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End of life nursing education consortium grant implementation project

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END-OF-LIFE NURSING EDUCATION CONSORTIUM GRANT IMPLEMENTATION PROJECT

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Science
in
Nursing

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by
Sheryl Ramona Terkildsen
June 2002

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ABSTRACT

This project addresses the continuing education needs of nursing staff and other health care professionals for delivering competent and compassion palliative or end-of-life care. The scope of this project included: writing a grant application; training and certification by the End-of-life Nursing Education Consortium and implementing an education program for staff at the Loma Linda Veterans Affairs Medical Center.

The review of the literature discusses the aspects of care that are important for patients, families, and staff. The importance of raising the community consciousness about care of the dying is also discussed. This project was implemented to provide staff with the knowledge and skills necessary to care well for dying patients.

On the national level, it is imperative that health care professionals receive training. Curriculums at nursing schools and medical schools must integrate aspects of end-of-life care. There is a need to provide access to everyone for quality end-of-life care. Conversations must begin in homes, churches, town hall meetings. Voices need to be raised until Congress hears the message and funds education and research in palliative care.

ACKNOWLEDGMENTS

To My Mother, the wind beneath my wings, who has always been there encouraging me to greater heights; To My Husband, my rock, who has supported me unconditionally through this program; and for Kathy, forever my very best friend, who always told me that I could do whatever I set my mind upon. To my advisor, Susan, who held my hand along the way and made me think outside of the box. To Debi, my mentor, who gave me so much support.

DEDICATION

Kathy Jean Garrison

April 6, 1962 - April 30, 2002

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CHAPTER ONE

BACKGROUND

Introduction

Palliative care or end-of-life care for the elderly, chronically ill patients with steady decline, or the terminally ill has not played a significant role in nursing or medicine curriculums. Very few medical schools and nursing schools have included content areas on end-of-life care. The closest content to palliative care is pain management and an insignificant amount of content on symptom control for the dying patient.

The need for competent curriculums that include a body of knowledge on end-of-life care can no longer be ignored. Over the course of the last decade, a collective voice of well-reasoned concern has lifted from health care professionals in America. Nurses and physicians alike have been acknowledging that they had little or no preparation for caring for the dying (Cassel & Field, 1997; Coyne, Ferrell, Grant, Uman, & Virani, 2000).

Dying is a part of life. Each of us that are born will surely die. The Committee on Care at the End-of-life from the Institute of Medicine issued a report that argued, "...we can do much more to relieve suffering, respect personal dignity, and provide opportunities for people to find meaning in life's conclusion" (Cassel & Field, 1997, p. v).

The realization that most of the health care professionals currently practicing in our country are ill-prepared to provide quality care at the end-of-life has prompted many nurse and physician educators and researchers to build the body of knowledge on end-of-life care through the use of generous grants. People should not have to fear that their dying will be marked by neglect, care that conflicts or disregards their wishes, or preventable pain or other treatable symptoms. There is a strong need to develop and expand this body of knowledge and train nurses and other health care providers in quality care for the dying patient. This project is a beginning step in that direction.

Purpose of the Project

The purpose of the project was to write an application and receive a grant to implement an End-of-Life Nursing Education Consortium program, attend training and obtain certification from the End-of-life Nursing Education Consortium Project (ELNEC) and to lastly, implement an educational program based on the

End-of-life Nursing Education Consortium Project curriculum for the staff members (e.g. nurses, doctors, social workers, dieticians, etc.) at a Veterans Affairs Medical Center thereby providing them with the necessary tools to improve the care of dying patients while caring for themselves.

The importance of the project is undeniable. People need the appropriate compassionate care delivered in their dying process. Health care professionals need the education and training to deliver the quality care so richly deserved at the end-of-life.

Context of the Problem

The context of the problem was to address the need of health care professionals for continuing education programs in end-of-life care. Many health care professionals are not only fearful of dying patients or perceive the death of a patient as a failure on their part, but many have not received proper training in their curriculums to care for dying patients. Nurses who work exclusively with dying patients experience even more stress than those in traditional settings because of the potential energy depletion the tremendous emotional investment in their work can entail (Amenta, 1986). A major source of stress in working with people who are dying is regular contact with the most fundamental human fear - fear of dying- and with suffering, hopelessness, meaninglessness, and uncertainty (Kemp, 1999). The educational needs of the health care professional must be met in order for them to be able to care for patients as well as themselves.

Scope of the Project

The scope of the project will include applying for an ELNEC grant training program, attending the training, and implementing an end-of-life education program at the Loma Linda Veterans Affairs Medical Center. The importance of developing continuing education programs specific for palliative care cannot be underestimated. Continuing education not only enhances clinical competence, it also enhances the individual's ability to effectively cope with the stressors of providing end-of-life care.

The project is innovative and provides a significant impact within my work environment. This program director (Sheryl Terkildsen) currently manages a 56-bed long-term care unit with the palliative care program patients at the place of employment. The significance of the project is that dying patients will receive better care by health care professionals who are fully prepared to deliver excellent end-of-life care without burning themselves out. The project not only impacts patients at the Loma Linda Veterans Affairs Medical Center (LLVAMC), it also impacts the nursing profession and health care system at large as nurses share their expertise with others as they move through their professional careers. Patients and their families will receive competent, compassionate care. Their symptoms will be managed. The dying will die well loved, comforted and cared for with dignity and respect.

Limitations

This project has a few limitations. First, the program director is not able to teach all nine contents areas of the curriculum within the time frame allotted for this project. Secondly, there are financial constraints at the LLVAMC related to educational training. Lastly, the current staffing shortage negatively impacts the availability of nurses for continuing education programs. Nurses have to be working not "learning." They do not have the time to attend educational programs while at work.

Definition of Terms

The following terms are defined as they apply to the project.

<u>Burnout</u> - a psychological syndrome that can occur among individuals who work with other people in some capacity, these individuals exhibit symptoms of emotional exhaustion, depersonalization, and reduced personal accomplishment (Maslach, Jackson, & Leiter, 1996, p 4).

<u>Pain</u> - "an unpleasant sensory and emotional experience associated with actual and potential tissue damage, or described in terms of such damage" (American Pain Society [APS], 1992, p. 2).

<u>Palliative care</u> - The active, compassionate care of the terminally ill at a time when their disease is no longer responsive to the traditional aims of cure and prolongation of life, and when the emphasis of care is on comfort and quality of life until death (Caring Together, 1987).

<u>Suffering</u> - personal distress or affliction and to "some extent is universal among people who are dying, even those who have no physical discomfort" (Byock, 1997, p. 82).

CHAPTER TWO

REVIEW OF THE LITERATURE

Introduction

Chapter Two consists of a discussion of the relevant literature regarding palliative care in America today. Specifically, the literature review looks at quality of life issues inherent to end-of-life care, a nursing theory that is most appropriate for clinical application in palliative care and aspects of care for the terminally ill or end-of-life patients.

Quality of Life Issues

Quality of life is a complex concept that has no common definition. Quality of life is multi-dimensional as well as multi-faceted. What gives one person a quality of life does not necessarily give it to another. Quality of life has both objective and subjective components. "In practice, it is difficult for us to judge another's quality of life without allowing our own value systems to override the beliefs, feelings, wants, needs, and aspirations of the other" (Goodhall, 1997, p. 219).

Any quality of life judgment made should reflect the patient's values, goals, and what constitutes a reasonable quality of life. Often times the interdisciplinary team is not able to make these decisions alone. "When quality-of-life issues drive the decisions to forgo treatment, caregivers should involve the hospital ethics committee or a multidisciplinary team of clinicians to mitigate ethical or legal conflict" (Reith, 1999, p. 23).

With an increasingly aging population, it is important that health care providers begin to understand how to provide better end-of-life care. There is much to be said about quality of life versus quantity of life. Palliative care is about having a quality end-of-life with dignity and comfort among the guiding principles. It is necessary to understand that there is so much more that can be done for our patients that ensure the preservation of dignity and comfort at the end-of-life.

Unfortunately, in the western model of medicine, the need to cure has been the main thrust in delivering care to patients and our ever advancing technology has reaffirmed in the public's mind our ability to prolong life regardless of quality. However, over the last decade a movement of care has arisen and opened our eyes to the necessity of quality palliative care when cure is no longer available. Physicians, nurses, psychologists, pharmacists, and social workers that work daily with the suffering patients who are dying have long championed this awakening.

M. L. Henderson (2000) stated:

> Dying is a universal phenomenon. Finally we, as a society, are beginning to face this fact and become mobilized around its importance. We are having to grow up and realize that technology is not the answer to terminal or end stage illness, though advancements in medical science are now able to expand the quantity and quality of people's lives at times. (p. 22)

People really need to understand that dying is a part of living and that we do have the means within our technologically advanced 'medical machine' to have a death filled with pain relief, compassion, true caring, comfort, respect, and dignity.

Nursing Theory

Jean Watson developed the theory, Nursing: The Philosophy and Science of Caring, between 1975 and 1979 while teaching at the University of Colorado. It was initially her treatise on nursing. It has evolved into a mid-range-level theory because of the abstract nature of some of Watson's concepts and it is deductive in origin (Sourial, 1996, 401).

She has devoted 26 years to expanding and clarifying her work. Watson (2001) recently made the following observation about her work:

> This work, in both its original and evolving forms, seeks to develop caring as an ontological and theoretical-philosophical-ethical framework for the profession and discipline of nursing and to clarify its mature relationship and distinct intersection with other health sciences. (p. 350)

Watson's theory represents phenomenological, existential, and spiritual orientations, blended with Eastern philosophy. Her theory incorporated five major concepts related to person, environment, health, illness, and nursing. She defined person as an integrated spiritual-mental-physical being in the world. The environment is an open system continuous with the person in time and space. Health is represented by the unity and harmony within the mind, body, and soul of the individual. Illness quite logically is the disharmony within the mind, body, and soul. And lastly, nursing is the transpersonal human care and caring transactions that promote restoration of a sense of inner harmony.

Sourial (1996) noted:

> Some of Watson's work can be considered metatheory, because she combines a number of world views consistent with her background in psychology and philosophy, and she analyzes the purpose and nature of theory that we need in nursing and the processes for its development. (p. 402)

Watson stated that caring can be effectively demonstrated and practiced only interpersonally. Effective caring promotes health and individual or family growth. Caring consists of carative factors that result in the satisfaction of certain human needs. Caring responses accept a person not only as he or she is now but as what he or she may become. A caring environment is one that offers the development of potential while allowing the person to choose the best action for him or herself at a given point in time. Caring is more "healthogenic" than is curing. The practice of caring integrate biophysical knowledge with knowledge of human behavior to generate or promote health and to provide ministrations to those who are ill. A science of caring is therefore complementary to the science of curing. And lastly, the practice of caring is central to nursing (Watson 1985, p. 8-9). Human caring involves values, a will and a commitment to care, knowledge, caring actions, and consequences (Watson, 1985, p. 29).

A basic premise of Watson's (1999) is that:

> A person's mind and emotions are windows to the soul. Nursing care can be and is physical, procedural, objective, and factual, but at the highest level of nursing the nurse's human care responses, the human care transactions, and the nurse's presence in the relationship transcend the physical and material world, bound in time and space, and make contact with the person's emotional and subjective world as the route to the inner self and the higher sense of self. (p. 50)

Indeed, as she so eloquently stated, "If our humanness is to survive, we need to become more loving, caring, and moral to nourish our humanity, advance as a civilization, and live together" (Watson, 1999, p. 51).

Transpersonal caring transactions can, according to Watson (1985), expand human capacities and offer new opportunities to both the nurse and the patient. She explained that when caring occasions are transpersonal and allow for the presence of the geist or spirit of both the nurse and the patient:

> The event expands the limits of openness and has the ability to expand human capacities. It thereby increases the range of certain events that could occur in space and time at the moment as well as in the future. The moment of the caring occasion becomes part of the past life history of both persons and presents both with new opportunities. (p. 59)

Holistic caring, the being-with, the empathy, the interconnectedness of need and response is the nurse's art. It is this art of caring that is the balancing qualifier of life.

Helen Allan (1996) developed a teaching session, which demonstrates her nursing students' ability to focus on caring in their practice. Its aims were to translate Watson's theory into practice using examples from their clinical experiences after their last clinical placement and to develop nursing knowledge through expressing what it is they do. "The students found the language in Watson's model difficult, describing it as "American" at first, but they were quickly able to find examples from their experience and use Watson's concepts skillfully and fluently" (p. 42). "Condon (1992) stated that the actualization of an ethic of caring will enable nursing to become a distinctive profession on its own which is based on the values of empowerment. Watson's model of caring (1988) enhances this process for students" (as cited in Allan, p. 44). Watson's theory is useful in nursing education. It also has validity in nursing research

According to Jacqueline Fawcett (1993):

> The conceptual model from which Watson's theory was derived is not explicit, but it can be inferred from her publications. It clearly reflects the metaphysical, spiritual, existential, and phenomenological orientation of her philosophical claims. The model comprises descriptions of human life, health, and nursing that provide a conceptual base for the Theory of Human Caring. (p. 222)

As Watson's theory has undergone scholarly analysis, there have been claims of dualism from a few scholars and internal consistency has been questioned.

> Mitchell and Cody noted that Watson presented inconsistent views of human beings. They pointed out that although Watson claimed that people are irreducible wholes, she also referred to several selves (real, inner, ideal) as distinct

> entities; to the mind, body, spirit, and soul; to physical, emotional, and spiritual spheres; and to the "I" and the "me". Watson (1992) apparently has attempted to overcome the charge of dualism and more effectively convey her idea of a holistic being by using the term "human mindbodyspirit" in a recent brief overview of her theory [p. 1481] (as cited in Fawcett, 1993, p. 232-233).

Watson's theory has semantic clarity as evidenced by the definitions and descriptions she provided for the concepts of the theory and most of their dimensions. "There is, however, some confusion about the precise definition of inter-subjectivity because that term is defined only in conjunction with transpersonal caring" (Fawcett, 1993, p. 233). Semantic consistency is also present.

Parsimony is also present as the theory is elegant in its simplicity and relative economy of words (Fawcett, 1993, p. 234). The theory is most definitely testable. Empirical adequacy continues to grow. According to Fawcett, "Watson has made a substantial contribution to nursing by explicating a new form of nursing care" (p. 239).

Nelson-Marten, Hecomovich, and Pangle (1998) presented two case studies that demonstrated the usefulness of Watson's theory of caring as a framework for advanced practice nursing. A recently diagnosed patient who is positive for the human immunodeficiency virus and a patient terminally ill with acquired immunodeficiency syndrome were reviewed in the case studies using the carative factors as a model for providing holistic, patient focused, nursing care. "The value of this exercise lies in the demonstration of the applicability of caring theory as a framework for both symptom management and palliative nursing care" (p. 76). Watson's theory is very useful in palliative nursing practice and research. I believe that the potential is only beginning to be realized and that further research in palliative nursing will only strengthen the validity of the carative factors! Sourial (1996) noted that further work is needed to validate all the carative factors with greater understanding of the spiritual domain, and empirical support is also required for the outcomes of transpersonal caring (p. 404).

Watson believes that caring is "a moral ideal, rather than an interpersonal technique" (Watson, 1985, p. 58), which can be demonstrated through ten primary carative factors (nursing interventions) that "allow for contact between the subjective world of the experiencing persons" (Watson, 1985, p. 58). The nurse co participates with the individual patient in a process of "being and becoming"

(Watson, 1985, p. 74). Her carative factors are all presupposed by a knowledge base and clinical competence. These carative factors are derived from a humanistic perspective combined with a scientific knowledge base. Her construction of the science of caring is under girded by her strong liberal arts background, her expanded worldview, and a strong humanistic value system. The carative factors are as follows:

1. The formation of a humanistic-altruistic system of values. (When nurses practice loving kindness with patients and family members in palliative care and have a value system that genuinely supports a caring consciousness, quality end-of-life care will occur.)
2. The instillation of faith-hope. (Nurses who are authentically present with their patients and provide the gift of presence are able to sustain not only their own belief system but the belief system of the patient in palliative care.)
3. The cultivation of sensitivity to one's self and to others. (Nurses who have cultivated their own spiritual practices and are able to open themselves to others with sensitivity and true

compassion are well suited for practicing in end-of-life care.)

4. The development of a helping-trust relationship. (Nurses who strive to develop genuine trust relationships with their patients and family members of the patients provide great comfort in end-of-life care.)
5. The promotion and acceptance of expression of positive and negative feelings. (Nurses who are able to accept the expressions of patients who are dying without placing value judgments against the patients have the ability to truly assist the patient with his last journey and allow him/her to simply be who they are.)
6. The systematic use of the scientific problem-solving method for decision-making. (Nurses who engage in the art of caring also need to have the ability to make decisions with clarity. This is important in end-of-life care.)
7. The promotion of interpersonal teaching-learning. (Nurses in palliative care need to engage in deep teaching-learning experiences with patients and families.)

8. The provision for a supportive, protective, and (or) corrective mental, physical, sociocultural, and spiritual environment. (Nurses who work in palliative care create healing environments for the patients and families. The patient's spiritual, physical, psychological and social needs are addressed. Healing and caring are sought, not curing.)
9. Assistance with gratification of human needs. (Nurses administering genuine compassion with their care of patients at the end of life assist with all aspects of holistic care and are tending to the human needs of the patient.)
10. The allowance for existential-phenomenological forces. (Nurses who have an understanding of their own life-death and open themselves up to the spiritual-mysterious provide wonderful end-of-life care.)

"The caring relationship established by the nurse with the patient and the family offers an opportunity for shared decision making during challenging times ahead, no matter what the outcome of the disease" (Griffie et al., 1999, p. 66). A focus on healing and caring rather than curing allows for palliative care to begin. Griffie et al clearly stated that "Basing nursing care on a relational response to the human need to experience genuine caring and relatedness with oneself and with another person provides the foundation for an ethic of palliative care" (p. 66). The challenge for nurses that Griffie et al so eloquently stated is that "the focus of nursing intervention becomes the need to preserve human dignity, to restore and preserve humanity in a fragmented, technological, and cure-oriented medical care system" (p. 66).

Jean Watson further explored and expanded her work when she published Nursing: Human Science and Human Care. She continues to focus more on the human care process and the transpersonal aspects of caring. The basic premises are a reflection of the interpersonal-transpersonal-spiritual aspects of her work. It represents an integration of her beliefs and values about human life and provides the foundation for the further development of her theory.

She clearly believes that a person's mind and emotions are windows to the soul. She also believes that people need each other in a caring, loving way. A person's body is confined in time and space, but the mind and soul are not confined to the physical universe. Access to a person's body, mind, and soul is possible as long as the person is perceived as and treated as whole. The spirit, inner self, or soul (geist) of a person exists in and for itself. To find solutions, it is necessary to find meaning. And the totality of experience at any given moment constitutes a phenomenal field.

Palliative care recognizes that death is a natural process and, importantly, an acceptable outcome of care. It recognizes that the family is the unit of care, not just the patient with the life threatening illness. "Nursing as a profession exists in order to sustain caring, healing, and health where and when they are threatened biologically, institutionally, environmentally, or politically by outside influences" (Watson, 1996, p. 141). Theoretical nursing frameworks, especially transpersonal caring theory, are consistent with this approach (Griffie et al, 1999, p. 66). Holistic caring, both for the patient and the family, is central to an effective palliative care approach.

Falk-Rafael (2000) noted that at least three factors make Watson's theory unique among nursing theories.

> First, it stresses the importance of the lived experience not only of the client, but also of the nurse. Both come together in a caring moment that becomes part of the life history of each person. Second, the theory acknowledges the

> unique dimensions of mindbody-spirit [sic] without compromising the wholeness of the person...Third, Watson's theory of nursing values and explicitly acknowledges multiple ways of knowing, including empirical, aesthetic, ethical and personal knowing. (p. 36)

It is this uniqueness that makes Watson's theory of care the most appropriate one to utilize within palliative care programs.

I believe that Jean Watson's theory is not culture specific and applies to humanity at large. Eddins and Riley-Eddins (1997) undertook an examination of Jean Watson's theory of human caring to ascertain its multicultural aspects and implications for multiculturalism. Their findings were as follows:

> Furthermore, we found her generalized theory of human activity (human nature), with its attendant philosophical foundation and its *specification of (basic) human needs to be* especially compatible with multiculturalism. Finally, we considered Watson's projections for nursing knowledge theory in the age of postmodernism. In the course of this analysis, we showed how Watson's theory of human activity could point the way for nursing theory to embrace paradigms appropriate to the demands of postmodernism, while avoiding the consequences of theoretical and moral nihilism. (p. 30-31)

Strickland (1996) looked at applying Watson's theory for caring among elders. The findings included a call for a new paradigm of nursing as directions are shifted in health care: one that abandons the reductionistic cure paradigm of Western medicine and embraces the caring/healing paradigm postulated by Watson that hold the subjective experience of the person as the central concern.

> A nurse's 'conscious intentionality,' or conscious effort to 'be with' the patient and not just 'do for' him or her, fosters 'transpersonal encounters' in which both the nurse and patient fully participate. Such human-to-human exchanges promote healing in not only the patient, but in the nurse as well. Ministering to the spirit, through listening (receiving the other person's experience), is indeed caring, transpersonal (larger than 'me and you'), and healing. (Strickland, 1996, p. 6)

I think that using Watson's theory in working with the interdisciplinary team approach is the best approach especially if one considers using carative factors in all of their relationships. The patient, nurse, and interdisciplinary team all benefit from transpersonal interactions.

Nursing scholars and researchers around the world are adding credence to the carative factors or caritas (from the Greek word meaning to "cherish, to appreciate, to give special attention, if not loving attention to") as Watson now refers to her carative factors. She has redefined them somewhat or enhanced their meaning from her original work and they are now even more fully explained than before. For example:

> Formation of humanistic-altruistic system of values becomes practice of loving kindness and equanimity within the context of caring consciousness. Instillation of faith-hope becomes being authentically present, and enabling and sustaining the deep belief system and subjective life world of self and one-being-cared for. Cultivation of sensitivity to one's self and to others becomes cultivation of one's own spiritual practices and transpersonal self, going beyond ego self, opening to others with sensitivity and compassion. Development of a helping-trusting, human caring relationship becomes developing and sustaining a helping-trusting, authentic caring relationship. .... (Watson, 2001, p. 347)

Jean Watson's theory ideals have goals that are associated with mental-spiritual growth for self and others, finding meaning in one's own existence and experiences, discovering inner power and control, and potentiating instances of transcendence and self-healing. The nurse is a co participant in change through the human care process. The premise that human care requires knowledge of human behavior and human responses to actual or potential health problems; knowledge and understanding of individual needs; knowledge of how to respond to others' needs; knowledge of our strengths and limitations; knowledge of who the other person is, his or her strengths and limitations, the meaning of the situation for him or her; and knowledge of how to comfort, offer compassion and empathy are all fully operational in her theory. I believe that it is clear that use of this theory makes a substantial difference in the lives of those for whom it is implemented.

