospice physician;
- the administrator or director of the hospice program;
- nurses, nursing assistants, and perhaps even a nurse practitioner and/or a clinical nurse specialist trained in the hospice mode of care;
- dietitians;
- social workers, psychologists and psychotherapists;
- clergy members;

- others, such as acupuncturists, speech and occupational therapists.

The goal of the hospice team is to compassionately provide the patient and family member with all the support they need in order to fulfill their palliative care needs. Hospice care aims to provide the dying person with a pain free death and the maintenance of dignity throughout the dying process. The patient and/or family members are actively involved in the plan of care and decision-making relating to all aspects of care.

COMFORT & SYMPTOM MANAGEMENT, INCLUDING PAIN MANAGEMENT

Some of the goals of palliative care include providing comfort and maintaining dignity. These goals are achieved through compassion, the relief of pain, freedom from physical and mental distress, and well-planned interventions to promote physical, psychological and spiritual comfort.

Physical comfort is accomplished through *physical symptom management*, including *pain management*.

Pain, and the fear of pain, often results from a combination of the disease process, depression, distress, insomnia, nausea and anxiety. Depression, anxiety, insomnia and distress can be ameliorated with psycho-social interventions, physical interventions such as a soothing bath or backrub, and pharmacological interventions when needed.

Offering the patient small sips of fluid and lighter meals at frequent intervals when requested can possibly prevent nausea and vomiting. We should strive to meet the patient's needs rather than structuring the person's meals around pre-established meal schedules designed to meet the facility's needs.

Family members often express concerns about their loved one's "getting enough to eat and drink" at the end of life. These family members should be educated about the fact that comfort can be maintained without food and water. In fact, artificial methods of hydration and nutrition, such as IVs, tube feedings, and parenteral nutrition, often add to a person's discomfort from complications and an unnatural sense of fullness. "The only reported discomfort associated with dehydration near death is xerostomia, which is easily relieved with oral swabs or ice chips." (Merck & Co., 2004).

Other effective measures include:

- the elimination of and/or substitution of alternative pharmacological agents when troublesome medications like the opioids and nonsteroidal anti-inflammatory drugs (NSAIDs) are causing or contributing to the nausea and vomiting;
- the use of appetite stimulants like the corticosteroids and megestrol; and
- good oral hygiene (ice chips, swabs, lip salves), an aspect of care that family members can participate in. (Merck & Co., 2004).

Constipation at the end of life results from a combination of one or more of the following:

- some medications, particularly the opioids and anticholinergic medications;
- poor dietary intake, particularly, less than adequate fiber;
- decreased fluid intake;
- immobility; and/or
- the lack of privacy.

Other than maintaining personal privacy for basic bodily functions, the following may relieve constipation:

- facilitate the person's individual bowel routines;
- increase mobility;
- increase fluid and fiber intake when possible;
- use prophylactic stool softeners, such as docusate, and stimulants, such as bisacodyl or senna, when an opioid therapy is anticipated or begun; and/or
- use suppositories, enemas and magnesium citrate if needed. (Merck & Co., 2004).

Dyspnea, perhaps the most feared of all the end of life symptoms, should be treated according to the etiology. For example, if the dyspnea results from congestive heart failure, this disorder should be treated to increase comfort and decrease anxiety. Other measures include simple approaches such as an open window or fan to decrease the distress associated with air hunger, meditation, a calm

environment, the soothing presence of the caregiver and/or loved ones, relaxation techniques, guided imagery and/or:

- oxygen,
- morphine to reduce the dyspnea and the anxiety,
- albuterol,
- steroids and
- benzodiazepines to decrease anxiety (Merck & Co., 2004)

Agitation can result from a number of causes including the poor management of pain, insomnia, and urinary retention, all of which can, and should, be readily corrected. Severe agitation may necessitate the use of pharmacological agents to protect the patient and others from harm when other measures have proven to be ineffective. (Merck & Co., 2004).

Confusion and delirium, often more distressful to the family and loved ones than the person at the end of life, also results from a number of underlying causes, including the disease process itself, hypoxia and some medications. Nonpharmacological measures, such as frequent re-orientation strategies and the presence of a loved one, are highly effective ways to decrease confusion. When delirium results from irreversible causes, medications such as haloperidol can be used; the goal of treatment is to increase the patient's comfort and their ability to maintain an optimal quality of life during the end of life. (Merck & Co., 2004).

Pain is the 5th vital sign and a subjective response by the patient. Tolerance for pain varies from individual to individual. The experience of pain also varies within an individual as a function of other stressors such as insomnia, fatigue and depression. These exacerbating stressors should be eliminated, or at least decreased in terms of intensity, whenever possible.

Pain must be properly assessed and a pain management plan must be established. There are a number of pain assessment scales in use. Some are numeric scales that verbally ask the patient to rate their pain level from one to ten, with 10 being the greatest level of pain possible and one being the complete absence of pain. Other scales, particularly useful for young children, nonverbal adult patients and patients with a language barrier, include those that use visual faces that progress from a smile to a teary eyed face.

Members of the healthcare team must also be able to assess pain when a pain assessment tool or scale, such as the ones described above, cannot be used. For example, the nurse, physician, and social worker must be able to assess pain using nonverbal cues or behaviors such as grimacing, guarding, restlessness, and facial or bodily tension.

The goal of the pain management plan is to relieve the pain according to the patient's desires. Some prefer minimal pain relief so that they can remain more active and communicative with loved ones; others prefer complete freedom from pain even if this regimen leads to heavy sedation. Fear of addiction should not prohibit the ordering or use of analgesics at the end of life.