Aspects of Care

Improved Communication and Patient Education

The end-of-life is not easily or openly discussed often in our society. It is often times difficult to have people begin to face their own mortality by asking direct questions regarding the kind of care they want to receive. These questions need to be asked and answered. F. W. Nelson (1994) noted, "The 'death culture' in America is largely one of denial. Not only do we not deal with death very well, we frequently refuse to say its very name" (p. 10). She further noted that "our societal denial of death has resulted in a lack of suitable death education, not just among the general public, but among physicians, staff and clergy—the very people who are our frontline care givers" (p. 10). The last decade has been seen an emphasis placed on the rights of the dying and the need to improve care at the end-of-life for all Americans.

One of the challenges for nurses and other members of the health care team are to communicate with patients and their families on a level that can be fully comprehended by the patient and family. Effective communication is the basis for any and all education that the patient and family receive regarding the illness and prognosis for the patient.

"The modern patient is expected to take an active role in health maintenance, and so patients must be effectively educated in order to be partners in their care" (Hamric, Hanson, & Spross, 2000, p 471). Advanced practice nurses are in a unique position to provide the education that the patient and the staff need to facilitate quality care and patient rights. The Joint Commission on Accreditation of Healthcare Organization (JCAHO) has provided stringent standards that all acute care facilities must meet in regards to patient and family education. JCAHO mandates that acute care hospitals have an ongoing, interactive, multidisciplinary approach to patient and family education that is consistent with the patient's plan of care (Krozek, C & Scoggins, A., 2001). "Education must ensure that patients and families understand their full responsibilities in the health care process and that they are given the knowledge and skills needed to carry them out" (Krozek & Scoggins, 2001, p 4).

Additional JCAHO standards require that patients be educated on pain management and their right to receive relief from pain. JCAHO has yet to fully require education regarding care at the end-of-life. They do have standards that address advance directives and do not resuscitate orders as well as organ donation. Advanced Practice Nurses who work daily in palliative care have the opportunity to do more than meet the JCAHO standards by teaching patients and their families about the care that is available at the end-of-life.

The Joint Commission is not the only regulatory body looking at the need for patient education. The World Health Organization in its' 1994 World Health Assembly declaration stated, "patients have the right to be given factual, supportable, understandable and appropriate information, to be provided in such a way as to allow them to decide whether they wish to receive therapy" (Collier, 1998, p. 1724).

Today's patient is a healthcare consumer and is more involved in their care than ever before. It is evident that patients should have education about care at the end-of-life when curative therapy is no longer appropriate. It would seem to be prudent to begin educating patients about such care at the time of diagnosis of a life threatening illness and not at the end.

Throughout nursing's history, nurses have had an important role in educating the patient and their family about wellness and illness. "Nursing's recognition of the importance of patient education is evident in nursing's history and in the early work of nurse theorists" (Sanford, 2000, p 1). Prominent nursing leaders including Florence Nightingale have viewed "the education of patients and families as core to nursing care"(Sanford, 2000, p. 2).

Advanced Practice Nurses who work in End-of-Life care have a wonderful opportunity to not only educate patients and their families but communities as well. Public awareness of the increased need for quality care at the end-of-life has risen over the last decade. As our society ages and people survive longer with chronic, debilitating diseases, it has become increasingly clear that there is a need for education about the care available at the end-of-life.

Pain Management

Pain management is one of the most important aspects of care for terminally ill persons whether they are dying from an aggressive cancer, old age, or an end-stage disease process. There is a tendency for health professionals to not only underestimate pain, but they also consistently under treat pain. We have the means to alleviate pain and suffering and yet practitioners are often hesitant to order the appropriate medications due to fear of reprisal or lack of adequate education about palliative care. Effective pain management is truly tantamount to quality end-of-life care.

The American Academy of Hospice and Palliative Medicine has issued a position statement on Comprehensive End-of-Life Care and Physician-Assisted Suicide that is available on their website, WWW.AAHPM.ORG:

> The central goal of hospice and palliative care is the relief of pain and suffering. In order to achieve this, a physical and social environment must be established conducive to comfort. This environment must include the patient's personal and cultural values in the face of expected death…The ability of hospice and palliative care to alleviate suffering is vastly under-estimated and under-utilized by the public and health-care professionals. Access to these services by a large portion of our population has been limited by cultural, financial, regulatory, and philosophical barriers. Their absence as an informed choice has regrettably compelled some patients to seek death prematurely. We therefore promote major efforts towards improving such access to hospice and palliative care by the ongoing education of health-care providers, training programs, third party payors, and society. This must include education in principles, practice, and benefits of palliative medicine. Scientific research with the goal of improvement of symptom relief and care of patients with end-stage illness remains essential. …It is through such an integrated approach to end-of-life care that fears and suffering are eased, personal growth and

> preparation for death can occur, and desire for a hastened death can be minimized. (AAHPM, 1996).

The Burnout Potential and Coping Mechanisms

Caring for patients at the end of their life is perhaps one of the most rewarding nursing experiences. Nurses truly make a difference in the level of comfort experienced by the dying patient. The personal expense of providing end-of-life care can be overwhelming unless the staff member is well practiced at employing coping mechanisms and self-renewal techniques.

Nurses who work exclusively with dying patients experience even more stress than those in traditional settings because of the potential energy depletion the tremendous emotional investment in their work can entail (Amenta, 1986). A major source of stress in working with people who are dying is regular contact with the most fundamental human fear - fear of dying- and with suffering, hopelessness, meaninglessness, and uncertainty (Kemp, 1999). Kabcenell, Lynch, and Lynn (2000) succinctly stated the following:

> Regardless of their professionalism, those who work in end-of-life encounter emotional challenges-the unpredictability of death, the repeated losses, the interaction with grieving and overwhelmed family members and loved ones. Although their potential for burnout is high, those who work in this field generally first

> speak of their satisfaction in caring for patients and families. (p. 179)

Hospice nurses who work exclusively with dying patients experience even more stress then those in traditional settings because of the potential energy depletion the tremendous emotional investment in their work can entail (Bohnet, 1986).

Stress levels affect people and the manner in which they care. Stress can be external or internal. External stressors are those that exist from outside the person whereas internal stressors are those that arise from individual perceptions of situations and value conflicts.

Coping behavior is a learned behavior. The ability to deal with a stressful situation without disruptive anxiety or depression is by definition effective coping (Harper, 1977). Healthcare professionals need to be emotionally available to the recipients they serve as well as their families and themselves.

Many caregivers do not fully comprehend the necessity of positive coping mechanisms and the integral nature of the implementation of these mechanisms in avoiding burnout. Staff does not always realize that they have reached burnout or the negative impact it has upon the delivery of compassionate care. Palliative care is about human companionship, sensitivity to unspoken feelings or fears, attention to fine details, and transpersonal caring. An understanding of coping mechanisms employed by staff members on a palliative unit can increase the level of transpersonal care given and decrease the burnout of the staff.

"It has been frequently noted that the feelings and fears of dying people can be too painful for professional carers to cope with on a day-to-day basis without considerable support" (Robbins, 1998, p. 89). Providing staff support is a major component of the strong foundation needed for effective palliative care.

B. C. Harper (1977) proposed a model that is divided into five stages and is known as the Line of "comfort-ability". She developed the model to explain the growth process of staff members caring for the terminally ill. The stages are intellectualization, emotional survival, depression, emotional arrival, and deep compassion. This "comfort-ability" is a growth process that begins when a staff member is new to care of the terminally ill and evolves over a period of one to two years. This process usually evolves over a two-year period.

Learning to provide care for the dying is a deeply moving personal and professional process. As with many learning experiences, the process is fraught with anxiety and trauma. The stages are painful and depressing, at times unbearably so, but growth is rewarding and a culmination of all that has transpired (Bohnet, 1986).

Stress management requires a high degree of self-awareness and personal responsibility for effective coping and personal growth. The staff member who takes the time to explore and understand personal feelings and behavior and accepts the responsibility for managing them will be rewarded with satisfaction and fulfillment in nursing care of the palliative patient. The importance of the individuals' understanding sources of stress and the need to take responsibility for managing stress cannot be overemphasized.

Clinical competency is tantamount to a decreased stress level. Social support is also a vital factor as is spiritual support. Another factor essential to minimizing or managing stress is setting reasonable goals. Lifestyle management is also a factor in stress reduction. Facilities and training programs can only offer programs pertaining to stress management that encompass these factors. These are a few of the strategies yet it is really up to the individual staff member to accept responsibility for effectively coping with and managing stress.

Ethics

In a culture where advanced technology abounds and our ability to prolong life has expanded well beyond the potential for quality life, health care professionals are confronted with the ethical dilemmas on a daily basis.

> Several factors have made nurses' ethical choices necessary and immediate, including expanded technology and the rising status of nurses as active participant in the health care system, and ethical arena. Improved communication, more highly educated practitioners who recognize a dilemma when confronted with one, and an expanded consciousness of nursing's responsibility and impact on society have also had an effect. (Wurzbach, 1995, p. 1060)

As nurses we are empowered with principles of deontological ethics to guide our practice. The principles of autonomy, beneficence and nonmaleficence guide many of our decisions. Autonomy requires us to respect an individual's right to self-determination, and to allow that each is the best judge of benefit and harm in her or his own case without allowing our own value system to interfere or influence the individual's choices. Beneficence requires us to consider the patient's total well being when working toward the good of the patient.

Nonmaleficence requires us to consider the amount of harm, indignity and stress that is likely to be associated with advanced treatments or invasive procedures.

Nurses must continue to receive education in ethics as well as end-of-life care. The nurse has to be committed to maintaining their knowledge and skills at a level that benefits their patients.

> Nurses must recognize when they should provide palliative or terminal care instead of treatments intended to preserve life. This requires and understanding of the process of dying. For instance, nutrition and hydration are no longer appropriate in a situation when the patient can absorb neither food nor liquids. To force these on a dying patient is not only distressing but can cause more pain owing to stomach cramp. The patient may vomit and develop inhalation pneumonia as a result of inappropriate attempts to prolong life by feeding. (Shotton, 2000, p. 138)

"Futile care diminishes the value of life and inhibits the professional and personal growth of health professionals" (Shotton, 2000, p. 140). Health care team members responsible for delivering continued futile care are often inwardly upset over their role in the futility. Nurses often feel very frustrated by the suffering that they continue to see in the patient that they are keeping alive with technology when there is truly no hope of recovery. Ethical dilemmas can arise from these feelings of frustration.

Surveys and Studies

The Robert Woods Johnson Foundation has initiated a project called, "Strengthening Nursing Education to Improve End-of-Life Care". The project included a survey of nursing faculty and state boards of nursing education.

The survey analysis uncovered some differences in opinion among the three professional organizations and between faculty and deans. The National Council of State Boards of Nursing, for example, rated the schools less adequate in their content areas than did the deans or faculty, and the same was true for the ratings of new graduates. (Ferrell, B., Grant, M. & Virani, R., 1999,).

In a recent survey that was completed by 2,333 nurses with vast experience and broad backgrounds, it was determined that they considered their basic nursing education inadequate preparation for end-of-life care. "The vast majority rated their basic nursing education inadequate in all areas (pain, overall end-of-life content, needs of family caregivers, symptom management, grief, goals of care, ethical issues, and care at the time of death). Clearly, changes in basic nursing education and more continuing education are keys to improving end-of-life care" (Coyne, Ferrell, Grant, Uman, & Virani, 2000, p 56).

It has been suggested by another recent survey that nurses are distressed by unrelieved pain or other symptoms and that their continual involvement in inadequate care of the dying strongly influences professional beliefs. "More research is needed to explore these concerns in depth" (Ferrell et al, 2000, p 57).

Education and Research

The need for schools of nursing to include end-of-life content is undeniable. Many scholars have recognized the need for fully prepared health care providers in palliative care.

> "There is a continual growing concern and impetus being placed on comprehensive care and treatment of the individual from birth to death. There is also strong evidence to lead one to believe that humanization of health care delivery must include attention to the development of health workers who are academically, emotionally, and psychologically prepared to deal with the dying patient and the family" (Harper, 1997, p 65).

Not only is there a present need to educate our society about the needs and care of the dying but also the need exists to educate our health care professionals. Health care professionals develop relationships with the patients they care for and need to be well educated themselves in order to advocate for the patient and assist with informed choices.

The importance of developing continuing education programs specific for palliative care cannot be underestimated. Continuing education not only enhances clinical competence, it also enhances the individual's ability to effectively cope with the stressors of providing end-of-life care. I return time and again to the literature and realize the sparse content that is available from which to make evidence-based statements.

Education, experience, and communication skills are important competencies for staff to possess and actually can decrease the stress level. Robbins (1998) articulated quite clearly that:

> "Acquiring the skills and expertise involved in palliative care is important for staff to feel confident in their work, and this again is intimately connected to feelings of stress and anxiety. Support for staff by providing access to in-service training, opportunities to learn new skills, and the formal recognition of increasing experience is a fundamental aspect of professional development"(p 92).

Many philanthropic organizations have funded grants for research and education on end-of-life care for physicians, nurses, and other health care professionals to receive training to enhance the quality of care provided at the end-of-life. There are currently several grants that have been awarded to consider the content of nursing books for end-of-life care. Private foundations, such as the Robert Woods Johnson Foundation, are already providing grants to some nursing researchers.

There is much research left to do in the palliative care specialty field. As the elderly population continues to grow, the need for professionals trained in care of the dying will become increasingly acute. The need for further research and educational offerings is quite clear. "Being a relatively new specialty, with an evolving and expanding multidisciplinary remit, the challenge of developing innovative and effective educational methods is real" (Sheldon & Smith, 1996, p. 104). Research on dying has the potential to touch every family and every individual in some way as death is a journey each of us will take.

Cassel and Field (1997) found that:

> As technologies, policies, organizations, and expectations change, formal continuing education will have a role to play in helping health professionals acquire new knowledge, hone existing skills, and continually improve their abilities to care well for dying patients. The education of professionals is a life-long experience. (p. 209)

Legislative Needs

Nurses are the people providing the direct care at the end-of-life and as such should be actively involved in establishing evidence-based practice and palliative care protocols for our aging society. At the national level, it is imperative that health care practitioners raise their collective voices and advocate for federal research that focuses on aggressive management of pain and other symptoms experienced by patients at the end of their life.

We must remain politically active and ensure that our Senators and Congressmen hear our collective voices. It is important to speak out about the need for continuing education for nurses and ask for legislation that protects and funds palliative care research and education.

It is time for our legislature to enact law that provides funding for research and education for palliative care and assures that patients receive effective pain management at the end of their life hopefully adding to the quality of their last days. We practice in an evidence-based environment and the need to establish this evidence has never been as great.

Summary

The literature important to the project was presented in Chapter Two. Specifically, an overview of the multitude of challenges and opportunities for professional and personal growth working in palliative care presents to the healthcare professional. In today's technologically advanced age, people facing life-threatening illnesses, whether from cancer or chronic disease processes, have many processes available to them to prolong and support their lives. When these processes no longer have value to the person and the decision is made to forego life-sustaining treatments, quality palliative care provided by competent health care professionals should be available for them regardless of their location.

For nurses working in palliative care, Jean Watson's theory of human care is the most appropriate theory to base care delivery upon. It encompasses many of the needs of patients who are dying as a basic premise for the theory.

Further education on the care of the dying is an absolute necessity as is research. People have an inherent right to the best care possible at the end of their life. Care delivered with compassion, empathy, dignity and respect. People should receive care that effectively manages their symptoms and allows for their psychological, spiritual, and social needs to be addressed. True holistic care of the patient and their family is the spirit of quality palliative care.

CHAPTER THREE

METHODOLOGY

Introduction

Chapter Three documents the steps used in developing the project. Specifically, the steps include applying for the End-of-life Nursing Education Consortium (ELNEC) grant and teaching two modules of the nine content areas at the Loma Linda Veterans Affairs Medical Center. The following goals were established: 1) To apply for and receive an ELNEC Project grant; 2) To receive training and become an ELNEC certified trainer; and 3) To implement an end-of-life education program at the Loma Linda Veterans Affairs Medical Center.

Goal 1: Grant Application

Methodology

After an extensive review of literature available on end-of-life care and attending numerous conferences on palliative care, I learned about the existence of an end-of-life nursing curriculum at an Education for Physicians of End-of-life Care (EPEC) conference in May 2001.

A search for information was begun on a group called ELNEC. I was fortunate to see Dr. Betty Ferrell at a hospice conference in June 2001. I introduced myself as a master's student from CSUSB deeply interested in end-of-life education. Questions were asked about ELNEC. Dr. Ferrell is one of the principle investigators on the project. She gave me the web address for the grant application information and encouraged me to apply.

Information was downloaded on ELNEC from the American Association of Colleges of Nursing (AACN) website (see Appendix A) and I began to work through the application process. Administrative support for the project was requested from the Director, Nursing Operations, at the Loma Linda Veterans Affairs Medical Center. A letter of application was written along with a teaching implementation plan, and my resume updated to submit to the AACN (see Appendix B). This information was submitted to Washington, D.C. and a response was anxiously awaited from the AACN.

Results

The response was received on September 10, 2001. I had been selected to attend the End-of-life Nursing Education Consortium Training Course scheduled for November 15 - 17, 2001 in Pasadena, California. To say that I was excited is an understatement. I was curious to see the curriculum that had been put together by some of our most renowned nursing scholars and researchers in end-of-life care.

Goal 2: Training

Methodology

I arrived in Pasadena on the afternoon of November 14th. I located the conference rooms and anxiously awaited the registration time. There was a welcome reception scheduled at 7 pm for participants and faculty.

The reception was great. I met and networked with many nurses from across the country. Some were involved with palliative care and others were not. Some of the nurses were continuing education providers and others were staff developers who were not directly involved with end-of-life care. It was a great opportunity to discuss the needs of the patients that we care for who are dying. The discussions were lively and passion filled.

The training began the next morning. I was captivated by the faculty. The content was well prepared and presented beautifully. The faculty was virtually a who's who in palliative care nursing. I was truly in awe and simply amazed at the knowledge, compassion, and genuineness of the presenters. The three day training session was incredible. It ended all too soon.

I was thrilled to receive two new textbooks as part of the training. The scarcity of books on palliative care in nursing has been diminished by the publication of these books : The Textbook of Palliative Nursing, Coyle, N. & Ferrell, B. R., (2001), New York: Oxford University Press and Palliative Care Nursing Quality Care at the end-of-life, Matzo, M. & Sherman, D. W. (Eds.), (2001), New York: Springer Publishing Co. I spent several hours the first night reading chapters in both books. I was overwhelmed with gratitude for the work done by these dedicated nurses. Copyright permission was received for educational program purposes (see Appendix C).

Results

The information that I obtained at the ELNEC training is invaluable. I left the training with a renewed sense of hope for a future where palliative care is readily available for everyone. The Loma Linda Veterans Affairs Medical Center prepared a news release announcing the completion of ELNEC training (see Appendix D).

Goal 3: Educational Program Implementation

Methodology

Realizing the time constraints imposed for completion of this project, each of the nine content modules from the curriculum were evaluated closely. Each content module was scrutinized for its appropriateness for immediate dissemination to the nursing staff and its impact on improving patient care swiftly.

Two modules were selected for immediate implementation: Module 1-Nursing Care at the End-of-life and Module 3-Symptom Management at the End-of-life. I believed that an overview (Module 1) of the current trends, issues, and realities in the care of the dying was needed and the most useful information to present and hoped to open the eyes, minds, and hearts of the nursing staff. I selected Module 3 as the next most important content area as I realized that many patients do not receive effective symptom management. Each module was scheduled to be presented twice so that as many staff as possible could attend.

These two modules were the selected because they had the potential of having the most positive impact on patient care at the LLVAMC. Raising staff awareness and increasing their knowledge base regarding symptom management in end-of-life care were top priorities for the project. The other seven modules will be taught in sequence over the next 8 months.

Module 1: Nursing Care at the End-of-life

An appointment was made with the nurse educators at the Loma Linda Veterans Affairs Medical Center. They were the first stakeholders that I had to confer with about the project implementation. Fortunately, they were nearly as excited as I was to see the curriculum.

A timeline was created for the project (see Appendix E). It was already late November and there was lots of preparation and planning tasks to accomplish. The first module, Nursing Care at the End-of-life was scheduled to be presented twice on January 10, 2002. The process of applying for continuing education units (CEU) for the nursing staff that would attend was initiated and completed.

The Nursing Education Department required a copy of the program director's curriculum vitae along with stated program objectives, an outline of the presentation and any handouts that would be provided to the participants. For the CEU to be issued, participants were required to complete a program evaluation that was provided by the Nursing Education Department. These evaluations remain on file along with the program information that was provided for a period of five years. This is to meet the California

Board of Registered Nursing requirements for issuing CEUs to program participants.

Once the requirements for the CEU issuance were met, the information was complied for the handouts (see Appendix F) for Module 1. The handouts were sent to reproduction and the program director began to consider how to make the program more interesting and relevant for the participants. The faculty outline in the curriculum was reviewed and notes made on places to incorporate care-giving stories that the program director had experienced in ten years of nursing at the VA. The program director used examples from her seven year intensive care unit experience as well as examples from her two and one-half year experience in palliative care.

Several books were read in preparation for teaching Module 1, including Final Gifts by Maggie Callanan and Patricia Kelly; The Good Death by Marilyn Webb; Dying Well Peace and Possibilities at the End-of-life by Ira Byock; and The Wheel of Life A Memoir of Living and Dying by Elisabeth Kubler-Ross. I made mental notes and actually used one of the stories from Final Gifts in my didactic lecture. Credit was given to the authors for the story and it was recommended that interested participants read their book.

The program director was nervous needless to say prior to the first lecture. Once she started speaking, she was no longer anxious. She was happy to share her knowledge and passion for end-of-life care with the nurses and other health care professionals who came to the session. Participation from the audience was encouraged by asking direct questions. There was a question and answer session at the end of the presentation.

Several participants approached the program director at the end of the first session to share their own personal experience with the death of a loved one. She was happy that she had thought to bring Kleenex to the class. The program director believes that people have a need to share their pain and fears about death in a safe environment. She believes that the only thing that truly heals people is unconditional love. It was slightly draining to bolster a few of the participant's and their stories.

Module 3: Symptom Management at the End-of-life

Methodology

The curriculum content for Module 3 was reviewed and it was realized that an opportunity to create an expanded non-drug therapy lab in addition to the one-hour didactic lecture existed. The decision was made to have the non-drug therapy lab presented over 90 minutes so that each participant could spend 15 minutes at each station. The stations were: imagery, massage, diversional activities, heat/cold, relaxation, and spirituality. The module would be taught on March 7, 2002.

Many hours were spent performing yet another exhaustive review of the literature. Several hours were spent at the bookstore looking for books on massage therapy, aromatherapy, spirituality, visualization, etc. Many books were purchased and I began marking pertinent passages to use in training the facilitators that I would recruit to assist with the lab. The information for the handout was compiled for both the module and the non-drug therapy lab and was sent to reproduction (see Appendix G).

Nursing peers were consulted who had an interest in non-drug interventions for symptom management. I explained the teaching project to them and asked for their assistance in providing the non-drug therapy lab. Several stated that they had limited knowledge or expertise about the areas that I was asking them to assist with. I explained that I would give them all of the information that they would require to provide a wonderful teaching experience to the staff at their individual stations. I recruited four other masters' prepared nurses to staff four of the six stations. The stations that they facilitated were: massage, relaxation, diversional activities, and heat/cold. I taught the imagery station.

Recruiting for the spirituality station proved to be the most challenging task in preparation for this module. None of the nurses approached had any comfort level with the topic. The hospital priest who visits with our palliative care patients daily was approached about teaching the spirituality station. A wonderful conversation about spirituality, not religion, was engaged and the program director was certain that she had asked the right person to present the rich, multi-faceted topic of spirituality at the non-drug therapy lab.

A handbook (see Appendix H) was created for the facilitators and a compiled reading list of the books that were available for them to expand their knowledge on their chosen content area for the lab. Artifacts such as Buddha images, Zen gardens, dream catchers, and novena candles were collected for the spirituality station. Different types of hot and cold compresses were purchased for the hot and cold station. Essential oils and massage lotions were available as well as video and audio at the guided imagery/aromatherapy station. The massage station had a massage table and a hand-held percussion vibrator available as well as other massage instruments. The participants were provided with a vast array of items to touch, feel, see, smell and experience as they worked their way through the non-drug therapy lab.

The CEU process for this module was again undertaken and each participant earned 2.5 hours credit for attending. Two separate teaching sessions were offered to the hospital staff.

Summary

The steps used in developing the project along with the methodology for the implementation of the end-of-life nursing education program were presented in chapter 3. Many hours were committed to the successful delivery of the educational program.

CHAPTER FOUR

RESULTS AND DISCUSSION

Introduction

Chapter Four discusses the result of completing the project. Further, the overwhelmingly positive reception of the educational program was extremely rewarding. The staff at the Loma Linda Veterans Affairs Medical Center was more than receptive to the curriculum.

Presentation of the Findings

Each of the modules was presented to the staff twice. The programs were well attended in spite on time limitations for staff. More than 100 staff members attended the modules.

Discussion of the Findings

The programs were well received by members of the nursing staff and other disciplines who attended. The program evaluations that were completed by participants as part of the California Board of Registered Nursing requirements for continuing education credit were excellent.

The staff had the opportunity to provide feedback regarding the programs overall quality, quality of content, recommendation to peers about the program, and applicability of the program to current nursing practice. The ratings were excellent, good, average, or poor. The vast majority of the evaluations were excellent in all four areas assessed.

Many participants gave feedback concerning the value of the programs. The comments were affirming the great need for this educational program and the participants' appreciation for the opportunity to receive the information. Several stated that the programs were much needed and should be repeated. Others asked for more programs on care at the end-of-life.

The program director inferred from the responses received that the nurses at the Loma Linda Veterans Affairs Medical Center are no different from the nurses who have been surveyed by other nurse researchers in their knowledge and comfort level with delivering end-of-life care or palliative care to their patients.

The responses validated the need that the program director had perceived for continuing education on care at the end-of-life. The need was based not only on personal clinical experiences with other nurses and patients, but also on the exhaustive review of the literature that had begun when I accepted the position as nurse manager of the unit with the palliative care program.

Summary

These findings indicate that the project was valuable for the staff and patients at the LLVAMC. It filled in gaps in knowledge for the staff that attended. The End-of-life Nursing Education Consortium has afforded nursing the opportunity to improve the quality of care patients receive as they die. Prior to the creation of the body of knowledge by the ELNEC Project, continuing education for end-of-life care was minimal and inconsistent.

CHAPTER FIVE

CONCLUSIONS AND RECOMMENDATIONS

Introduction

Included in Chapter Five was a presentation of the conclusions gleamed as a result of completing the project. Further, the recommendations extracted from the project are presented. Lastly, the Chapter concludes with a summary.

Conclusions

The conclusions extracted from the project follow:

1. Nurses modeling good communication skills with dying patients and their families are one of the hallmarks of successful accomplishment of this project.
2. The impact of this educational offering will be realized when a caring and competent staff are able to cope with the demands of providing quality end-of-life care on a daily basis without reaching burnout. Through educational offerings the staff will be better equipped to provide palliative care to patients and families. "Professionals and staff working in end-of-life need time and opportunity to

recognize their own humanity, to consider their own mortality, and to integrate-and separate-their personal and professional lives" (Kabcenell, Lynn, & Schuster, 2000, p.188).

3. Affording nurses the opportunity to express their feelings, fears and beliefs in a protected environment was very beneficial to all who were present during the sharing experienced at the programs. The relevance is nation wide. Nurses across the country need to have the ability to share their feelings, fears and beliefs in protected environments where learning and healing can occur.
4. Additional outcomes will be realized when there is greater public awareness of the need for palliative care research and education and monies are available through state and federal agencies to provide funding for this endeavor. With communities more aware of the needs of the dying and with an understanding of the community responsibilities to the dying, it is hoped that more available palliative care programs will be funded.

5. At the national level, it is imperative that health care practitioners raise their collective voices and advocate for federal research that focuses on aggressive management of pain and other symptoms experienced by patients at the end of their life.

Recommendations

The recommendations resulting from the project follows.

1. It is important to complete the implementation of the nine module content areas of the curriculum at the Loma Linda Veterans Affairs Medical Center. Once presented in its entirety, the modules should be repeated again for the staff with new information incorporated into the content.
2. The education of health care professionals is a life-long experience. The need for healthcare systems to offer quality, current, evidence-based educational programs that are relevant to practice areas is essential to the delivery of quality palliative care will not lessen. Continuing education providers and staff

developers must continue to include end-of-life content in their programs.

3. Within professional nursing curriculums, there is a nationwide need for end-of-life content to be offered at the beginning of a nursing career. Nurses must be equipped with the necessary skills to care for the increasing elderly population as this population approaches the end-of-life.
4. Nurses need to actively seek research grants for delving into the arena of palliative care. We must establish the evidence base. Working with people who are actively dying makes the research just a little more challenging in that many of the subjects die before the study is ended.
5. At the state and local levels, we need to be advocating for pain management and other symptom control for dying people. We need to raise public awareness about end-of-life care. We must speak out about end-of-life issues and care wherever the forum presents itself.
6. Influencing policy and legislation at all levels of government will be part of assuring improvement in not only the quality of

palliative care, but also the availability of palliative care for everyone.

7. Cassel and Field noted, "...that health professions education can do better in conferring a basic level of competence in the care of the dying for all practitioners"(1997, p. 208). All health care professionals who work with patients must possess core competencies in the care of the dying.

Summary

Chapter Five reviewed the conclusions extracted from the project. Lastly, the recommendations derived from the project were presented.

Palliative care needs to be offered across many settings, not just hospice, and society must be educated to expect a high standard of care at the end-of-life (Ferrell & Virani, 1999). It is important for the ever growing number of elderly who continue to live even longer life spans than the last generation to demand and receive appropriate end-of-life care. The conversations about the care desired at the end-of-life need to begin in homes across this nation.

These conversations also need to be repeated in public arenas as well. Discussions are essential to develop a better understanding of the modern experience of dying, the options available to dying patients and families, and the obligations of communities to those approaching death (Cassel & Field, 1997). Hospitals need to develop and implement continuing education programs for their staff, which will enable them to provide the high caliber of care that dying patients deserve.

Personal Learning

I have come to understand that my future nursing career is in nursing research and education for palliative care. I want to make a difference in a nurse's ability to provide end-of-life care well and remain emotionally intact while doing this incredible work. Although nursing has proclaimed to be holistic providers of care, the present constraints of resources often focus nursing care on just the immediate needs of the patient. However, at the end-of-life, the needs of the patient shift and true holistic care is the immediate need of the patient.

I also have learned that speaking out about the need for continuing education for nurses is important. Asking for legislation that protects and funds palliative care research and education is also extremely important.

The end-of-life is our last great journey and nurses make the difference in the last days and hours along the way. Their concern, compassion, and care, not only for the dying, but the family as well make the transition between life and death more bearable. I want to take an active role in creating a better understanding of palliative care and developing protocols and policies for nurses delivering end-of-life care.

APPENDIX A

END-OF-LIFE NURSING EDUCATION CONSORTIUM PROJECT

American Association of Colleges of Nursing

ELNEC Project

About ELNEC

The End-of-Life Nursing Education Consortium (ELNEC) project is a comprehensive, national education program to improve end-of-life care by nurses, and is funded by a major grant from The Robert Wood Johnson Foundation. Primary project goals are to develop a core of expert nursing educators and to coordinate national nursing education efforts in end-of-life care.

This 3½-year project began in February 2000, and is a partnership of the American Association of Colleges of Nursing (AACN) and the Los Angeles-based City of Hope National Medical Center (COH). ELNEC actually is a consortium of many organizations that are represented on the ELNEC Advisory Board. This diverse group insures that the ELNEC project brings together leading nursing groups and perspectives to form a collaborative approach to improve end-of-life education and care. AACN is coordinating the project, while nurse researchers at COH developed and continue to revise the curriculum, as well as evaluate the educational program. The project also has representation from the national program "Educating Physicians on End-of-Life Care" (EPEC) to foster strong collaboration with our medical colleagues. The ELNEC curriculum has been developed through the work of highly qualified subject matter experts serving as consultants, with extensive input from the Advisory Board and reviewers. Courses are designed to prepare educators to disseminate this important subject matter into nursing schools and health care agencies.

Originally five courses were planned, but the call for applicants for the first course elicited an overwhelming response from the nursing education community. Supplemental funding by the Robert Wood Johnson Foundation has resulted in a total of eight ELNEC courses to be sponsored by AACN and COH during the 3½-year project. Five additional courses are planned in conjunction with Last Acts Regional Conferences.

The 13 total courses sponsored by the ELNEC project are designed to meet the unique needs of several specific groups of nursing educators:

- **baccalaureate and associate degree nursing faculty** who will facilitate integration of end of-life care in basic nursing curricula (five courses)

- **nursing continuing education providers and clinical staff development educators** who will offer educational activities to improve the end-of-life care by practicing nurses. This group includes nurses providing continuing education in colleges and universities, state and specialty nursing organizations, and independent businesses, as well as continuing education/staff development in clinical settings such as hospitals, hospices, home care, and long term care (seven courses)

- **state board of nursing representatives** to strengthen their commitment to encouraging end-of-life care education and practice initiatives in their states (one course)

About: (click on logo)

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City of Hope

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Please direct comments and suggestions to webmaster@aacn.nche.edu.

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American Association
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ELNEC Project

ELNEC Courses and Application Information

The End-of-Life Nursing Education Consortium (ELNEC) project will offer a total of 13 ELNEC courses during the 3-½ year project. Each ELNEC course provides knowledge and skills in end-of-life care as well as specific teaching/learning resources to use in improving end-of-life nursing care education and practice. Courses are offered for several distinct groups of nurse educators including baccalaureate and associate degree nursing faculty, nursing continuing education providers/clinical staff development educators, and State Board of Nursing representatives. Registration for each of the courses is limited, and application is a competitive process.

The ELNEC courses will produce a core of educators trained in the ELNEC curriculum. These educators then will be prepared to offer end-of-life care programs in a variety of educational contexts. As educators complete the courses their names will be added to the expanding list of **ELNEC Trainers** on this web site. These educators can serve as resources and provide ELNEC training for nursing colleagues.

The **ELNEC curriculum** was developed by a group of nationally recognized experts in end-of-life care. It is revised regularly based on participant recommendations and new advances in the field, and is modified for each distinct group of educators. The ELNEC curriculum consists of nine **content modules**. For each module, the syllabus contains objectives, student note-taking outlines, detailed faculty content outlines, slide copy, reference lists, and supplemental teaching materials. These materials are furnished both in hard copy as well as on a CD. Curriculum materials are designed for use by educators as prepared, with minimal revision. Minor modification of the curriculum to meet institutional needs is acceptable, and the CD format facilitates this process. Permission to use, duplicate, and modify copyrighted materials is given to participants.

In addition to the materials described above, two new textbooks are provided to participants:

Ferrell, B.R. and Coyle, N. (Eds.) (2001). *The Textbook of Palliative Nursing*, New York: Oxford University Press

Matzo, M. L. and Sherman, D. W. (2001). *Palliative Care Nursing: Quality Care to the End of Life.* New York: Springer Publishing Company

Four types of courses are offered, each designed to meet the unique needs of a particular group of nursing educators. See course descriptions for specific information.

- Baccalaureate and Associate Degree Nursing Faculty
- Nursing Continuing Education Providers and Clinical Staff Development Educators who have limited experience in end-of-life care
- Nursing Continuing Education Providers and Clinical Staff Development Educators who are experienced in end-of-life care - Last Acts Regional Conferences
- State Board of Nursing Representatives

Courses for Baccalaureate and Associate Degree Nursing Faculty

(These faculty courses are coded F1 - F 5)

These 3-day courses for baccalaureate and associate-degree faculty offer knowledge and skills to facilitate integration and teaching end-of-life care in baccalaureate and associate-degree nursing programs. Due to overwhelming response to the first call for applicants in summer 2000, the first four faculty courses are filled, but spaces remain for the fifth course to be held in January 2002.

Note: Due to occasional cancellations, limited spaces may exist in courses. Applicants who can attend a course, possibly on short notice, may be able to be accommodated on an individually-arranged basis. Applicants must be fully qualified and from schools not represented in any of the courses. For information about these vacancies contact Nicole Brown at nbrown@aacn.nche.edu.

Courses Scheduled:

F1
January 18-20, 2001
Pasadena, CA
completed

F2
March 15-17, 2001
Pasadena, CA
completed

F3
June 21-23, 2001
Cleveland, OH
completed

F4
August 2-4, 2001
Washington, DC
completed

F5
January 10-12, 2002
Pasadena, CA
applications being accepted
space limited to 125 participants
application deadline August 23, 2001 -
late applications considered on a space available basis
notification October 4, 2001

Eligibility Requirements:

1. An interest in end-of-life care and in integrating knowledge and skills in this subject into baccalaureate and associate degree nursing education
2. A full or part-time faculty appointment in a baccalaureate or associate degree nursing education program with plans to continue with that program
3. Support from program dean/director for participating in the course and implementing end-of-life care education within the curriculum

Expectations of those who attend the course:

1. Participate in pre-course assessment and post-course evaluations at course end, and at 6 and 12 month post-course intervals
2. Commitment to integration of end-of-life care content into the program's curriculum

Applications for the 125 spaces in course F5 will be accepted from faculty in schools/programs not represented in courses F1-F4. Each school of nursing should submit only one application. Application guidelines and forms can be downloaded below. Selection is competitive. A mix of baccalaureate and associate-degree faculty will be selected to attend the course. Application deadline for course F5 is August 23, 2001. Early application is encouraged and may be a selection factor if the number of qualified applicants exceeds available spaces. Applicants will be notified of their status no later than October 4, 2001. Costs of registration, lodging, course materials, and continental breakfast and lunch during the course are underwritten by the grant for F1-F5 participants. Travel and incidental expenses are the responsibility of each individual. Each faculty course attendee receives a $350 stipend to partially offset travel and additional expenses.

For questions about the courses for baccalaureate and associate-degree nursing faculty (F1-F5), or to inquire about a school/program's representation, please contact Nicole Brown at nbrown@aacn.nche.edu.

Application Form for Baccalaureate and Associate Degree Nursing Faculty (F1 - F5)
(This application requires Adobe Acrobat to download. If you do not have Adobe, please contact Carla Gazlay at cgazlay@aacn.nche.edu or (202) 463-6930, x227 to receive an application by fax.)

Courses for Nursing Continuing Education Providers and Clinical Staff Development Educators who have limited experience in end-of-life care

(These courses are coded P1 and P2)
(Note: Continuing education/staff development educators who are experienced in end-of-life care are directed to the regional courses R1-R5 described below.)

These 3-day courses are designed specifically for continuing education/staff development nurse educators who have limited experience in end-of-life care. Participants include those who provide continuing education in colleges and universities, independent businesses, and state and specialty nursing organizations, or provide staff development for nurses practicing in hospitals, hospice, palliative care, long-term, home care, and other clinical settings. Those who will teach end-of-life content in CE/staff development activities are the most appropriate attendees, but those who manage or sponsor these types of classes are eligible to apply.

Two courses are scheduled:

P1
November 15 - 17, 2001
Pasadena, CA
applications being accepted
space limited to 125 participants
application deadline August 20, 2001 *(Applications after this date considered on a space-available basis.)*
notification August 2001

P2
June 20 - 22, 2002
Chapel Hill, NC
applications being accepted
space limited to 100 participants
application deadline March 22, 2002 *(Applications after this date considered on a space-available basis.)*
notification April 2002

Space is limited in both courses, and selection is competitive. **Each sponsoring organization should submit only one application.** Early application is encouraged and may be a selection factor if the number of qualified applicants exceeds available spaces. Participants selected will represent a variety of CE/staff development settings. Application guidelines and forms can be downloaded below.

As part of the application to attend a course, applicants must submit a plan describing how they will implement end-of-life education/training in the work setting or community within 12 months of attending the ELNEC course. The plan should identify audiences to be trained, project a timetable for sessions/courses, and describe the course as it will be presented. Refer to Specifications for Use of the ELNEC Curriculum for further information.

Costs of registration, course materials, and continental breakfast and lunch during the course are underwritten by the grant for P1-P2 participants. Travel, lodging, and incidental expenses are the responsibility of each individual. Each P1-P2 course attendee receives a $100 stipend to partially offset their expenses.

For questions about the courses for continuing education providers/clinical staff development educators with limited experience in end-of-life care (P1 and P2), contact Nicole Brown at nbrown@aacn.nche.edu or (202) 463-6930, ext 240.

Application Form for Nursing Continuing Education Providers and Clinical Staff Development Educators who have limited experience in end-of-life care (P1 and P2)
(This application requires Adobe Acrobat to download. If you do not have Adobe, please contact Carla Gazlay at cgazlay@aacn.nche.edu or (202) 463-6930, x227 to receive an application by fax.)

Courses for Nursing Continuing Education Providers and Clinical Staff Development Educators who are experienced in end-of-life care - Last Acts Regional Conferences

(These regional courses are coded R1 - R 5)

These 2-day regional courses are designed specifically for continuing education/staff development nurse educators who are experienced in end-of-life care. Participants include those who provide continuing education in colleges and universities, independent businesses, and nursing specialty organizations, or provide staff development for nurses practicing in hospitals, hospice, palliative care, long-term, home care, and other clinical settings.

These courses are scheduled in conjunction with Last Acts Regional Conferences. The Last Acts Regional Conferences start the evening of the second day of the ELNEC course and include the day following. Regional conference attendance is encouraged but not required.

ELNEC Courses	Last Acts Regional Conferences
R1 September 10-11, 2001 Denver, CO	September 11 evening and September 12, 2001
R2 November 27-28, 2001 Philadelphia, PA	November 28 evening and November 29, 2001
R3 February 19-20, 2002 Tampa, FL	February 20 evening and February 21, 2002
R4 June 18-19, 2002 San Francisco, CA **or** Seattle, WA (TBA)	June 19 evening and June 20, 2002
R5 September 17-18, 2002 St. Louis, MO **or** Chicago, IL (TBA)	September 18 evening and September 19, 2002

Course	Application Deadline	Notification
R1 September 10-11, 2001	July 15, 2001	July 2001
R2 November 27-28, 2001	August 27, 2001	September 2001

R3 February 20-21, 2002	January 2, 2002	January 2002
R4 June 19-20, 2002	March 18, 2002	April 2002
R5 September 18-19, 2002	June 17, 2002	July 2002

Applications for these regional courses (R1 - R 5) are now being accepted. Space is limited to 100 participants for each course, and selection is competitive. **Each sponsoring organization should submit only one application.**

As part of the application to attend a course, applicants must submit a plan describing how they will implement end-of-life education/training in the work setting or community within 12 months of attending the ELNEC course. The plan should identify audiences to be trained, project a timetable for sessions/courses, and describe the course as it will be presented. Refer to Specifications for Use of the ELNEC Curriculum for further information.

The application form can be downloaded below.

The registration fee is $200 for R1 - R5 courses. Each participant receives a full set of course materials and two textbooks. Continental breakfasts and lunches are provided each day of the course. Applicants selected to attend will be billed for the registration fee. Registration fee should not be mailed with an application.

For questions about courses for continuing education providers/clinical staff development educators experienced in end-of-life care (in conjunction with Last Acts Regional Conferences) contact Susan Taylor at the Hospice of the Florida Suncoast, susantaylor@thehospice.org or telephone (727) 773-2538. For questions about Last Acts regional meetings visit the web site, www.lastacts.org.

Application Form for Nursing Continuing Education Providers and Clinical Staff Development Educators who are experienced in end-of-life care - Last Acts Regional Conferences (R1 - R5)
(This application requires Adobe Acrobat to download. If you do not have Adobe, please contact Carla Gazlay at cgazlay@aacn.nche.edu or (202) 463-6930, x227 to receive an application by fax.)

Course for State Boards of Nursing Representatives

This course will be held in Pasadena, CA in January 2003. Watch this site for updated information about dates and the application process.

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Please direct comments and suggestions to webmaster@aacn.nche.edu.

American Association of Colleges of Nursing
One Dupont Circle, NW, Suite 530
Washington, DC 20036
Phone: (202) 463-6930 - Fax: (202) 785-8320

American Association
of Colleges of Nursing

ELNEC Project

ELNEC Curriculum

The ELNEC curriculum has been developed to prepare qualified nurse educators to provide end-of-life education for nursing students and practicing nurses, and to provide resources to facilitate that instruction. These educators in turn will use the curriculum to integrate end-of-life content for students in undergraduate nursing programs, and offer staff development/continuing education programs for clinical nurses who provide end-of-life care.

Curriculum and course development occurred during the period February 2000 - January 2001 under the guidance of City of Hope National Medical Center investigators **Betty Ferrell, PhD, RN, FAAN** and **Marcia Grant, DNSc, RN, FAAN**. The curriculum was developed in collaboration with four nationally recognized end-of-life care experts:

- **Patrick Coyne, MSN, RN, CHPN**, Medical College of Virginia Hospitals at Virginia Commonwealth University
- **Kathy Egan, MA, RN, CHPN**, The Hospice Institute of the Florida Suncoast
- **Judith Paice, PhD, RN, FAAN**, Northwestern University Medical School, and
- **Joan Panke, MA, RN, APRN**, Palliative Care Program, New York University

Content Modules

The curriculum focuses on a range of core areas in end-of-life (EOL) care reflecting AACN's publication in 1998 of Peaceful Death: Recommended Competencies and Curricular Guidelines for End-of-Life Nursing Care. Content is divided into the following nine modules, and includes topics as shown:

1. ***Nursing Care at the End of Life:*** Overview of death and dying in America, principles and goals of hospice and palliative care, dimensions of and barriers to quality care at EOL, concepts of suffering and healing, role of the nurse in EOL care.