As you know, there are many different medications that can be used to relieve pain. This course is not intended to give you this kind of information. However, in the future we will have courses on pain management, so visit us soon.

There are also many nonpharmacological pain management measures. Some of these interventions include the elimination of the exacerbating factors discussed above and:

- physical interventions such as the use of heat or cold, acupuncture, acupressure, massage, cutaneous stimulation, transcutaneous electrical nerve stimulation (TENS) and repositioning;
- palliative, surgical procedures such as a nerve block and ablative surgery;
- psychological measures like meditation, prayer, guided imagery, biofeedback, relaxation techniques, and distraction;
- psychosocial interventions such as psychotherapy, counseling, and support groups;
- spiritual interventions, such as chaplaincy and prayer;
- educational interventions to enable the patient and family members to learn about pain, pain management and the relief of pain.

PSYCHOLOGICAL SUPPORT AT THE END OF LIFE

The healthcare team must be able to provide psychological and emotional support not only to the patient, but also to family and friends. This may be a very difficult task because of the complex

feelings that the patient and/or family members may express. All may be experiencing different phases of the death and dying process. All may be affected by and expressing different feelings relating to their loss and grieving. Often, these feelings might include anger, fear, sadness, hopelessness, guilt, depression, hostility, and/or anxiety.

Each person's experience and perception of loss is individual and must be treated as something unique and individual to the person. The interpretation and meaning of the loss is directly dependent on the previous experiences of the person encountering the loss. (Breitbart,2002).

Some ways to provide psychological support to the dying person, their family and significant others include:

- *Establishing trust.* Establishing trust is the first step of psychological intervention. Healthcare providers must establish trust with the patient, family and significant others. Some ways that trust can be established are spending time with the person, accepting the person as a unique individual with their own thoughts, feelings, fears and beliefs, being open and honest with the person, and active listening. All those who are experiencing end of life must be comfortable and able to trust those who care for them.
- *Facilitating the patient and family to ventilate their feelings, fears, and concerns.* Every person experiencing the end of life must be able to ventilate, and express their most profound feelings, fears and concerns, regardless of whether or not the individual's feelings, fears and concerns are realistic and valid. Listen in silence when appropriate.
- *Breaking bad news in a therapeutic manner.* Sharing distressing news with patients and family members is always a difficult challenge for the healthcare provider. Distressing news should be shared with the patient and significant others in an open and honest manner. It is best to choose an appropriate time and place, in which privacy, confidentiality and conversation can be facilitated. This news should be given with direct dialogue , without medical jargon, and in a manner that is understandable to the receiver(s) of the message. Listen to the person and assess their reaction(s) to the distressing news in an empathetic, caring and unhurried way.
- *Helping the person maintain and/or refocus on realistic hope.* Realistic hope often consists of looking forward to something that is still possible. It is often not realistic to hope for a miracle

cure or a dramatic turnaround in terms of the certainty of imminent death. For some, realistic hope may consist of meaningful goals such as those expressed in their last wishes. For example, a person's last wish may be teaching a young great grandchild to read or to help their daughter to select and purchase a new home. For some, these realistic goals offer hope and a sense of meaning to the person at the end of life.

- *Promoting an environment that is open and nonjudgmental.* The multidisciplinary team must establish and maintain a psychologically therapeutic environment that is open, honest, nonjudgmental, and fully accepting and supportive of the person, their needs, their feelings and their wishes.
- *Listening and maintaining silence when indicated.* Listening empathetically is essential to psychological well being at the end of life, as is silence. Silence, often uncomfortable for the healthcare provider, is very therapeutic when it is indicated.
- *Being present and accessible.* The patient and family members need some privacy and time alone; however, there are also many occasions that they can benefit from the presence and ready accessibility of their healthcare providers, particularly those who they have the closest relationships with.
- *Facilitating communication and caring among members of the family.* Family members greatly benefit from participating in the care of their loved one, particularly if they are feeling somewhat useless in terms of the person's medical condition. Participation in care should be encouraged when acceptable to the patient and the family member. Additionally, conflicts among family members may become apparent as we are caring for those at the end of life. These conflicts should be resolved, as much as possible, during this difficult time.
- *Treating depression, anxiety and delirium at the end of life.*
- *Assessing and treating caregiver stress.* Giving care to the dying is exhausting work, physically and emotionally. Toward the very end of life, the patient may need around-the-clock care. Primary caregivers can become overwhelmed with this role and responsibility. Caregiver stress should be assessed. Referrals to respite care for the loved one and other community resources, such as homecare, have proven to be highly successful.
- *Facilitating coping mechanisms.* An assessment of how the family and patient have coped with prior stressful events in their lives is an appropriate way to begin to assess how we can facilitate their current coping efforts as they deal with the end of life. Careful observation of behaviors is also appropriate. The nurse and other healthcare providers must provide emotional

support to reduce anxiety and permit an open expression of fears, concerns, and feelings. Referrals to psychological grief counselors for anticipatory grieving and for post death grieving are often highly beneficial for both the patient and the family members. There are also many support groups that focus on specific types of medical problems and grief. After the death, the surviving family and friends can be encouraged to attend bereavement support groups. Many palliative care and hospice care programs offer bereavement counseling to family members for one year, or more, if indicated.

SUMMARY

End of life palliative care is a highly specialized multidisciplinary field within healthcare that requires special skills and knowledge. This course has provided you with information about palliative care and ways that this knowledge can be translated into practice. Develop these skills and share them with other members of the palliative care team.

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