2. ***Pain Management:*** Definitions of pain, current status of and barriers to pain relief, components of pain assessment, specific pharmacological, and non-pharmacological therapies including concerns for special populations.

3. ***Symptom Management:*** Detailed overview of symptoms commonly experienced at the EOL, and for each, the cause, impact on quality of life, assessment, and pharmacological/non-pharmacological management.

4. ***Ethical/Legal Issues:*** Recognizing and responding to ethical dilemmas in EOL care including issues of comfort, consent, prolonging life, withholding treatment; euthanasia, and allocation of resources; and legal issues including advance care planning, advance directives, and decision making at EOL.

5. ***Cultural Considerations in EOL Care:*** Multiple aspects of culture and belief systems, components of cultural assessment with emphasis on patient/family beliefs about roles, death and dying, afterlife, and bereavement.

6. ***Communication:*** Essentials of communication at EOL, attentive listening, barriers to communication, breaking bad news, and interdisciplinary collaboration.

7. ***Grief, Loss, Bereavement:*** Stages and types of grief, grief assessment and intervention, and the nurse's experience with loss/grief and need for support.

8. ***Achieving Quality Care at the End of Life:*** Challenge for nursing in EOL care, availability and cost of EOL care, the nurses' role in improving care systems, opportunities for growth at EOL, concepts of peaceful or "good death", "dying well", and dignity.

9. ***Preparation and Care for the Time of Death:*** Nursing care at the time of death including physical, psychological, and spiritual care of the patient, support of family members, the death vigil, recognizing death, and care after death.

Specifications for Use of the ELNEC Curriculum by ELNEC Trainers

Curriculum integrity. The ELNEC curriculum is the product of a national grant-funded initiative and is a copyrighted scholarly work. As a result, maintaining integrity of the curriculum and its use are critical elements of the program during the initial grant period (February 2000 - July 2003).

ELNEC Trainers. ELNEC trainers are nurse educators who have attended one of the 13 ELNEC courses sponsored by the project.

Planning ELNEC Training.

a. The 13 grant-sponsored ELNEC courses address the nine modules in slightly different ways.

(1) The 3-day courses for undergraduate nursing faculty and continuing education/staff development educators who have limited experience in end-of-life care divide each module into two segments. First, the specialty content is presented to the audience to assure a common understanding of the specialty concepts. This is followed by a session that provides detailed descriptions of resources and strategies helpful in teaching the module to others. Each segment is allowed approximately one hour.

(2) The 2-day courses for continuing education/staff development educators who are experienced in end-of-life care is modified slightly, decreasing the time spent on basic end-of-life care content which participants are expected to know. The primary emphasis is on teaching this specialty content to others.

b. ELNEC Trainers may design and implement end-of-life care education in a variety of ways.

(1) Those who wish to designate nurses as "ELNEC trained" or "trained in the ELNEC curriculum" must offer educational programs that meet the following criteria:

- include all nine modules of the ELNEC curriculum in the educational program
- ensure the course duration is a minimum of nine clock hours, one for each module. Educators are encouraged to be creative to meet the needs of learners and the organization. Various configurations are possible to accomplish this, such as:
  - two 60-minute sessions twice a week for four and one-half weeks
  - a weekly 1-hour session for nine weeks
  - three 3-hour sessions
- utilize only qualified faculty (not necessarily a designated ELNEC trainer)

(2) Educational activities based on the ELNEC curriculum but not including all nine modules may be offered within an agency or school, but these activities may not designate participants as "ELNEC trained."

c. The terms "ELNEC trained" or "trained in the ELNEC curriculum" is used only to describe registered nurses beyond the undergraduate education program. Students are not given this designation, regardless of how ELNEC materials are incorporated into the curriculum.

Information on ordering ELNEC textbooks.

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Please direct comments and suggestions to webmaster@aacn.nche.edu.

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One Dupont Circle, NW, Suite 530
Washington, DC 20036
Phone: (202) 463-6930 - Fax: (202) 785-8320

End-of-Life Nursing Education Consortium (ELNEC)
P1 – P2 Course Application
for Nursing Continuing Education and Clinical Staff Development Educators
who have limited experience in end-of-life care

***Submit only one application from each sponsoring organization.** Please print or type all information. A computer-generated facsimile that contains all the same information is acceptable.*

A. General Information

Name: ____
Last First Middle Credentials

Home Address: ____

____

Home Phone: __________________ Home e-mail: ____________________________

Ethnicity: ___ Asian ___ African-American ___ American Indian or Alaskan Native
___ Caucasian ___ Hispanic/Latino ___ Other-Specify ______________

For continuing education credit:

Gender: ___ Male ___ Female RN License Number: __________ State: _______

This course is designed for nurse educators who have limited experience in end-of-life care. Please indicate your level of direct experience in end-of-life care using this three-point scale:

1	2	3
None	Very Little	Moderate

B. Sponsoring Organization Information

Organization: ____

Title/Position: ____________________________ % of Time as Educator __________

Organization Address: ____

Phone: ________________ Fax: ________________ e-mail: ________________

Send mail to: organization____ home_____ Send e-mail to: organization____ home _____

Primary setting where you will be using ELNEC materials:

- ____ College/University Continuing Education Department
- ____ Independent Continuing Education Provider – Specify: __________________
- ____ State or Specialty Nursing Organization – Specify: ____________________
- ____ Clinical Staff Development/Continuing Education
  - ___ Hospital ___ Home Health ___ Clinic/Outpatient
  - ___ Long Term Care ___ Palliative Care ___ Hospice
  - ___ Other - please specify: ______________________________

C. ELNEC Course Preferred – please check one: *application deadline*:

- ____ P1: November 15-17, 2001, Pasadena CA August 20, 2001
- ____ P2: June 20-22, 2002, Chapel Hill NC March 22, 2002
- ____ I can attend either course *Please meet the application deadline of the course you prefer to attend.*

D. Applicant Experience

Attach a curriculum vitae/resume that includes the following information regarding your experience:

- Professional education (degrees earned)
- Professional experience in end-of-life care
- Teaching experience (please be specific regarding topics and settings)
    - Curriculum development experience
    - Teaching methods used (lecture, case studies, distance learning, role play, etc.)
    - Experience teaching hospice, palliative care, and/or end-of-life content
- Specialty certifications held
- Professional association memberships

Note: You do not need to reformat your CV/resume. If the above information is not addressed, you may attach a separate piece of paper that describes the missing elements. Not all applicants will have experience in all areas.

E. Training Plan

ELNEC courses are intended to provide educators/trainers with materials and suggested teaching approaches to facilitate development of education programs on end-of-life care. **As part of the application to attend a course, you must submit a plan describing how you will implement end-of-life education/ training in your setting or community within 12 months of attending the ELNEC course.** The plan should identify audiences to be trained (i.e. specialty organization members, faculty, staff nurses in the facility, etc.); project a timetable for your sessions/courses (i.e. monthly local organization meetings, semi-annual conferences, three two-day classes in one year); and describe the course as you plan to deliver it. You also will be expected to provide data to the ELNEC Project Office regarding your programs presented.

F. Letter of Administrative Support

The successful implementation of ELNEC programs will depend on support from your sponsoring organization. Each applicant must include a letter from administration expressing support of course attendance and proposed implementation plans. Only one application per organization will be accepted.

Checklist for complete application:

___ Completed application form
___ Curriculum vitae or resume, and additional information if required
___ Training plan
___ Letter of administrative support

Return completed applications to:

American Association of Colleges of Nursing
Attention: Nicole Brown
One Dupont Circle, NW Suite 530
Washington, DC 20036-1120

For more information on the ELNEC P1 and P2 courses, please email Nicole Brown at nbrown@aacn.nche.edu.

APPENDIX B

GRANT APPLICATION AND
CERTIFICATES OF TRAINING

SHERYL TERKILDSEN, RN, MSN(C)

August 2, 2001

American Association of Colleges of Nursing
Attention: Nicole Brown
One Dupont Circle, NW Suite 530
Washington, DC 20036-1120

Dear Nicole Brown,

Please find enclosed my completed application for participation in the End of Life Nursing Education Consortium to be held in Pasadena, CA in November. I am presently the nurse manager of a 56-bed long-term care unit which provides palliative care. I am also entering the third year of a Master of Science in Nursing program at California State University-San Bernardino with an emphasis in Nurse Educator. Over the last year I have presented several in-services in both a long-term care setting and an acute hospital setting on topics such as tube-feeding, pain management for patients with dementia, and was a co-presenter of the Bill Moyers' series, On Our Own Terms for continuing education credit. I have also written and presented a presentation titled, "The Joys of Caring in Nursing".

On a weekly basis I facilitate the Full Circle Group on my unit and present current articles in the palliative care literature as well as debrief staff on difficult patient and family situations. I attend as many continuing education programs on End-of-Life care as I can. In May of this year I attended a two-day EPEC train the trainer course. I recently attended the 2nd Annual National Leadership Conference on Pain Management and End of Life Care in Alexandria, VA. I always share the information received at continuing education offerings with my staff and any one else who will listen. It is my professional goal to become a highly qualified educator teaching nurses the importance of quality end of life care and their role in achieving the same.

If you need any additional information, please contact me. I am looking forward to attending this training.

Sincerely,

Sheryl R. Terkildsen

Sheryl R. Terkildsen, RN, MSNc
Nurse Manager, 1 South

11670 MOUNT MIRIAH DRIVE •RANCHO CUCAMONGA, CA • 91737
PHONE: 909-483-3406 • FAX: 909-777-3210

Training Plan to Implement End of Life Education/Training

Significance of Training: To provide nursing staff members with the knowledge and clinical expertise needed to provide quality end of life care in whatever setting they work.

Target Audiences: Nursing Staff members to include Nursing Assistants from both the acute hospital and long-term care areas of the Loma Linda VAMC.

Time Table: a) 4 four-hour training sessions presented quarterly covering ELNEC content in a sequential manner OR
b) Monthly training sessions of 1.5 hours covering ELNEC content in a sequential manner

Delivery Plan: A combination of Power Point presentations, Lecture, Case Scenarios, and Group Discussion/Feedback. A course outline with objectives will be prepared for each session.

May do a pre and post test to compare data.

May do a pre-course survey then follow it up with a thirty day survey with questions developed from session content.

DEPARTMENT OF VETERANS AFFAIRS
Jerry L. Pettis Memorial Veterans Affairs Medical Center
11201 Benton Street
Loma Linda, CA 92354

July 5, 2001 In Reply Refer To: 605/118

American Association of Colleges of Nursing
Attention: Nicole Brown
One Dupont Circle, NW suite 530
Washington, DC 20036-1120

Dear Ms. Brown,

It is my pleasure to highly recommend Ms. Sheryl Terkildsen as an applicant for ELNEC Courses. Ms. Terkildsen is currently Nurse Manager for our Long Term and Extended Care Unit. Her responsibilities include oversight of our Palliative Care Program. Ms. Terkildsen manages this program and her staff in a responsible and compassionate manner that supports our strategic plan. Her attendance at your program, "End-of Life Nursing Education Consortium" will further our strategic plans for meeting Veterans end of life needs.

Ms. Terkildsen will be responsible for implementing your program within our medical facility.

Christine A. Lund
Director, Nursing Operations

Approve/~~Disapprove.~~

Anne Gillespie
Vice President, Patient Care & Administration

ELNEC

Advancing End-of-Life Nursing Care

END-OF-LIFE NURSING EDUCATION CONSORTIUM

September 10, 2001

Dear ELNEC Course Applicant:

Congratulations! You have been selected to participate in the End-of-Life Nursing Education Consortium (ELNEC) Training Course scheduled for **November 15 – 17, 2001** at the **Pasadena Hilton Hotel in Pasadena, California.** Because space is limited, if your plans have changed and you are not able to attend, please contact Nicole Brown (202/463-6930 or nbrown@aacn.nche.edu) immediately so that an alternate can be notified.

Participation in this exciting initiative will prepare you to be an ELNEC Trainer, one of an elite group of nurse educators who share a common vision and a national network. Your participation will include attending the three-day course, and completing both pre- and post-course assessment and evaluation surveys. Post-course evaluations will be conducted at the end of the course and at 6 and 12-month intervals. Participation in the full three days of the course is expected, and continuing education credit will be awarded for successful completion of the course. No partial credit will be awarded.

Documents to Complete and Return. Two important documents are enclosed for you to complete. Please mail both to arrive at the ELNEC Project Office no later than Friday, **October 5, 2001**. A pre-addressed, stamped envelope is enclosed for your convenience.

- **Confirmation Form**
  This form provides essential details about your participation. Please complete it carefully and return it promptly.

- **Pre-Course Assessment**
  This is a critical element of ELNEC project activities and if not returned, you will not be able to attend the course.

End-of-Life Educational Materials to Share. We enjoy sharing your good ideas about teaching end-of-life care. If you have outlines, course descriptions, bibliographies, instructional materials such as case studies, or other resources to share with your colleagues, please send one copy to the ELNEC Project Office to arrive by Monday **October 29, 2001.** We will place participant submissions in notebooks that will be in the back of the meeting room for you to see. This has been a very popular aspect of previous courses. Please make sure your submission contains your name and e-mail address so that others can contact you. We will not be able to return these materials, so make sure you keep a copy. ELNEC faculty members occasionally

American Association of Colleges of Nursing

ELNEC Project Office
American Association of Colleges of Nursing
One Dupont Circle, NW ✦ Suite 530 ✦ Washington, DC 20036-1120
Tel: 202.463.6930 ✦ Fax: 202.785.8320
www.aacn.nche.edu/elnec

City of Hope

identify particularly interesting or useful examples to duplicate and share with previous participants. ***By submitting materials, you agree to this resource sharing.***

<u>**Hotel**</u>. The course will be held at The Hilton Pasadena, 150 South Los Robles Ave., Pasadena, CA 91101, telephone (626) 577-1000. You can find more information on the Web at www.hilton.com.

- Although you **will be responsible for your hotel charges**, the ELNEC Project Office will make reservations for participants at the Hilton. Your accommodations, including extra nights and special needs should be indicated on your confirmation form. *Do not call the hotel to make reservations.* The hotel will reserve rooms for our course only through the ELNEC Project Office.

- We have negotiated an excellent special room rate at the Hilton for our participants -- $144.72 per night (single or double), including tax. This is a substantial reduction over the normal rate of $179 (plus tax), and significantly less than the relatively few nearby hotels. If you are planning to travel with family or friends, one person may stay with you in your room at no extra charge. There may be a charge for additional guests in your room. We will work with the hotel to try to get the conference rate for additional nights or additional rooms for your guests. We will notify you if we are unsuccessful.

<u>**Meals.**</u> Continental breakfast, lunch and breaks will be provided for course participants, Thursday, Friday and Saturday, November 15-17. Dinners are on your own. There are numerous restaurants of all kinds within walking distance of the Hilton.

<u>**Travel Information.**</u>

- <u>Travel to Pasadena</u>

  Travel arrangements to Pasadena are your responsibility. Nearby airports are Los Angeles (LAX) or Ontario (ONT) and Burbank. Note: the course will end approximately 3:00P.M. on Saturday, November 17th.

- <u>Ground Transportation to/from Airport and Hotel</u>

  From LAX (Los Angeles), ONT (Ontario) and Burbank airports, ground transportation available are (prices are one way unless otherwise indicated):

• Airport Bus (from LAX only)	$20.00 (round trip)
	w/enclosed voucher only
	$24.00 without voucher
• Taxis	
Approximate fare from LAX to Pasadena Hilton:	$60.00 - $65.00/one way
Yellow Cab – LA 800/711-8294	(approximately 25 miles)
Approximate fare from ONT to Pasadena Hilton:	$80.00 - $85.00/one way
Yellow Cab – Ontario 909/622-1313	(approximately 35 miles)
Approximate fare from Burbank Airport To Pasadena Hilton:	$30-35.00
City Cab – Burbank 818/848-1000	(approximately 12 miles)

- Super Shuttle 800/258-3826 (call 24 hours in advance)
  Approximate fare from LAX to Pasadena Hilton: $16.00/person/one way
  Approximate fare from ONT to Pasadena Hilton: $42.00/person/one way
  $9.50/added person
  Approximate fare from Burbank Airport to Pasadena Hilton: $14.00/person/one way
  $9.50 per added person

Welcome Reception. We will host a reception for participants and faculty on Wednesday evening, November 14th from 7-8 PM. This is a wonderful opportunity to meet colleagues from around the country. Please indicate on the Confirmation Form whether or not you will be able to join us.

Stipend. $100 stipend checks will be distributed at the end of the course with certificates. On the Confirmation Form, please validate to whom this check should be made payable.

We are very pleased you will be joining us in Pasadena! We look forward to meeting you and to your active participation in this project. Please contact Nicole Brown at (202) 463-6930 ext. 240 or nbrown@aacn.nche.edu with questions. Remember to return your Confirmation Form and Pre-Course Assessment by the October 5 deadline.

Sincerely,

Barbara K Penn

Barbara Penn, Ph.D., RN
Associate Director, ELNEC Project

City of Hope

CITY OF HOPE NATIONAL MEDICAL CENTER/
BECKMAN RESEARCH INSTITUTE
1500 East Duarte Road
Duarte, CA 91010
Nursing Research

This declares that

Sheryl Terkildsen CA 554097

(NAME) **(REGISTERED LIC. NO.)**

has completed 19 **contact hours in**

End of Life Nursing Education Consortium

Betty Ferrell PhD, FAAN

November 15-17, 2001
(Dates of Course)

Betty R. Ferrell, PhD, FAAN
Nursing Research and Education

BRN Provider #: CEP 13380

This certificate must be retained by the licensee for a period of four years after the course concludes.

Certificate of Training

Sheryl Terkildsen

has completed training in the

End-of-Life Nursing Education Consortium (ELNEC) Curriculum

Supported by a Grant Funded through the Robert Wood Johnson Foundation

November 15-17, 2001

Presented by

American Association of Colleges of Nursing	City of Hope National Medical Center Nursing Research and Education
Geraldine D. Bednash	Betty Ferrell PhD, FAAN
Geraldine Bednash, PhD, RN, FAAN	Betty R. Ferrell, RN, PhD, FAAN

APPENDIX C

END-OF-LIFE NURSING EDUCATION CONSORTIUM COPYRIGHT PERMISSION

ELNEC

Advancing End-of-Life Nursing Care

END-OF-LIFE NURSING EDUCATION CONSORTIUM

January 2001

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Geraldine Bednash, PhD, RN, FAAN	Betty Ferrell, PhD, FAAN
Executive Director	Research Scientist
American Association of Colleges of Nursing	City of Hope National Medical Center

American Association of Colleges of Nursing

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City of Hope

APPENDIX D

NEWS RELEASE

Department of
Veterans Affairs

FOR IMMEDIATE RELEASE
February 6, 2002

VA Nurse Selected to Attend End-of-Life Nursing Education Consortium

Loma Linda, Calif. - Sheryl Terkildsen, RN Nurse Manager at the Loma Linda VA was one of 85 nurses from across the United States selected to attend the End-of-Life Nursing Education Consortium. Nurses spend more time with patients who are facing the end-of-life than any other member of the health care team. Yet, studies have shown that many nurses feel inadequately prepared to provide the comprehensive care so important at the end-of-life.

The American Association of Colleges of Nursing (AACN) and the City of Hope (COH) Cancer Center received a 3 ½ year grant from the Robert Wood Johnson Foundation to conduct this training program. This program, held in partnership with Last Acts is entitled, "End-of-Life Nursing Education Consortium" for nurses who provide/conduct continuing education courses. This project is led by Geraldine Bednash, RN, PhD, FAAN (AACN) and Betty R. Ferrell, RN, PhD, FAAN (COH) as the principal investigators.

The principal goal of the training program is to provide nursing continuing education providers with information on end-of-life care and resources to integrate end-of-life content into their in-service programs or courses. Course content was presented in several participatory formats including lecture, open forum discussion, small group activities and training sessions.

The training program was conducted by a distinguished faculty of researchers, educators, authors, and leaders in the field of palliative care. Topic areas included nursing care at the end of life; pain and symptom assessment and management; cultural considerations; ethical/legal issues; communication; grief, loss and bereavement; preparation and care for the time of death and achieving quality care at the end of life.

###

APPENDIX E

END-OF-LIFE NURSING EDUCATION CONSORTIUM TIMELINE

Task Timeline for End-of-Life Nursing Education Consortium Grant Implementation

August 2001 - Obtain institutional support for grant application from LLVAMC. Submit Grant application to the AACN

September 2001- Continue Literature review of relevant EOL topics

October 2001- Continue Literature review

Receive confirmation of grant acceptance for training in ELNEC

November 2001- Receive training Nov 15- 17th in Pasadena

Familiarize self with content of the nine training modules

Select two modules to implement for project

December 2001- Arrange for class room and do logistics for project i.e. BRN applications for CEUs, flyers written and reproduced, write pre and post-test questions.

Meet with chair of committee for approval of timeline.

Develop Proposal & Powerpoint presentation

January 2002- Teach Content Module 1: Nursing Care at the End of Life (1/10)

February 2002- Teach Content Module 2: Symptom Management (2/14)

March- May 2002- Finalize the written project

APPENDIX F

END-OF-LIFE NURSING EDUCATION CONSORTIUM MODULE 1; NURSING CARE AT THE END OF LIFE

IV. Palliative care helps gain access to needed health care providers and appropriate care settings.

It...

- Uses many kinds of trained care providers - doctors, nurses, pharmacists, clergy, social workers, and personal care givers.
- Makes sure, if necessary, someone is in charge of seeing that your needs are met.
- Helps you use hospitals, home care, hospice, and other services, if needed.
- Tailors options to the needs of you and your family.

V. Palliative care builds ways to provide excellent care at the end of life.

It...

- Helps care providers learn more about the best ways to care for dying people by listening to patients and loved ones. It gives them the education and support they need.
- Works to make sure there are good policies and laws in place.

The Five Principles are a vision for better care at the end of life.

They were developed for people who are dying, their families, and their loved ones, by the Last Acts Task Forces on Palliative Care and the Family. Last Acts is a coalition of more than 300 organizations representing health care providers and consumers nationwide.

We believe that everyone can make a difference in the care given to dying people and their families. We need to work together toward a health care system that offers all Veterans

the services that meet their individual needs given by health care providers well trained in palliative care.

This will make the Five Principles of Palliative Care a reality.

What You Can Do

The role you can play in making this come about is to share this vision of end-of-life care with your family, friends, and health care providers. Discuss with them the care you want and who will provide it. Talk to your doctor about a Palliative Care consult or for more information contact:

02-3205

Sheryl Terkildsen, RN ext 1743
Debra J. Stelmach, RN, MSN ext 2003
Dr. Russell Hoxie, ext 1136

JERRY L PETTIS MEMORIAL
VA MEDICAL CENTER
LOMA LINDA

A Division of VA Desert Pacific Healthcare Network

PALLIATIVE CARE SERVICES

A Vision for Better Health Care at the End of Life

Death and dying are not easy to deal with. Perhaps you or someone you love is facing an illness that cannot be cured. Few of us are really ready for the hard choices that may have to be made at the end of life. It can be hard for everyone involved - the dying person, their family and loved ones, and health care providers too.

But there are ways to ease pain and make life better for people who are dying and for their loved ones. It is called palliative care.

Palliative care means taking care of the whole person - body, mind, spirit - heart and soul. It looks at dying as something natural and personal. The goal of palliative care is that you have the best quality of life you can during this time.

Some health care providers - doctors, nurses, social workers, pharmacists, clergy, and others - have learned how to give this special kind of care. But all health care providers should know how to give good palliative care or to help you find someone who can.

Five Principles of Palliative Care

The following Five Principles of Palliative Care describe what care can and should be like for everyone facing the end of life. Some of these ideas may seem simple or just common sense. But all together they give a new and more complete way to look at end-of-life care.

* * *

I. Palliative care respects the goals, likes, and choices of the dying person.
It...

- Respects your needs and wants as well as those of your family and other loved ones.
- Finds out from you who you want to help plan and give you care.
- Helps you understand your illness and what you can expect in the future.
- Helps you figure out what is important.
- Tries to meet your likes and dislikes: where you get health care, where you want to live, and the kinds of services you want.
- Helps you work together with your health care provider and health plan to solve problems.

II. Palliative care looks after the medical, emotional, social, and spiritual needs of the dying person.
It..

- Knows that dying is an important time for you and your family.
- Offers ways for you to be comfortable and ease pain and other physical discomfort.
- Helps you and your family make needed changes if the illness gets worse.
- Makes sure you are not alone.
- Understands there may be difficulties, fears and painful feelings.
- Gives you the chance to say and do what matters most to you.
- Helps you look back on your life and make peace, even giving you a chance to grow.

* * *

III. Palliative care supports the needs of the family members.
It...

- Understands that families and loved ones need help too.
- Offers support services to family caregivers, such as time off for rest, and advice and support by telephone.
- Knows that caregiving may put some family members at risk of getting sick themselves. It plans for their special needs.
- Finds ways for family members to cope with the costs of caregiving, like loss of income, and other expenses.
- Helps family and loved ones as they grieve.

One Step Further

Do more than exist LIVE

Do more than touch FEEL

Do more than look OBSERVE

Do more than read ABSORB

Do more than hear LISTEN

Do more than listen UNDERSTAND

Do more than think REFLECT

Do more than just talk SAY SOMETHING

Author Unknown

Module 1
Nursing Care at the End of Life

Module Overview

This module creates the foundation for the ELNEC curriculum. It is an overview of the need to improve end of life care and the role of nursing as a member of an interdisciplinary team in providing quality care. Basic principles of palliative care are presented within a quality of life (QOL) framework.

Key Messages

- There are major deficiencies in current systems of care for patients and families at the end of life.
- Social and economic forces influence care provided at the end of life.
- Nurses should not work in isolation but rather as partners in collaboration with physicians and other disciplines.
- Caring for the dying means not only "doing for" but also "being with". Palliative nursing care combines caring, communication, knowledge, and skill.

Objectives

At the completion of this module, the participant will be able to:

1. Identify the need for collaboration with interdisciplinary team members while implementing the nursing role in end of life care.
2. Recognize changes in population demographics, health care economics, and service delivery that necessitate improved professional preparation for end of life care.
3. Describe the philosophy and principles of hospice and palliative care that can be integrated across settings to effect quality care at the end of life.
4. Discuss aspects of suffering for patients and families facing a life-threatening illness or event.
5. Describe the role of the nurse in providing quality end of life care.

Module 1: Nursing Care at the End of Life
Participant Outline

I. THE NEED FOR IMPROVED CARE AT THE END OF LIFE (EOL)
  A. Death and dying in America: Changes over the last century
    1. Late 1800s
    2. Early to middle 1900s
    3. Cause of death
      a. Degenerative diseases replaced communicable diseases as leading causes of death
      b. Infant and maternal death rates have declined dramatically
    4. Demographics and social trends (see Table 1)
      a. Decreased death rate
      b. Increased life expectancy
      c. Racial and ethnic differences
      d. Aging of the population
    5. Site of death
    6. Disease/dying trajectories
      a. Sudden, unexpected death
      b. Steady decline, short terminal phase
      c. Slow decline, periodic crises, death
    7. SUPPORT study
    8. Impact
  B. Disparity between the way people die, and they way they want to die
    1. Patient/family perspective
    2. Barriers to quality care at the end of life
      a. The realities of life-limiting diseases
      b. Lack of adequate training of professionals
      c. Delayed access to hospice and palliative care services
        1) Services not well understood
        2) Rules and regulations
        3) Denial of death
    3. Need for palliative care

II. PRINCIPLES OF HOSPICE AND PALLIATIVE CARE
  A. Hospice
    1. Definition of hospice
    2. History
    3. Eligibility
  B. Palliative care
    1. Definition
    2. History

- C. Philosophy and principles of hospice and palliative care
    - 1. Philosophy of care
    - 2. Goals of care: Comfort and quality end-of-life closure
    - 3. General principles of palliative care
        - a. The patient and family as the unit of care
        - b. Attention to physical, psychological, social and spiritual needs
        - c. The interdisciplinary team (IDT)
        - d. Education and support of patient and family
        - e. Extends to all patients and families across diverse life-threatening illnesses
        - f. Bereavement support

III. INDIVIDUAL ASSESSMENT OF CARE AT THE END OF LIFE BASED ON A MODEL FOR QUALITY OF LIFE

- A. Quality of Life Model
- B. Achieving quality of life at the end of life: Addressing multiple dimensions of care
    - 1. Physical well-being
    - 2. Psychological well-being
    - 3. Social well-being
    - 4. Spiritual well-being
- C. Concept of suffering
- D. Depth of suffering
- E. Focus on cure may increase suffering

IV. OPPORTUNITIES FOR GROWTH AT THE END OF LIFE

- A. Personal growth
- B. Achieving a peaceful death
    - 1. Patient/family perspective
    - 2. Professional perspective

V. LIFE CLOSURE: A PERSONAL EXPERIENCE

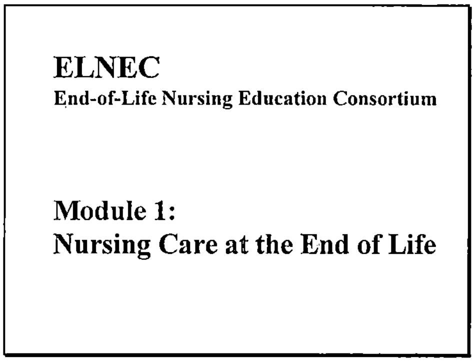
- A. The outer perspective
- B. The inner perspective

VI. THE ROLE OF THE NURSE: EXTENDING PALLIATIVE CARE PRINCIPLES ACROSS SETTINGS TO IMPROVE END OF LIFE CARE

- A. The importance of presence
- B. Maintaining a realistic perspective
- C. Nurses as the constant across all settings
- D. Expanding the concept of healing
- E. The role of the nurse

VII. CONCLUSION

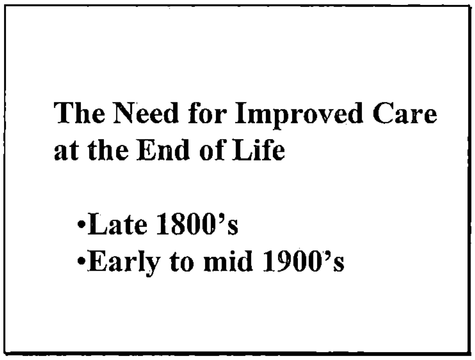
Slide 1



ELNEC
End-of-Life Nursing Education Consortium

Module 1:
Nursing Care at the End of Life

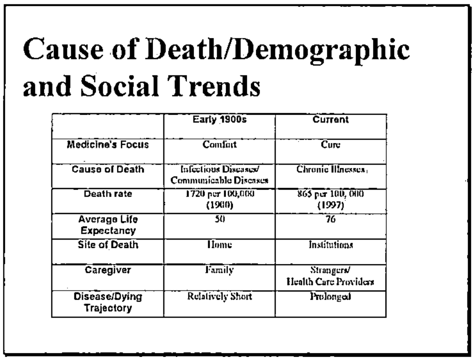
Slide 2



The Need for Improved Care at the End of Life

- Late 1800's
- Early to mid 1900's

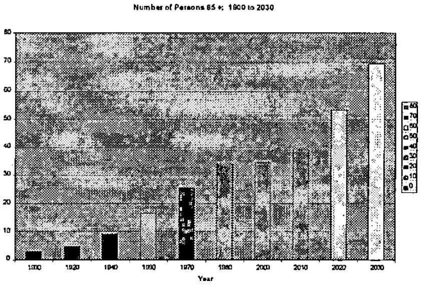
Slide 3



Cause of Death/Demographic and Social Trends

	Early 1900s	Current
Medicine's Focus	Comfort	Cure
Cause of Death	Infectious Diseases/ Communicable Diseases	Chronic Illnesses
Death rate	1720 per 100,000 (1900)	865 per 100, 000 (1997)
Average Life Expectancy	50	76
Site of Death	Home	Institutions
Caregiver	Family	Strangers/ Health Care Providers
Disease/Dying Trajectory	Relatively Short	Prolonged

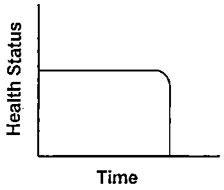
Slide 4



Slide 5

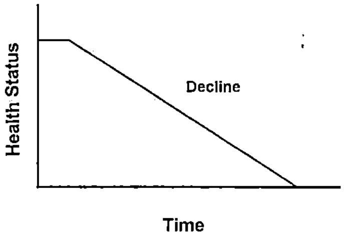
Sudden death, unexpected cause

< 10 % (e.g. MI, accident)



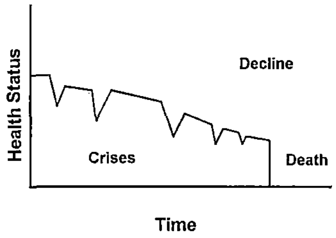
Slide 6

Steady decline, short terminal phase



Slide 7

Slow decline, periodic crises, sudden death



Slide 8

Death and Dying in America

↖ **SUPPORT STUDY**

↖ **Impact**

Slide 9

Death and Dying in America (cont.)

- **Disparity between the way people die/the way they want to die**
- **Patient/family perspective**

Slide 10

Barriers to Quality Care at the End of Life

- The realities of life limiting diseases
- Lack of adequate training of professionals
- Delayed access to hospice/palliative care

Need for Palliative Care

Slide 11

Curative and Palliative Approaches to Care

Curative/Disease Focus	**Palliative Focus**
-Diagnosis of disease & related symptoms	-Pt/family identify unique end-of-life goals
-Curing of disease	-Assess how symptoms, issues are helping/hindering reaching goals
-Treatment of disease	-Interventions to assist in reaching end-of-life goals
-Alleviation of symptoms	-Quality of life closure

Slide 12

Principles of Hospice and Palliative Care

- Hospice
- Palliative Care

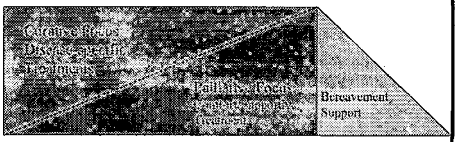
Slide 13

Philosophy and principles of Hospice and Palliative Care

- Philosophy of care
- Goals of care

Slide 14

Palliative Care

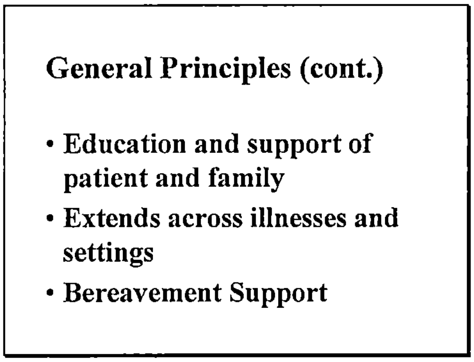


Slide 15

General Principles of Palliative Care

- Patient and family as unit of care
- Attention to physical, psychological, social and spiritual needs
- Interdisciplinary team approach

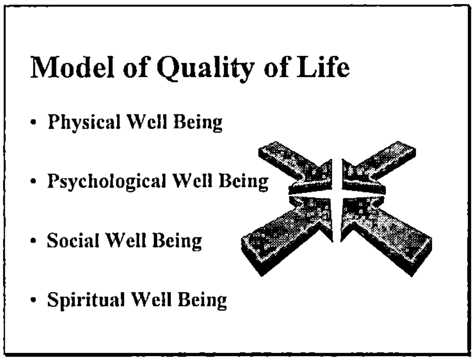
Slide 16



General Principles (cont.)

- Education and support of patient and family
- Extends across illnesses and settings
- Bereavement Support

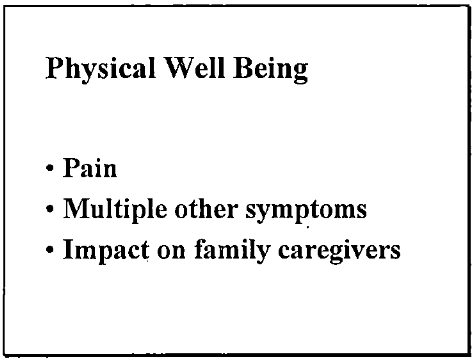
Slide 17



Model of Quality of Life

- Physical Well Being
- Psychological Well Being
- Social Well Being
- Spiritual Well Being

Slide 18



Physical Well Being

- Pain
- Multiple other symptoms
- Impact on family caregivers

Slide 19

Psychological Well Being

- Wide range of emotions and concerns
- Meaning of illness
- Depression
- Coping
- Cognitive assessment

Slide 20

Social Well Being

- Relationship/role description
- Caregiver burden
- Sexuality concerns
- Impact on children
- Financial concerns

Slide 21

Spiritual Well Being

- Religion and spirituality
- Seeking meaning
- Hope vs. despair
- Importance of ritual

Slide 22

Physical
Functional Ability
Strength/Fatigue
Sleep & Rest
Nausea
Appetite
Constipation
Pain

Psychological
Anxiety
Depression
Enjoyment/Leisure
Pain Distress
Happiness
Fear
Cognition/Attention

Quality of Life

Social
Financial Burden
Caregiver Burden
Roles and Relationships
Affection/Sexual Function
Appearance

Spiritual
Hope
Suffering
Meaning of Pain
Religiosity
Transcendence

Adapted from Ferrell, et al. 1991

Slide 23

Concept of Suffering

- State of severe distress that threatens intactness of the person
- Failure to respond to patient needs intensifies suffering
- Sources of suffering

Slide 24

Opportunities for Growth

- The Last Phase of Life Provides Continued Opportunity for Positive Growth in the Face of Suffering

Slide 25

Life Closure: A Personal Experience

- Completion with worldly affairs
- Completion of community relationships
- Meaning about one's individual life
- Love of self
- Love of others

Slide 26

Life Closure: A Personal Experience (cont)

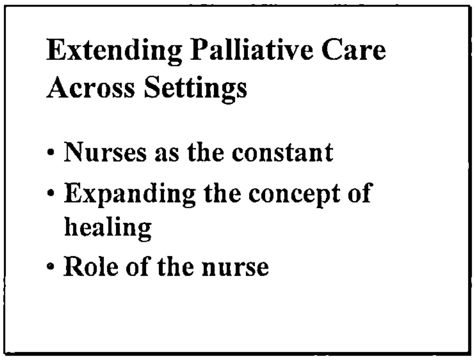
- Completion of family/friend relationships
- Acceptance of the finality of life
- New self beyond personal loss
- Meaning about life
- Surrender to the unknown "Letting go"

Slide 27

Improving End of Life Care

- Some things cannot be "fixed"
  -Use of therapeutic Presence
- Maintaining a realistic perspective

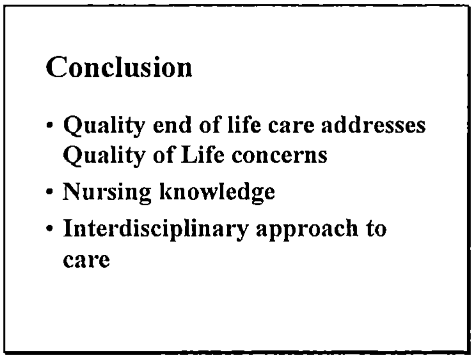
Slide 28



Extending Palliative Care Across Settings

- Nurses as the constant
- Expanding the concept of healing
- Role of the nurse

Slide 29



Conclusion

- Quality end of life care addresses Quality of Life concerns
- Nursing knowledge
- Interdisciplinary approach to care

Module 1
Table 3: Spiritual Assessment

Key Assessment Areas	**Sample question**
• Concept of God or deity • Sources of hope and strength • Important religious practices • Relationship between spiritual beliefs and health	• Is religion or God significant to you? Can you describe how? • Who do you turn to when you need help? Are they available? • Are any religious practices important to you? • Has being sick made any difference in your feelings about God or the practice of your faith?

Source: Highfield, M.E.F. (2000). Providing spiritual care to patients with cancer. Clinical Journal of Oncology Nursing, 4(3): 115-120. Reprinted with permission.

Module 1
Table 4: SPIRITual Interview

- **S** - Spiritual belief system (religious affiliation)
- **P** - Personal spirituality (beliefs and practices of affiliation that patient/family accepts)
- **I** - Integration with a spiritual community (role of the religious/spiritual group; individual role in that group)
- **R** - Ritualized practices and restrictions (healthcare activities that patient/family's faith encourages or forbids)
- **I** - Implications for medical care (beliefs that healthcare providers should remember during care)
- **T** - Terminal events planning (impact of beliefs on advance directives; contacting clergy)

Source: Highfield, M.E.F. (2000). Providing spiritual care to patients with cancer. Clinical Journal of Oncology Nursing, 4(3): 115-120. Reprinted with permission.

Module 1
Table 5: Spiritual Distress

Patient Symptoms	Descriptions	Response
Abandonment	By family, friends, health care professionals or religion	Human presence
Anger	Directed or undirected	Urge expression and accept feeling
Betrayal	"Punishment" by God	Contact clergy if patient/family agree
Despair	Without hope	Contact clergy if family/patient agree
Fear	Of dying process or of death	Explain dying process
Guilt	Concern over misdeed	Urge seeking forgiveness; contact clergy or social worker
Meaningfulness	Life without purpose	Validate life accomplishments
Regret	Dreams unfulfilled	Life review and validation
Sorrow/Remorse	Profound sadness due to acute depression	Urge verbalization - validate feelings
Depression	Turning to wall; fetal position; non-responsive	Talk with them to provide tie to humanity

Source: Fauser, M., Lo, K., & Kelly, R. (1996). Spiritual care. Trainer Certification Program [Manual]. Largo, FL: Hospice Institute of the Florida Suncoast. Reprinted with permission.

Module 1
Table 6: Interventions to Foster Hope

Experiential Processes

- Prevent and manage end-of-life symptoms
- Encourage patient and family to transcend their current situation
  - Encourage aesthetic experiences
  - Encourage engagement in creative and joyous endeavors
  - Suggest literature, films, and art that is uplifting and highlights the joys in life
  - Encourage reminiscing
  - Assist patient and family to focus on present and past joys
  - Share positive, hope-inspiring stories
- Support patient and family in positive self-talk
- Utilize lightheartedness and humor appropriately

Spiritual/Transcendental Processes

- Facilitate participation in religious rituals and spiritual practices
- Make necessary referrals to clergy and other spiritual support people
- Assist the patient and family in finding meaning in the current situation
  - Suggest keeping a journal
  - Suggest literature, films, and art that explore the meaning of suffering

Relational Processes

- Minimize patient and family isolation
- Establish and maintain an open relationship
- Affirm patients' and families' sense of self-worth
- Recognize and reinforce the reciprocal nature of hopefulness between patient and support system
- Provide private time for relationships (especially important in institutional settings)
- Assist the patient to identify significant others and then to reflect on personal characteristics and experiences that endear the significant other to the patient
- Communicate one's own sense of hopefulness

Rational Thought Processes

- Assist patient and family to establish, obtain, and revise goals without imposing one's own agenda
- Assist in identifying available and needed resources to meet goals
- Assist in procuring needed resources
- Assist with breaking larger goals into smaller steps to increase feelings of success.
- Provide accurate information regarding patient's condition and treatment
- Help patient and family identify past successes
- Increase patients' and families' sense of control when possible

Adapted from Ersek, M. (2001). The meaning of hope in the dying. In B.R. Ferrell, & N. Coyle (Eds.) Textbook of Palliative Nursing. New York, NY: Oxford University Press.

Module 1

Table 7: Developmental Landmarks and Taskwork for Life completion and Life Closure

1. Sense of Completion with Worldly Affairs	Transfer of fiscal, legal and formal social responsibilities
2. Sense of Completion in Relationships with Community	Closure of multiple social relationships employment, business, organizational, congregational) Components include: expression of regret, expressions of forgiveness, acceptance of gratitude and appreciation Leave-taking; the saying of good-bye
3. Sense of Meaning About One's Individual Life	Life review The telling of "one's stories" Transmission of knowledge and wisdom
4. Experience of Love of Self	Self-acknowledgement Self-forgiveness
5. Experience Love of Others	Acceptance of worthiness Acceptance of forgiveness
6. Sense of Completion in Relationships with Family and Friends	Reconciliation, fullness of communication and closure in each of one's important relationships Component tasks include: expression of regret expressions of forgiveness and acceptance, expressions of gratitude and appreciation, expressions of affection Leave-taking; the saying of good bye
7. Acceptance of the Finality of Life - of One's Existence as an Individual	Acknowledgment of the totality of personal loss represented by one's dying and experience of personal pain of existential loss Expression of depth of personal tragedy that dying represents Decathexis (emotional withdrawal) from worldly affairs and cathexis (emotional connection) with an enduring construct Acceptance of dependency
8. Sense of a New Self (Personhood) Beyond Personal Loss	Acceptance of new definition of self Acknowledgment of the value of that new self
9. Sense of Meaning About Life in General	Achieving sense of awe Recognition of transcendent realm Developing/achieving a sense of comfort with chaos
10. Surrender to the Transcendent, to the Unkown - "Letting Go"	Will to die Acceptance of death Saying goodbye Withdrawal from family, friends and professional caregivers
Adapted from: Byock, IR. (1996). The nature of suffering and the nature of opportunity at the end-of-life. Clinics in Geriatric Medicine, 12(2): 237-252.	

Source: The Hospice Institute of the Florida Suncoast, 2001. Reprinted with permission.

Module 1
Table 8: A Guide for Spiritual Care Planning

The Guide for Spiritual Care Planning can be used as a tool to provide language for spiritual care documentation. In this collection of Standards, the intention was to categorize chaplaincy issues within three major area: Ethical/Moral issues, Religious issues and Spiritual issues.

Ethical/Moral Issues		
Problem/Issues Opportunities	*Areas for Goal Development with Patient/Family*	*Suggested Intervention*
Treatment Choices	To be able to put treatment choices into personal faith and experience context.	Act as sounding board and spiritual guide as patient/family struggle with choices. Explore patient's & familiy's fears/hopes in treatment choices.
Advance Directives	To be able to understand the relationship between life choices and faith.	Facilitate discussion of patient's under-standing of need for advance directives. Validate personal beliefs of life and death. Reaffirm continuity of life. Establish means for hope amidst death, through affirmations of possibilities.
Medication Concerns	To be able to distinguish/identify the pertinence of religious and personal beliefs.	Assess impact of religious beliefs, re: medication concerns. Assess personal beliefs, wishes. Assist patient/family in resolution of conflict. Address conflicts between faith and situational dilemmas.
Estate Concerns	To come to an understanding of the issues within a faithful and relational context. To find a sense of peace through the process of disposing of material possession.	Foster communication/reconciliation between patient & family/others. Review understanding of what it means to be faithful within current context.
Custody Concerns	To gain a sense of peace regarding choices made impacting custody issues.	Foster communication/reconciliation between patient & family others. Review understanding of what it means to be faithful within current context.
Autonomy (as it relates to self image)	Ownership of decision within one's tradition of faith.	Empower patient in decision-making process through reflection on tradition of faith and meaning of decisions.

Competency (as it Relates to Responsibility and Decision Making)	To balance independence/selfhood with the possibility of causing harm. Frame issues within a faithful and relational context to find a sense of peace. Receive assistance with identifying a faithful health care surrogate.	Foster communication/reconciliation between patient & family/others. Review understanding of what it means to be faithful within current context. Provide patient/family with guidance in methods of ensuring that advance directives are followed at the appropriate time.
Life Choices/Morals	To develop acceptance of spiritual compassion in life decisions.	Affirm presence of Divine compassion in life choices.
Pain/Suffering	To be able to embrace the suffering. To find hopefulness united with spiritual meaning. To find meaning in suffering.	Facilitate open expression of feelings. Assist in finding the Divine in the midst of suffering. Offer reassurance of Divine presence that allows patient to embrace both the suffering and its hopeful meaning.

Religious Issues

Religious/Faith Affiliation	*Areas for Goal Development with Patient/Family*	*Suggested Intervention*
Religious/Faith Affiliation	Reconcile beliefs/values with patient's needs from faith/religious community.	Evaluate patient's religious needs. Assess need for a liaison between patient/family and faith community, if needed. Provide assistance in expressing faith outside of a faith community (If patient/ family do not seek community connectedness).
Faith Community Connectedness	Establish relationship with faith community.	Evaluate patient's needs from a faith community. Address issues of alienation as desire. Act as a liaison with appropriate faith community.
Relationship with Clergy	Establish/reestablish positive connection with clergy.	Identify troubling issues/previous experience with clergy. Facilitate positive clergy relationship with patient and family.
Relationship with Denomination	To establish/reestablish positive connection with faith community, tradition.	Identify previous experience. Facilitate positive denominational connection, if patient desires.
Sacraments/Rituals/ Rites/Traditions (e.g. Intervention of Healers)	To be able to utilize belief system support. To discover an understanding of blessing.	Identify patient's proper source for blessing. Arrange or provide instruments of the sacred/holy and sacramental ministry. To facilitate or provide desired rituals.

Sacred Writings/Readings/ Music	To have validation/enhancement of spiritual support.	Explore needs for religious/spiritual support. Establish a presence of the holy. Provide devotional support.
Prayer/Meditation	To utilize spiritual centeredness/inner resources. To explore choices available.	Provide opportunity for prayer/meditation support. Provide devotional support.
Faith Tradition Teachings	To better understand faith tradition teachings. To reconcile tradition of personal faith structure.	Facilitate discussion of faith/belief tradition. Assist in reconciling faith history with present circumstances.
Conversion/ Commitment	To be able to utilize faith understanding for spiritual.	Assist patient in clarifying personal definitions. Seek an understanding of the patient's need/reconversion/commitment. Attend to patient's need for healing of brokenness.
Closure Rituals	Experience a sense of completion.	Identify needs/desires/wishes of patient/ family. Provide leadership for ritual experience of hope. Conduct closure ritual.
Memorial Services/Funerals	Affirmation of life and faith. Resolution of spiritual journey. To receive assistance with issues related to grief.	Help patient/family plan services. Perform/attend memorial service/funeral. Provide experience.
	Spiritual Issues	
Problem/Issues Opportunities	*Areas for Goal Development with Patient/Family*	*Suggested Intervention*
Acceptance	To accept what is and find meaning for the rest of the journey.	Empower to take the risk of trust. Model supportive listening and vulnerability. Explore understanding of control.
Wholeness/ Brokenness	Embrace spiritual healing process. To develop comfort in present state of brokenness.	Offer assurance of Diving presence. Empower spiritual healing through expression of their faith tradition.
Grief/Mourning/ Bereavement	Come to an acceptance of personal beliefs about life/death afterlife. Experience the reality of the faith, hope, spiritual strength. Find spiritual focus in losses.	Assess the grief process. Conduct/affirm life/illness/death review. Emphasize continuity of life. Share grief literature. Reaffirm spiritual connectedness. Facilitate recasting of goals. Validate beliefs. Offer words of encouragement/emotional support.

Denial/Fear	Acceptance of possibilities and powerlessness. Explore fears. Establish hopefulness amidst threats.	Facilitate discussion of possibilities and outcomes. Enhance perception of self in relation to Divine in the midst of threat.
Anger	Discover sources of anger. Seek reconciliation. Discover spiritual peace.	Facilitate discussion/expression of feelings. Offer possibilities of reconciliation. Offer avenues of spiritual peace. Encourage ownership of feelings.
Wisdom	Seek insight into spiritual awareness.	Discuss meanings of relationship to Transcendent.
Preparedness to Die	Come to an understanding of personal beliefs of life and death. To be able to utilize faith in acceptance of death. To embrace a sense of meaning, wholeness and purpose.	Validate personal beliefs of life and death. Reaffirm continuity of life. Establish means for hope amidst death, through affirmations of possibilities.
Sense of Chaos	To be able to feelings of disorder. Discover personal limits of control. Find spiritual meaning in chaos.	Discuss feelings of chaos. Discuss emergence of creativity amidst chaos.
Healing	Discover/understanding of healing. Enrich understandings of hope. To have suffering reduced.	Delineate parameters of healing. Discuss personal definitions of healing. Explore acceptance of dimensions of healing.
Beliefs/Values	To reconcile belief and values.	Offer possibilities of integration of beliefs and values with their spiritual journey amidst presence of death.
Self-Respect	Explore existential worth.	Enhance perception of identity. Affirm personal worth.
Separation/ Abandonment	Receive help with the pain of disappointing relationships.	Examine relationship and feelings. Provide pastoral presence. Offer assurance of divine presence. Facilitate open expression of feelings. Explore possible paths to reconciliation.
Trust/Distrust	To have trust restored (Divine/ relationships/beliefs).	Review ownership of belief system. Examine sources of trust/distrust. Address sources of fears and apprehension. Help them with the pain of disappointing relationships. Explore human relationships within context of relationship with Divine. Empower them to take the risk to trust again. Model supportive listening and vulnerability.

Isolation	To establish sense of belonging with community (faith, family, social, etc). Find comfort in isolation.	Encourage reflection of anxiety related to communion. Assist in becoming comfortable with isolation. Offer a trust in God's presence.
Bitterness	Come to an understanding of source of bitterness.	Re-examine and explore experience. Explore the possibilities of forgiveness and reconciliation. Identify the implications/outcomes of bitterness.
Hope/Despair	Accept beliefs, claim possibilities.	Affirm belief system. Help patient/family to own the hope that their faith embodies. Celebrate the emergence of hope.
Peace/Struggle/ Coping/Inner Resources	Reconnect with their spiritual strengths. Find peace.	Identify inner resources. Encourage spiritual revitalization for inner peace. Empower understanding of the presence of God in the midst of struggle.
Grace/Mercy	Embrace blessing.	Encourage celebration. Affirm spiritual support/presence.
Security/Assurance	To find comfort in spiritual connections.	Explore what it means to be "secure". Help them to embrace the faithfulness of God.
Helplessness	To gain a sense of power/strength.	Empower their ability to make choices through strength/freedom/faith gives them. Explore the understanding of power.
Blessing/Curse (in context of illness)	Accept beliefs and/or claim possibilities.	Explore possibilities for transformation. Assist in the revision of spiritual connection.
Judgment/Testing	Delineate faith understanding. To find hope.	Enable delineation of faith understanding. Assist in clarifying experience within a spiritual/faith context.
Justice/Fairness	To find peace.	Enhance understanding of Divine compassion and forgiveness. Assist in clarifying experience within a spiritual/faith context.
Conscience/Guilt/ Shame	Develop sense of acceptance/forgiveness.	Review spiritual beliefs. Offer opportunity for forgiveness, hope and reconciliation. Offer opportunity for confession.

Meaning of Existence Existential Identity (purpose/aimless-ness)	To find my reason for existence. Experience a sense of belonging, connectedness. Establish a sense of purpose. Ownership of direction/goal-setting.	Facilitate life/illness review. Enhance perception of self in relation to Transcendent. Affirm worth of personhood. Affirm life choices/history. Facilitate recasting of goals. Review understanding of selfhood.
Forgiveness	Acceptance/understanding of reconciliation. To find peace when reconciliation is not possible.	Identify, assess and explore understandings of forgiveness – human and divine.
Afterlife	To clarify personal belief. Develop sense of assurance/security. Come to a sense of peaceful dying process.	Foster sense of assurance/security. Facilitate examination of personal spiritual beliefs/meaning. Validate beliefs. Offer opportunity of hope.
Anxiety/Fear/ Courage	Reduce anxiety and fear. Increase sense of security.	Examine source of anxiety/fear and/or address resources for courage. Assess spiritual aspects of anxiety/fear/courage. Ameliorate spiritual distress.
Meaning of Suffering "Whys?"	To find purpose or meaning of suffering.	Examine personal/spiritual/religious beliefs of suffering. Assess dimension of suffering. Facilitate discussion of spiritual beliefs, re: suffering.
Relationship with God	To come to terms with my relationship with God.	Facilitate reflection upon relationship with God. Offer reassurance of divine presence. Encourage reflection of God's relationship with the individual.
Relationship to Transcendence	To come to an understanding of relationship to transcendence.	Encourage reflection of transcendent connection. Identify the nature of reality through thought process.
Inner Peace	Find a sense of peace.	Identify understanding of peace. Encourage enrichment of the spirit, via spiritual connectedness and disciplines. Explore sense of isolation. Review past sources of connectedness.
Loss of Faith/Hope	Gain sense of faith/hope.	Encourage enrichment of the spirit, via spiritual connectedness and disciplines. Explore sense of isolation. Review past sources of connectedness.

Paranormal Phenomenon	To gain affirmation and understanding of experience.	Identify and frame their experience. Encourage verbalization and open expression of experience. Affirm spiritual possibilities.

Source: The Hospice of the Florida Suncoast, 1998, Largo, FL: Author. Reprinted with permission.

Module 1
Figure 7: Core Principles for Care of Patients

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

Source: Cassel, C. K., & Foley, K. M. (1999). Principles of care of patients at the end-of-life: An emerging consensus among the specialties of medicine. New York, NY: Milbank Memorial Fund. (http://www.milbank.org/endoflife/index.html)

Module 1
Figure 8: Sample Spiritual Care Interventions

1. Renewal of vows
2. Readings
3. Faith reaffirmation & rededications
4. Spiritual life review
5. Guided meditation
6. Receiving sacraments
7. Fostering hope
8. Addressing spiritual pain issues

Source: Fauser, M., Lo, K., & Kelly, R. (1996). Spiritual care. In Trainer Certification Program [Manual]. Largo, FL: Hospice Institute of the Florida Suncoast. Reprinted with permission.

Module 1
Figure 9: Poetry/Literature to Use in Small Group Discussions

There is much suffering in the world - very much. And this material suffering is suffering from hunger, suffering from homelessness, from all kinds of diseases, but I still think the greatest suffering is being lonely, feeling unloved, just having no one.

I have come more and more to realize that it is being unwanted that is the worst
disease that any human being can ever experience.

Nowadays we have found medicine for leprosy, and lepers can be cured.
There's medicine for TB, and
consumptives can be cured.
For all kinds of diseases there are
medicines, and cures,
but for being unwanted, except where there are willing hands to serve and there's a
loving heart to love, I don't think this terrible disease can ever be cured.

Mother Teresa

Ref: Spink, K. (Ed). (1983). Mother Teresa of Calcutta: Life in the Spirit. (p 65). San Francisco, CA: Harper & Row.

Healing:
Five aspects of relationship completion

"I forgive you"

"Forgive me"

"Thank you"

"I love you"

"Goodbye"

Source: Byock, I. (1997). Dying Well: The Prospect for Growth at the End of Life. New York, NY: Riverhead Books.

"Let us not underestimate how hard it is to listen and to be compassionate. Compassion is hard because it requires the inner disposition to go with others to the place where they are weak, vulnerable, lonely and broken. But this is not our spontaneous response to suffering. What we desire most is to do away with suffering by fleeing from it or finding a quick cure for it. As busy, active, relevant people we want to earn our bread by making a real contribution. This means first and foremost doing something to show that our presence makes a difference. And so we ignore our greatest gift, which is our ability to be there, to listen and to enter into solidarity with those who suffer." (Nouwen 1981:34)

Source: International Journal of Palliative Nursing, 1997; 3(1): 11-12.

"An expert in palliative care is not a person who gets it right all the time: an expert is someone who gets it wrong less often - and is better at concealing or coping with his or her fluster and embarrassment. We're, after all, only human beings."

Robert Buckman

Source: Buckman, R. (1998). Communication in palliative care: A practical guide. In Doyle, D., Hanks, G., & MacDonald, N. (Eds). Oxford Textbook of Palliative Medicine (2nd Ed). (pp. 141-156). New York, NY: Oxford University Press.

"Acceptance is not something an individual can choose at will. It is not like some light switch that can at will be flicked on or off. Deep emotional acceptance is like the settling of a cloud of silt in a troubled pool. With time the silt rests on the bottom and the water is clear."

Michael Kerney, MD

Kerney, M. (1996). Wounded Healer. New York, NY: Simon & Schuster

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"In the beginning of life, when we are infants, we need others to survive, right? And at the end of life, when you get like me, you need others to survive, right? ... But here's the secret: in between, we need others as well."

Morrie Schwartz

Albom, M. (1997). Tuesdays with Morrie. New York, NY: Bantum Doubleday Dell Publishing Group, Inc.

PROGRAM EVALUATION

Employee Name: ______________________________ **Position:** RN LVN NA SN **Unit:** __________

Program Title: ______________________________ **Date:** __________ **Time:** ______ **Length:** ____

Type of Program: ○ InService ○ Continuing Ed. ○ CAI Program ○ SLM ○ Unit-Based

☛ *Please rate the program with respect to:*

Overall quality:	☐ Excellent	☐ Good	☐ Average	☐ Poor
Quality of Content:	☐ Excellent	☐ Good	☐ Average	☐ Poor
Recommendation you would give about this program to your peers:	☐ Excellent	☐ Good	☐ Average	☐ Poor
Applicability of the program to your current nursing practice:	☐ Excellent	☐ Good	☐ Average	☐ Poor

Your recommendations for future Continuing Education programs needed? ______________________________

____

____

General Comments: ____

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cs:insvc:programeval

Department of Veterans Affairs

Certificate of Training

This certificate is given to

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License Number________________________________

for satisfactory completion of the course in

Nursing Care at the End of Life

*Given at: **Jerry L. Pettis Memorial VA Medical Center***
Loma Linda, California 92357

This 10th day of January, 2002

VA DESERT PACIFIC HEALTHCARE NETWORK

Mary Anne Collins, MSN, RN,C

Mary Anne Collins, MSN, RN,C Educator
Nursing Research & Education Department
Olivia Catolico, MSN, RN, Director

Provider approved by the California Board of Registered Nursing, Provider #02633, for1 contact hour(s).

VA FORM 3904, MAR 1989

APPENDIX G

END-OF-LIFE NURSING EDUCATION CONSORTIUM MODULE 3; SYMPTOM MANAGEMENT IN END-OF-LIFE CARE

Module 3
Symptom Management

Module Overview

This module builds on Module 2: Pain Management, by addressing other symptoms common at the end of life.

Key Messages

- There are many physical and psychological symptoms common at the end of life.
- Optimum treatment of symptoms involves comprehensive assessment and use of drug and nondrug interventions.
- Nurses must work collaboratively with physicians and other disciplines in symptom management.

Objectives

At the completion of this module, the participant will be able to:

1. Identify common symptoms associated with end of life processes.
2. Identify potential causes of symptoms at end of life.
3. Describe assessment of symptoms at end of life.
4. Describe interventions that can prevent or diminish symptoms at end of life.

Module 3: Symptom Management
Participant Outline

I. Introduction
  A. Essential elements of symptom management
    1. Assessment and evaluation
    2. Interdisciplinary teamwork
    3. Economics
    4. Indications for diagnostic tests
    5. Research
  B. Priority symptoms in end of life care
  C. Symptoms and suffering

II. Common symptoms
  <u>Respiratory Symptoms</u>
  A. Dyspnea
    1. Definition/overview
    2. Causes
      a. Pulmonary
      b. Cardiac
      c. Neuromuscular
      d. Other
    3. Assessment
      a. Impact on function and quality of life
      b. Clinical assessment
    4. Treatments
      a. Pharmacologic
      b. Non-pharmacologic
      c. Other
  B. Cough
    1. Definition/overview
    2. Causes
    3. Assessment
    4. Treatment
      a. Pharmacologic
      b. Non-pharmacologic
  <u>GI Symptoms</u>
  C. Anorexia/Cachexia
    1. Definition/overview
    2. Causes
      a. Disease related
      b. Psychological
      c. Treatment related

    3. Assessment
        a. Physical findings
        b. Impact on function
        c. Impact on self/family
        d. Calorie counts/daily weights
        e. Laboratory tests
    4. Treatment
        a. Dietary consult/Dietary interventions
        b. Medications
        c. Parenteral or enteral nutrition
        d. Problem odors
        e. Counseling

D. Constipation
    1. Definition/overview
    2. Causes
        a. Disease related
        b. Treatment related
    3. Assessment
        a. Bowel history
        b. Abdominal assessment
        c. Rectal assessment
        d. Medication review
    4. Treatment
        a. Medications
        b. Dietary and fluid interventions
        c. Additional approaches

E. Diarrhea
    1. Definition/overview
    2. Causes
        a. Disease related
        b. Psychological
        c. Treatment related
    3. Assessment
        a. Bowel history
        b. Medication review
        c. Evaluate for infectious process
    4. Treatment
        a. Treat etiology as appropriate
        b. Dietary modifications (increase bulk, decreased gas-producing foods)
        c. Medications
        d. Hydration

F. Nausea/vomiting
  1. Definition/overview
  2. Causes
    a. Physiological
    b. Psychological
    c. Disease related
    d. Treatment related
    e. Other
  3. Assessment
    a. Clinical/physical
    b. History
    c. Laboratory values
  4. Treatment
    a. Pharmacologic
    b. Non-pharmacologic
    c. Invasive therapies

<u>General/Systemic</u>

G. Fatigue
  1. Definition/overview
  2. Causes
    a. Disease related
    b. Psychological
    c. Treatment related
  3. Assessment
    a. Subjective
    b. Objective
    c. Laboratory data
  4. Treatment
    a. Pharmacologic
    b. Non-pharmacologic

H. Depression
  1. Definition/overview
  2. Causes
    a. Disease related
    b. Psychological
    c. Treatment related
  3. Assessment
    a. Situational factors
    b. Previous psychiatric history/treatment
    c. Presence of risk factors
    d. Questions for depression assessment
    e. Suicide assessment

      - 3. Treatment
        - a. Pharmacologic
        - b. Non-pharmacologic
  - I. Anxiety
    - 1. Definition/overview
    - 2. Causes
    - 3. Assessment
      - a. Symptoms
      - b. Questions for assessment
    - 4. Treatment
      - a. Pharmacologic
      - b. Non-pharmacologic
  - J. Delirium/Agitation/Confusion
    - 1. Definition/Overview
    - 2. Causes
    - 3. Assessment
    - 4. Treatment

- III. CONCLUSION
  - A. Symptom management challenges
  - B. Key nursing roles

Slide 1

ELNEC

End-of-Life Nursing Education Consortium

Module 3:
Symptom Management

Slide 2

Introduction

- There are many physical and psychological symptoms common at the end of life
- Ongoing assessment and evaluation of interventions is needed
- Requires interdisciplinary teamwork

Slide 3

Introduction (cont.)

- Reimbursement concerns
- Limit diagnostic tests
- Research is needed

Slide 4

Symptoms and Suffering

- Symptoms create suffering and distress. Psychosocial intervention is key to complement pharmacologic strategies

Slide 5

Common Symptoms

Respiratory
- Dyspnea
- Cough

GI
- Anorexia
- Constipation
- Diarrhea
- Nausea/Vomiting

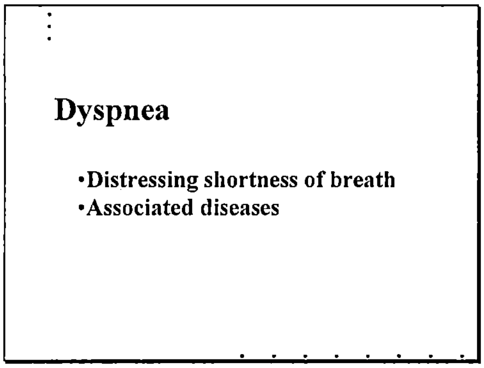
Slide 6

Common Symptoms (Cont.)

General/Systemic
- Fatigue/Weakness

Psychological
- Depression
- Anxiety

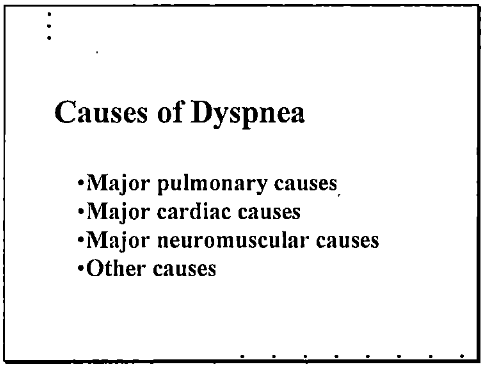
Slide 7



Dyspnea

- Distressing shortness of breath
- Associated diseases

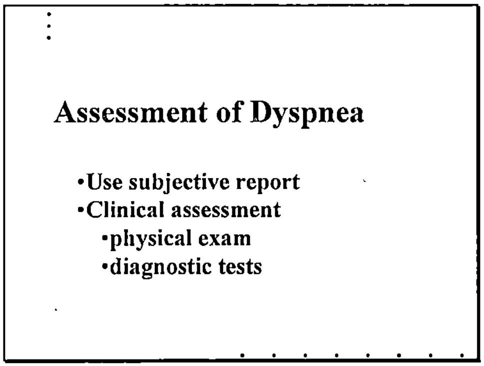
Slide 8



Causes of Dyspnea

- Major pulmonary causes
- Major cardiac causes
- Major neuromuscular causes
- Other causes

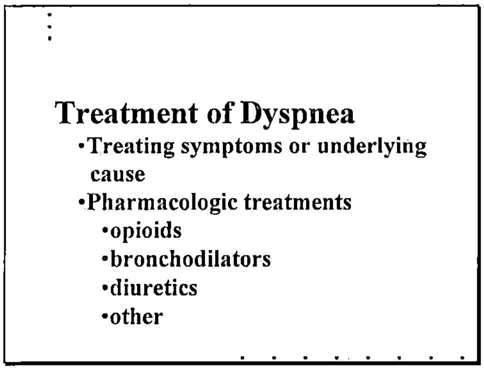
Slide 9



Assessment of Dyspnea

- Use subjective report
- Clinical assessment
    - physical exam
    - diagnostic tests

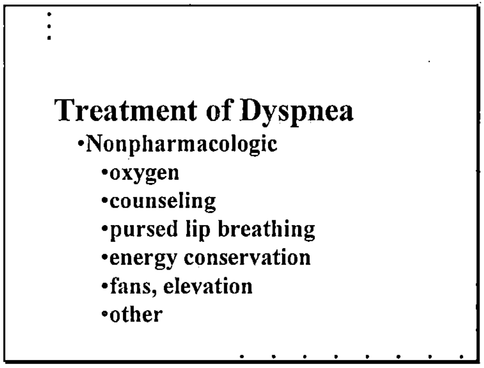
Slide 10



Treatment of Dyspnea

- Treating symptoms or underlying cause
- Pharmacologic treatments
  - opioids
  - bronchodilators
  - diuretics
  - other

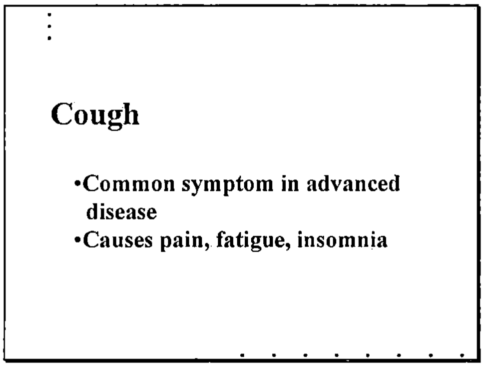
Slide 11



Treatment of Dyspnea

- Nonpharmacologic
  - oxygen
  - counseling
  - pursed lip breathing
  - energy conservation
  - fans, elevation
  - other

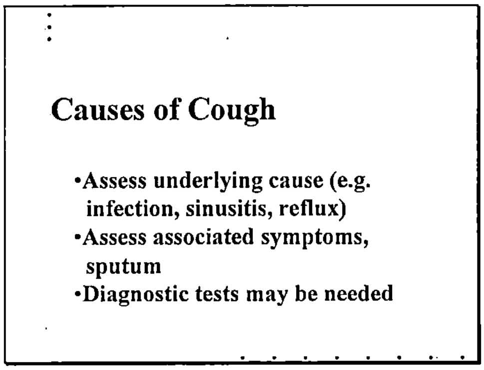
Slide 12



Cough

- Common symptom in advanced disease
- Causes pain, fatigue, insomnia

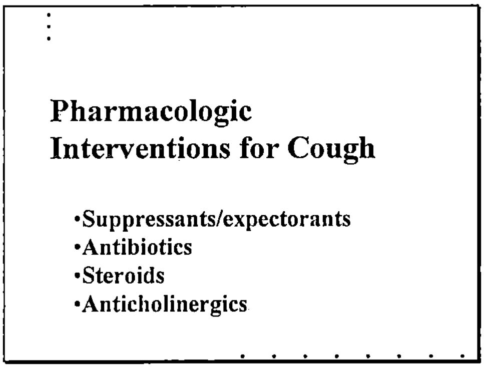
Slide 13



Causes of Cough

- Assess underlying cause (e.g. infection, sinusitis, reflux)
- Assess associated symptoms, sputum
- Diagnostic tests may be needed

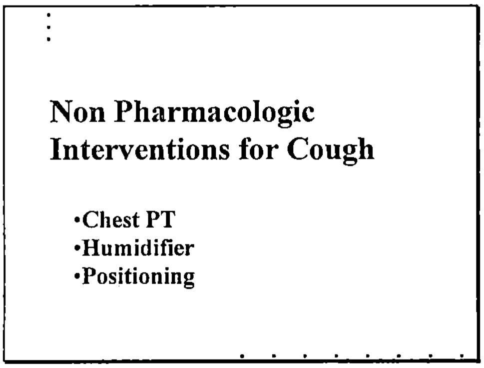
Slide 14



Pharmacologic Interventions for Cough

- Suppressants/expectorants
- Antibiotics
- Steroids
- Anticholinergics

Slide 15



Non Pharmacologic Interventions for Cough

- Chest PT
- Humidifier
- Positioning

Slide 16

Anorexia and Cachexia

- Anorexia - loss of appetite, usually with decreased intake
- Cachexia - lack of nutrition and wasting

Slide 17

Causes of Anorexia and Cachexia

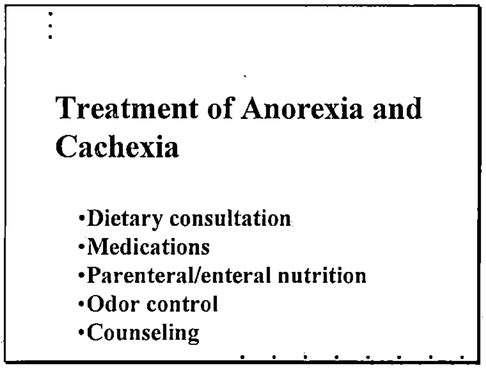
- Disease related
- Psychological
- Treatment related

Slide 18

Assessment of Anorexia and Cachexia

- Physical findings
- Impact on function and QOL
- Calorie counts/daily weights
- Lab tests

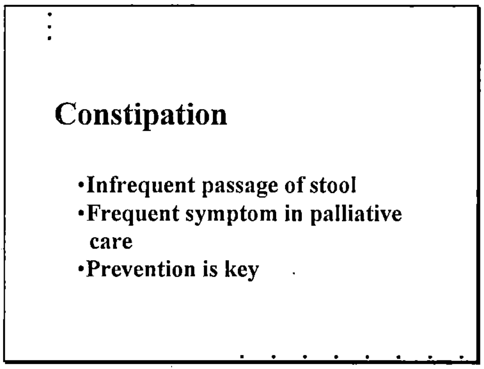
Slide 19



Treatment of Anorexia and Cachexia

- Dietary consultation
- Medications
- Parenteral/enteral nutrition
- Odor control
- Counseling

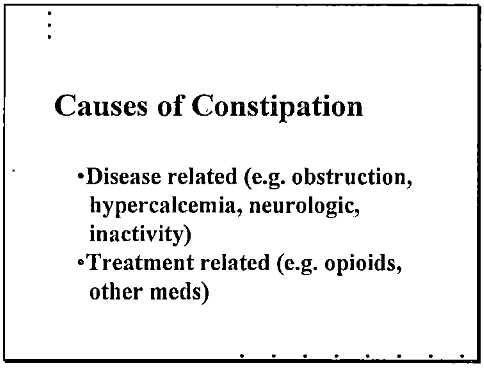
Slide 20



Constipation

- Infrequent passage of stool
- Frequent symptom in palliative care
- Prevention is key

Slide 21



Causes of Constipation

- Disease related (e.g. obstruction, hypercalcemia, neurologic, inactivity)
- Treatment related (e.g. opioids, other meds)

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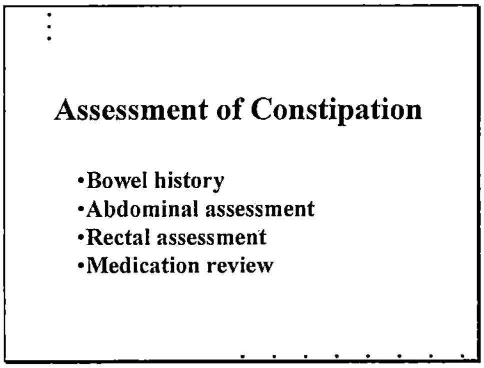

Assessment of Constipation

- Bowel history
- Abdominal assessment
- Rectal assessment
- Medication review

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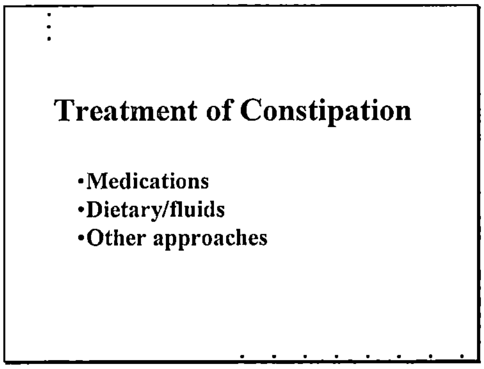

Treatment of Constipation

- Medications
- Dietary/fluids
- Other approaches

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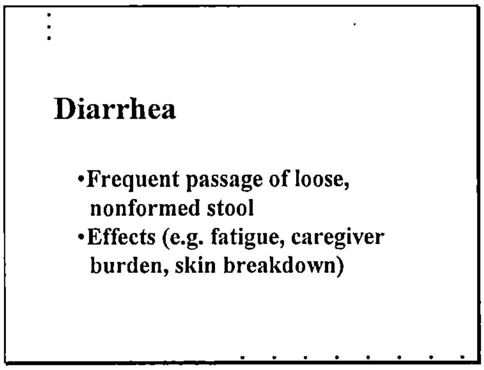

Diarrhea

- Frequent passage of loose, nonformed stool
- Effects (e.g. fatigue, caregiver burden, skin breakdown)

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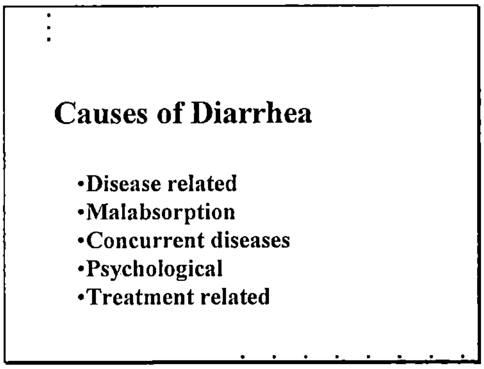
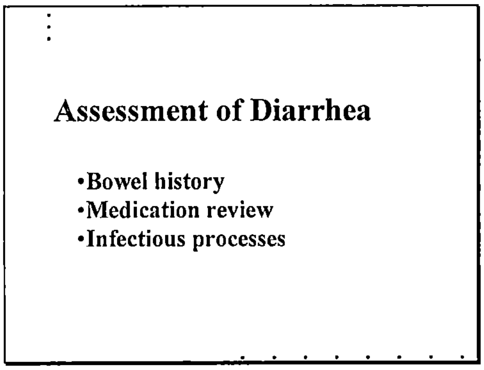


Causes of Diarrhea

- Disease related
- Malabsorption
- Concurrent diseases
- Psychological
- Treatment related

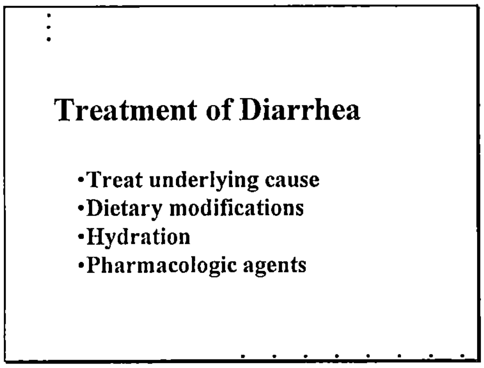
Slide 26



Assessment of Diarrhea

- Bowel history
- Medication review
- Infectious processes

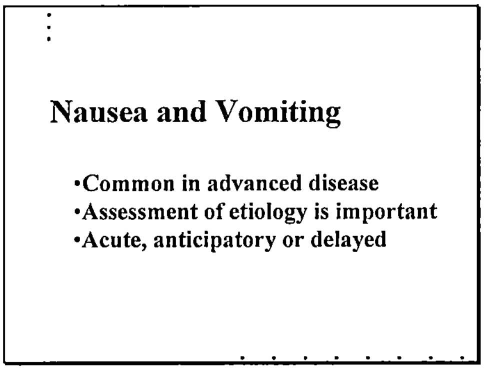
Slide 27



Treatment of Diarrhea

- Treat underlying cause
- Dietary modifications
- Hydration
- Pharmacologic agents

Slide 28



Nausea and Vomiting

- Common in advanced disease
- Assessment of etiology is important
- Acute, anticipatory or delayed

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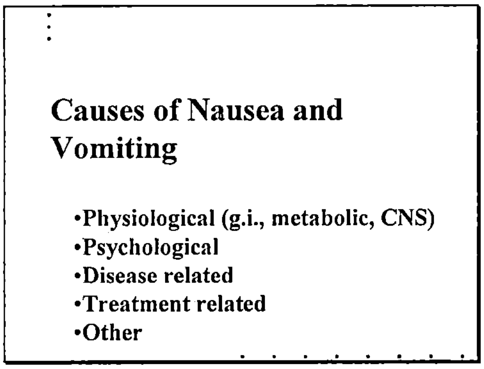

Causes of Nausea and Vomiting

- Physiological (g.i., metabolic, CNS)
- Psychological
- Disease related
- Treatment related
- Other

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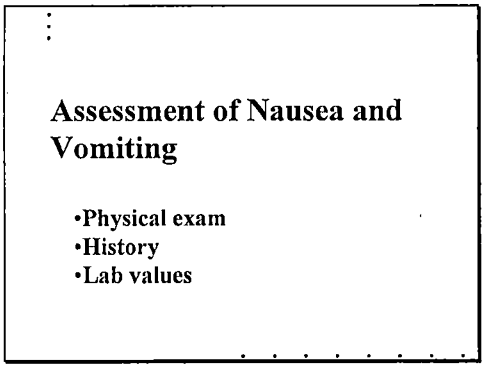
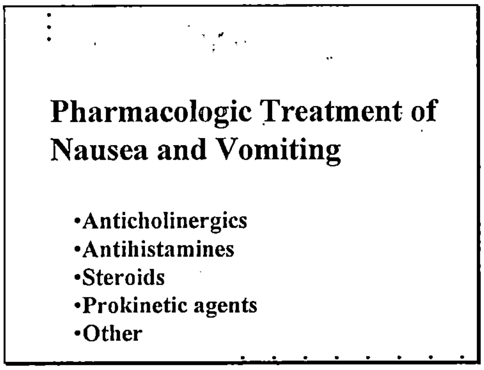


Assessment of Nausea and Vomiting

- Physical exam
- History
- Lab values

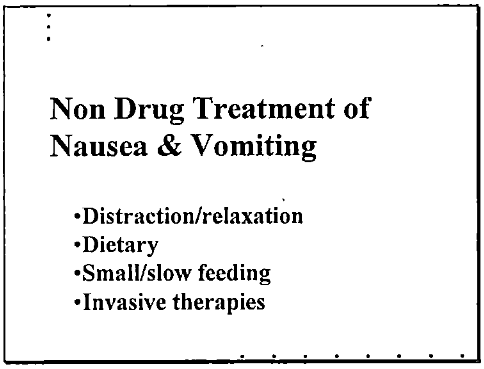
Slide 31



Pharmacologic Treatment of Nausea and Vomiting

- Anticholinergics
- Antihistamines
- Steroids
- Prokinetic agents
- Other

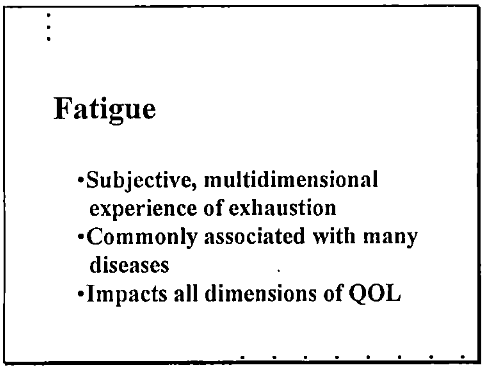
Slide 32



Non Drug Treatment of Nausea & Vomiting

- Distraction/relaxation
- Dietary
- Small/slow feeding
- Invasive therapies

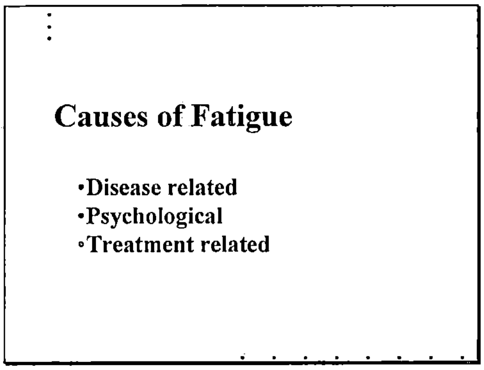
Slide 33



Fatigue

- Subjective, multidimensional experience of exhaustion
- Commonly associated with many diseases
- Impacts all dimensions of QOL

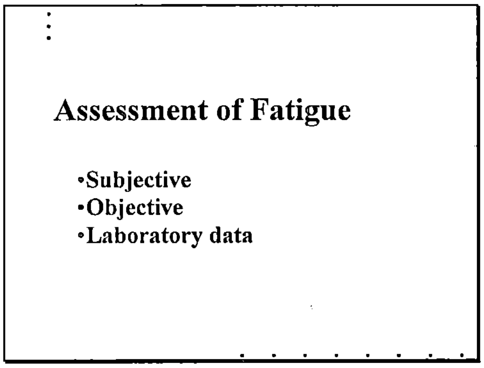
Slide 34



Causes of Fatigue

- Disease related
- Psychological
- Treatment related

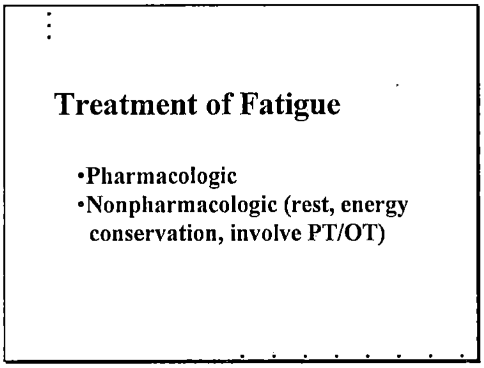
Slide 35



Assessment of Fatigue

- Subjective
- Objective
- Laboratory data

Slide 36



Treatment of Fatigue

- Pharmacologic
- Nonpharmacologic (rest, energy conservation, involve PT/OT)

Slide 37

Depression

- Ranges from sadness to suicidal
- Often unrecognized and undertreated
- Occurs in 25-77% of terminally ill
- Distinguish normal vs. abnormal

Slide 38

Causes of Depression

- Disease related
- Psychological
- Treatment related

Slide 39

Assessment of Depression

- Situational factors
- Previous psychiatric history
- Other factors (e.g. lack of support system, pain)

Slide 40

Example Questions for Depression Assessment

- How have your spirits been lately?
- What do you see in your future?
- What is the biggest problem you are facing?

Slide 41

Suicide Assessment

- Do you think life isn't worth living?
- Have you thought about how you would kill yourself?

Slide 42

Pharmacologic Interventions for Depression

- Antidepressants
- Stimulants
- Nonbenzodiazepines
- Steroids

Slide 43

Non Pharmacologic Interventions for Depression

- Promote autonomy
- Grief counseling
- Draw on strengths; reframing

Slide 44

Anxiety

- Subjective feeling of apprehension
- Often without specific cause
- Categories of mild, moderate, severe

Slide 45

Causes of Anxiety

- Medications and substances
- Uncertainty

Slide 46

Assessment of Anxiety

- Physical symptoms
- Cognitive symptoms
- Questions for assessment

Slide 47

Pharmacologic Interventions for Anxiety

- Antidepressants
- Benzodiazepines/anticonvulsants
- Neuroleptics
- Nonbenzodiazepines

Slide 48

Nonpharmacologic Interventions for Anxiety

- Empathetic listening
- Assurance and support
- Concrete information/warning
- Relaxation/imagery

Slide 49

Delirium/Agitation/Confusion

- Delirium-Acute change in cognition/ awareness
- Agitation-accompanies delirium
- Confusion-disorientation, inappropriate behavior, hallucinations

Slide 50

Causes

- e.g. infection, hypoxemia, bladder distention, etc.

Slide 51

Assessment

- Physical exam
- History
- Spiritual distress
- Other symptoms

Slide 52

Treatment

- Pharmacologic
- Evaluate medications
- Reorientation
- Relaxation/distraction
- Hydration

Slide 53

Key Nursing Roles

- Patient advocacy
- Assessment
- Pharm tx
- Non-Rx tx
- Pt/family teaching

Slide 54

Conclusion

- Multiple symptoms common
- Coordination of care with physicians and others
- Use drug and nondrug treatment
- Patient/family teaching and support

Module 3: Symptom Management
Supplemental Teaching Materials/Training Session Activities

Module 3
Table 1: Symptoms Common at End of Life

GI Function	**Bowel Function**	**Mood**
Anorexia Nausea/vomiting Dysphagia Weight loss Unpleasant taste Ascites	Constipation Diarrhea Loss of function or control	Depression Anxiety
Bladder Function	**Cognition**	**Skin Integrity Issues**
Incontinence Changes in function or control Bladder Spasms	Insomnia Confusion/dementia/delirium Memory changes	Decubitus Mucositis Candidiasis Pruritis Edema Ascites Hemorrhage/blood loss Herpes Zoster
Breathing	**Functional Ability**	**Other**
Dyspnea Cough/congestion/rattles Hiccups Altered breathing patterns	Fatigue Immobility Pathological fractures/ Spinal cord compression Weakness	Fever Diaphoresis

Source: Hope: Home care Outreach for Palliative care Education Project. (1998). Funded by the National Cancer Institute. B.R. Ferrell, PhD, FAAN, Principal Investigator.

Module 3
Table 2: Pharmacologic Treatment of Dyspnea

Class of Drug	Examples	Mechanism of Action	Dosages/Comments
Opioids.	Morphine Fentanyl	Exact mechanism for dyspnea is not completely understood	IV - 1-4mg q15min - 4hrs SQ - 1-4mg q30min - 4hrs PO -5-15mg, pill or liquid form q 1-4 hrs Rectal - 5-15mg q 1-4hrs suppository. May need to be compounded. IV - 25-40mcg q15 min prn SL - 25-40mcg q15 min prn Nebulizer - 25mcg (Coyne et al, 2000)
Bronchodilators (Used frequently in airway obstruction, COPD, and asthma conditions)	Albuterol	Relax smooth muscles of respiratory tract relieving bronchospasm Stimulates β 2 agonist, adrenergic receptors of sympathetic nervous system. Relaxing smooth muscles of bronchial tree.	Dosages are highly variable and dependent on patient's overall health status, smoking history, age, and presence of co-morbid factors. May cause anxiety, cough while worsening dyspnea. Drugs are available in metered dose inhalers, nebulizers or orally.
Diuretics (Used in heart failure, reduce fluid overload)	Furosemide	Inhibits reabsorption of electrolytes in ascending limb of the loop of Henle, enhancing excretion of sodium chloride, potassium, calcium and other electrolytes	PO - 20-80mg IV - 20-40mg Dosage varies widely and should be adjusted to patients requirement and response.

Class of Drug	Examples	Mechanism of Action	Dosages/Comments
Benzodiazpines	Lorazepam (There are conflicting reports about the efficacy in the treatment of dyspnea. Therefore it should not be considered a first line treatment).	Appear to act on thalamic/ hypothalamic areas of the CNS producing anxiolytic, sedative, hypnotic and skeletal muscle relaxation.	IV - 0.5-2mg q8-q12hrs PO - 0.5-2mg q8-q12hrs IM - 0.5-2mg q6-q12 hrs All routes q8-q12hrs for anxiety. Dosages may vary significantly and should be adjusted to patient's requirements and responses.
Nonbenzodiazepine Anxiolytic	Buspirone	No effect on pulmonary function tests or arterial blood gases, but improves exercise tolerance and decrease sensation of breathlessness in patients with COPD.	
Steroids (Used in asthma and COPD).	Dexamethasone	Mechanism not fully understood. Affects antibody systems. Appears to decrease inflammation (especially associated with vena cava syndrome) and suppresses immune response.	Aerosol - 0.25mg-20mg IV - 0.25-20mg PO - 0.25-20mg IM - 0.25-20mg
Antibiotics	Penicillin	Varies by agent	Varies according to antibiotic given
Antifungals (used to treat pulmonary infections).	Fluconazole	Varies by agent	Dose varies, typically 200mg po day one then 100mg qd.
Anticoagulants	Heparin Warfarin	Prevents clot formation which may prevent future incidence of pulmonary emboli	Varies according to lab results

Module 3
Table 3: Pharmacologic Treatments for Fatigue

Class of Drug	Examples	Mechanism of Action	Comments
Corticosteroids	Dexamethasone Prednisolone Methyl-prednisolone	Mechanism of action is unclear. Duration and benefits limited to weeks.	Insufficient data on optimal type and dosage. (Can improve appetite & elevate mood, thus improving a sense of well-being, but the duration of effect may be limited)
Stimulants	Methyl-phenidate	Stimulates CNS and respiratory centers, increases appetite & energy levels, improves mood, reduces sedation (Bruera, Chadwick & Brennis, 1985).	Starting dose 5-10mg qAM and 12Noon, titrate to effect.
• Anti-depressants • Selective Serotonin Reuptake • Inhibitors (SSRIs)	Paroxetine Fluoxetine	Reduces depressive symptoms associated with fatigue. Can improve sleep. Primary choice for treatment of depression in cancer patients. Inhibits Serotonin reuptake	Some SSRI's have long half-lives and should be used cautiously in the terminally ill.
• Tricyclic Antidepressants	Amitriptyline Nortriptyline	Block reuptake of various neurotransmitters at the neuronal membrane. Can improve sleep.	Starting dose 10-25 mg q hs
Erythropoeitin		Increases hemaglobin with effects on energy, activity & overall quality of life while decreasing transfusion requirements (Krammer et al, 1999).	150 Units/kg SQ q 3 times a week

Module 3
Table 4: Pharmacologic Treatment for Constipation

Class of Drug	Examples	Mechanism of Action	Comments
Stimulant	Senna or Senna combinations	Stimulates bowel.	Should be used with caution when liver disease is present.
Laxatives			
Bulk	Psyllium	Increase intestinal transit time.	Not recommended if bowel obstruction is impending or patient has limited fluid intake (< 8 glasses/day), may not be appropriate in end of life care.
Lubricant	Mineral Oil	Lubricates and softens stool	Decreases absorption of vitamins and minerals. Associated with aspiration pneumonia in the frail elderly.
Detergent/ Softener	Docusate	Softens stool, may stimulate colon.	
Combination	Casanthrol and Docusate	Combines mild stimulant with softener.	
Osmotic	Sorbitol, Lactulose	Nonabsorbtable sugars that pull fluid into GI tract.	Typically used in patients with chronic constipation especially in opiate use.
Magnesium Salts	Milk of Magnesia	Osmotic	Prolonged use or overdosage of saline laxative may lead to life threatening eletrolyte disturbances.
Note: Multiple over the counter preparations are available, see individual dosing guidelines.			

Module 3
Table 5: Pharmacologic Treatments for Diarrhea

Class of Drug	Examples	Mechanism of Action	Comments
Opioids	Diphenoxylate Hydrochloride Loperamide Hydrochloride	Suppress forward peristalsis and increase sphincter tone.	5 mg po qid Start at 4 mg po, then 2 mg after each loose stool, not to exceed 16 mg a day.
Bulk-Forming Agents	Psyllium (Metamucil)	Promote absorption of liquid and increase thickness of stool.	Give 1-3 times a day, many preparations available Patient must be able to drink at least 8 glasses of water daily.
Antibiotics	Flagyl	To eliminate infectious processes.	Antibiotic choice is based on etiology.
Steroids	Dexamethasone (Decadron)	Decrease inflammation in the gut and provides some relief in partial bowel obstruction & ulcerative colitis.	
Somatostatin	Octreotide (Sandostatin)	Slows transit time by decreasing secretions.	Suppress diarrhea associated with carcinoid tumors and AIDS.

Module 3
Table 6: Pharmacologic Treatments for Depression

Class of Drug	Examples	Mechanism of Action	Comments
Antidepressants	SSRI's: - Fluoxetine - Paroxetine - Sertraline Tricyclic: - Amitriptyline - Nortriptyline	Blocks serotonin reuptake. Blocks reuptake of various neurotransmitters at the neuronal membrane. Improves sleep.	Some SSRI's have long half-lives and thus may have limited use for the terminally ill.
Stimulants	Methylphenidate	Stimulates CNS and respiratory centers, increases appetite & energy levels, improves mood, reduces sedation (Bruera et al, 1985).	Starting dose 5-10mg qAM and 12 Noon, titrate to effect. Acts quickly.
Non-benzodiazepines	Buspirone Hydrochloride	Mechanism of action is complex - acts on multiple CNS sites to produce anxiolytic activity.	Useful in patients with mixed anxiety and depressive symptoms. Starting dose 10-15 mg. po daily in divided doses, then titrated up to no higher than 60 mg. po a day. Slow onset. Duration of effect may be limited.
Steroids	Dexamethasone	Improves appetite & elevates mood, thus improving a sense of well-being.	

Module 3
Table 7: Pharmacologic Treatments for Anxiety

Class of Drug	Examples	Mechanism of Action	Comments
Antidepressants	SSRI's: -Fluoxetine -Paroxetine - Sertraline	Blocks serotonin reuptake.	Useful in treating transient anxiety and panic attacks; use cautiously in terminally ill.
Benzodiazepines/ Anticonvulsants	Alprazolam Lorazepam Clonazepam Temazepam Midazolam	Appear to act on limbic - thalamic - hypothalamic areas of the CNS producing anxiolytic, sedative, hypnotic, skeletal muscle relaxation.	Dose varies. Midazolam and Lorazepam are used parenterally in terminal restlessness/agitation.
Neuroleptics	Haloperidol	Precise mechanism unclear, depresses the CNS at level of brain, midbrain, brain stem reticular formation.	Used in severe agitation when benzodiazepines are not effective and are especially useful when treating delusions and hallucinations that accompany anxiety, and in demented patients.
Non-benzodiazepines	Buspirone	Mechanism of action is complex - acts on multiple CNS sites to produce anxiolytic activity.	Useful in patients with mixed anxiety and depressive symptoms.

Module 3
Table 8: Pharmacological Interventions for Cough

Class of Drug	Examples	Mechanism of Action	Comments
Bronchodilators	Terbutaline	Relax smooth muscles and decrease cough in airway disease.	Dosages vary widely.
Cough Suppressants:			
- Opiates	Morphine Sulfate	Central CNS action, suppresses cough.	
- Local anesthetics	Tessalon Perles	Suppresses cough stimulus (anecdotal reports).	5 ml of 2% Lidocaine via nebulizer q 4 hrs. prn.
	Benzonatate	Inhibits cough by anesthetizing stretch receptors which mediate cough reflex.	100 mg. po 3 times a day; may be administered q 4 hours up to 600 mg. daily. Should not be chewed or dissolved in mouth.
Cough Expectorants	Guaifenesin	Increases bronchial secretion viscosity.	
Antibiotics	Penicillin	To treat pneumonias or infections of the airway passages	Infrequently used in palliative care but may prove useful in an infectious process.
Steroids	Dexameth-asone	To decrease inflammation of airways or compression of an airway by tumor.	
Anticholinergics	-Atropine -Hydroscine Hydrobromide	Decrease secretion production; decrease cough.	
Nebulized saline or humidifier		Used to thin secretions.	

Module 3

Table 9: Anorexia Assessment

A	Aches and pains
N	Nausea
O	Oral candidiasis
R	Reactive (or organic) depression
E	Evacuation problems (constipation, retention)
X	Xerostomia (dry mouth)
I	Iatrogenic (radiation or chemotherapy)
A	Acid-related gastritis or peptic ulcers

Source: Storey, P. (1994). Symptom control in advanced cancer. Seminars in Oncology, 21(6): 748-753.

Module 3

Table 10: Delirium, Agitation, Restlessness

Assess for underlying cause:

D	Drugs (especially psychotropics)
E	Electrolyte or glucose abnormality
L	Liver failure
I	Ischemia or hypoxia
R	Renal failure
I	Impaction of stool
U	Urinary tract (or other) infection
M	Mestastases to the brain

Source: Storey, P. (1994). Symptom control in advanced cancer. Seminars in Oncology, 21(6): 748-753.

Module 3
Table 11: Dyspnea Management

B	Bronchospasm—if present, consider nebulized albuterol or oral steroids; if not present, consider lowering the dose of theophylline and adrenergic agents to reduce the tremor and anxiety that often exacerbates dyspnea.
R	Rales—if volume overload is present, reduce artificial feeding or stop IV fluids. Diuretics are occasionally needed. If pneumonia seems likely, decide whether an antibiotic will rehabilitate the patient or just prolong the dying process. (Patient and family participation in this decision-making process is essential).
E	Effusions—thoracentesis can be effective but if the effusion recurs and the patient is ambulatory, consider chest tube pleurodesis. If the patient is close to death , palliate the dyspnea with opioids.
A	Airway obstruction—make sure tracheostomy appliances are cleaned regularly. If aspiration of food is likely, puree solids and thicken liquids with cornstarch (or Thick-it).
T	Thick secretions—if the cough is still strong, loosen them with nebulized saline. If the cough is weak, dry them with oxybutanin (Ditropin) 5-10 mg three times per day, Transderm Scop 1-3 patches every three days or add scopolamine 0.8-3.2 mg per day to the subcutaneous infusion. These drugs will also reduce a "death rattle".
H	Hemoglobin low—occasionally a blood transfusion can add energy and reduce dyspnea for a few weeks. More often, the hemorrhage or marrow failure, like the pneumonia, will be part of the dying process and is best palliated with opioids.

Source: Storey, P. (1994). Symptom control in advanced cancer. Seminars in Oncology, 21(6): 748-753.

Module 3

Table 12: Preparation and Education of Family Caregivers with Respect to Children at the End of Life

Needs of Family Caregivers	Professional Interventions
Practical Needs	
• Is home care, hospice care, or care in the hospital appropriate for my child? • How will we pay for end of life care at home, in the hospital, or in hospice? • How will we pay our other bills? • Where do I get equipment and supplies? • How does the equipment work? • Who do I call if equipment malfunctions? • How should we arrange our house to best meet the needs of our child? • Will there be help available to us at home? • Who do I call for medical questions?	• Explore family's preferences for home care or hospice as appropriate. • Evaluate family's funding source and provide resources and assistance as necessary. • Provide family with appropriate telephone numbers and contact people for questions about equipment and medical care. • Plan for availability of caregiver's family (i.e. parents, family, friends, professionals) and help coordinate a schedule for provision of care. • Provide contact person for family to call with concerns or questions.
Personal Care	
• How do I give my child a bath? • How do I give my child a bed bath? • How do I wash my child's hair in bed? • How do I change linen with my child in bed? • How do I perform skin care? • How do I perform mouth care? • How do I administer medications? • What do I do if my child does not want to eat? • Is there something I can do to get my child to eat? • Are there alternate forms of feeding? • Does my child need supplements or a special diet?	• Instruct all caregivers about providing daily care to the child. • Provide written instructions and reference material for caregivers to review. • Assess the child's nutritional status and parent's view on supplemental nutrition. • Educate family on decreased nutritional needs and potential complications with over-feeding or over-hydration.

Needs of Family Caregivers	Professional Interventions
Physical Care	
• How do I assess my child's pain? • When should I give pain medications? • What do I do when pain management is ineffective? • What should I do when our child is constipated or has diarrhea? • How do I control nausea and vomiting? • What do I do if my child has a fever? • What do I do if my child has seizures? • What do I do if my child has trouble breathing?	• Assess the child's current comfort status and educate family on current interventions. • Educate family about assessing the child's comfort level. • Instruct the family that the child may be uncomfortable for a variety of reasons (i.e., constipation, anxiety, fever, headache, muscle cramp, disease) and educate them • about appropriate interventions for particular circumstances. • Provide an accessible supply of medications that can help alleviate discomfort (i.e., laxative, sedative, antipyretic). • Encourage caregiver to telephone contact person for questions or ineffective interventions.
Activity and Social Interactions	
• Can we safely travel and enjoy family gatherings with our child? • In which activities can we engage our child? • Should friends and family be encouraged to visit? • What interventions can I do to help my child relax and rest comfortably?	• Encourage family to engage in fun and memorable activities with the child. • Encourage visitors when appropriate. • Encourage family to employ relaxation techniques that have previously been beneficial to the child.

Source: Texas Children's Cancer Center, Texas Children's Hospital. (2000). End of Life Care for Children. Austin, TX: The Texas Cancer Council, pp. 30-31.

Module 3
Table 13: Pediatric Pharmacologic Interventions for Anorexia

Dose	Comments
Megestrol Acetate (Megace)	
Children and adults: 10 mg/kg PO either as 1 dose or in 2 divided doses (maximum 800 mg/day)	Stimulates appetite to promote weight gain in anorexic or cachexic patients.
Dronabinol (Marinol)	
Children and adults: 2.5 mg/m2/dose 3-4 times/day	Increases appetite to promote weight gain in anorexic or cachexic pateints.
Dexamethasone	
15 mg/m2/day	Works well for short-term stimulation of appetite. Reassess in 2 weeks for effect; consider tapering.
Multivitamins	
Infant drops: 1 ml PO qd: children and adults may take 1 chewable or 1 table PO qd.	Anecdotal evidence suggests that B vitamins may increase appetite.

Source: Texas Children's Cancer Center, Texas Children's Hospital. (2000). End of Life Care for Children. Austin, TX: The Texas Cancer Council, p. 37.

Module 3
Table 14: Pediatric Pharmacologic Management of Nausea and Vomiting

Drug	Dose	Comments
Nausea and vomiting caused by increased ICP		
• Dexamethasone	1-2 mg/kg IV/PO initially, then 1 to 1.5 mg/kg/day divided q 6h; max: 16 mg/day	• May reduce bowel obstruction, relieving nausea and vomiting. • May need to increase dose periodically as disease worsens. • Side effects include weight gain, edema, and GI irritation.
Nausea and vomiting caused be intestinal obstruction & opioid use		
• Promethazine	0.5 mg/kg IV/PO q 4-6h; max: 25 mg/dose	May cause drowsiness, paradoxical reaction.
Nausea and vomiting caused by anorexia & GE reflux		
• Metoclopramide	1-2 mg/kg/dose IV q 2-4h; max: 50 mg/dose	May cause paradoxical reaction. Do not use if intestinal obstruction present or if opioids used for pain control.
Nausea and vomiting caused by opioid use		
• Droperidol	0.05 to 0.06 mg/kg IV q4-6h	May cause hypotension, sedation.
• Haloperidol	0.2 to 0.6 mg/kg PO/IV/SC	Commonly used in hospice care.
• Ondansetron	0.15 mg/kg/dose IV or 0.2 mg/kg dose PO q 4h; max: 8 mg/dose	Expensive, may not relieve vomiting due to other causes.

Source: Texas Children's Cancer Center, Texas Children's Hospital. (2000). End of Life Care for Children. Austin, TX: The Texas Cancer Council, p. 37.

Module 3
Table 15: Pediatric Management of Constipation

Dose	Comments
Senna (Senakot®)	
• Children < 12 years: 1-2 tablets PO qhs • 2-4 years of age: Syrup: 1/4-1/2 tsp PO qhs • 4-6 years of age: Syrup: 1/2-1 tsp PO qhs • 6-10 years of age: Syrup: 1 tsp PO qhs	Acts on wall of distal colon to stimulate peristalsis; natural vegetable product; well tolerated; does not cause cramping pain.
Bisacodyl (Dulcolax®)	
• Children 3-12 years: 5 mg PO qhs • Children > 12 years: 10-15 mg PO qhs	Irritates smooth muscle of the intestine to stimulate peristalsis; well tolerated; works in 12-24 hours.
Lactulose	
• Children: 7.5 ml PO qhs • Adults: 30-45 ml/dose PO tid	Produces an osmotic effect in the colon, stimulates peristalsis; may cause cramping; may take several days to have an effect; mix with fruit juice to improve taste.
Docusate sodium (Colace®)	
• Children <3 years: 10-40 mg/day PO in 1-4 divided doses • 3-6 years: 20-60 mg/day PO in 1-4 divided doses • 6-12 years: 50-150 mg day PO in 1-4 divided doses • Over 12 years: 50-100 mg day PO in 1-4 divided doses	Allows increased absorption of water into stool, providing softening action; may take 1-3 days to have an effect; mix with milk, infant formula, or fruit juice to mask the bitter taste.
Mineral Oil	
• Children 5-12 years: 15-45 ml PO in 2 divided doses • Over 12 years: 30-60 ml PO in 1 to 2 divided doses	Lubricates stool to facilitate passage; avoid use in children under 5 years due to the risk of aspiration; do not give with meals due to risk of aspiration; may cause abdominal cramping.
Glycerin suppositories	
• Children < 6 years: 1 suppository 1-2 times/day • Over 6 years: 1 adult suppository 1-2 times/day	Draws fluid into colon and stimulates evacuation; works quickly; avoid in neutropenic or thrombocytopenic patients.
Enemas	
• Children > 12 years: Docusate enema; Add 50-100 mg docusate liquid to enema fluid, give as retention or flushing enema • Children > 12 years: Mineral oil enema; one adult enema used as retention enema	Docusate is a surfactant that eases passage of stool; mineral oil lubricates stool to facilitate passage; may cause abdominal cramping; works quickly; avoid in neutropenic or thrombocytopenic patients.

Source: Texas Children's Cancer Center, Texas Children's Hospital. (2000). End of Life Care for Children. Austin, TX: The Texas Cancer Council, p. 40.

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Table 16: Antidiarrheal Medications for Pediatrics

Dose	Comments
Loperamide (Immodium) Initial doses (first 24 hours) for 2-12 years: • 2-5 years: 1 mg PO tid • 6-8 years: 2 mg PO bid • 8-12 years: 2 mg PO tid After initial dose, 0.1 mg/kg doses after each loose stool (not to exceed the initial dose) • >12 years: 4 mg PO x 1 dose; then 2 mg PO after each loose stool (maximum dose: 16 mg/day)	• For acute diarrhea. • Acts on intestinal muscles to inhibit peristalsis and increase transit time. • Contraindicated in certain enteric infections.
Diphenoxylate and Atropine (Lomotil) • 2-5 years: 2 mg PO tid (not to exceed 6 mg/day) • 5-8 years: 2 mg PO qid (not to exceed 8 mg/day) • 8-12 years: 2 mg PO 5 times/day (not to exceed 10 mg/day) • >12 years: 2.5-5 mg po 2-4 times/day (not to exceed 20 mg/day)	• For acute diarrhea. • Decreases GI motility with subsequent decrease in diarrhea. • Structurally similar to narcotic analgesics, but has no analgesic properties. • Contraindicated in certain enteric infections.
Tincture of Opium 0.25-0.5 ml/kg dose 1-4 times/day	• Decreases GI motility and peristalsis • Contains 45% alcohol • Use cautiously in patients receiving CNS depressants.

Source: Texas Children's Cancer Center, Texas Children's Hospital. (2000). End of Life Care for Children. Austin, TX: The Texas Cancer Council, p. 42.

Module 3

Table 17: Medications to Improve Respiratory Symptoms for Pediatrics

Dose	Indications/Comments
OPIOIDS **Oxycodone** • Immediate release: 0.1 to 0.3 mg/kg/dose PO q 4 to 6 hr • Sustained release: for patient's taking > 20 mg/day of oxycodone can administer 10 mg PO q 12 hr **Morphine** • 0.2 to 0.5 mg/kg/dose PO q 4 to 6 hr prn for solution of immediate release tablets • 0.3 to 0.6 mg/kg/dose PO q 12 hr for sustained release • 0.1 to 0.2 mg/kg/dose IV/SC q 2 to 4 hr **Hydromorphone (Dilaudid)** • 0.03 to 0.08 mg/kg/dose PO q 4 to 6 hr • 15 mcg/kg IV q 4 to 6 hr • Hydromet (solution combination of hydrocodone and homatropine) • 0.6 mg/kg/day divided 3-4 doses/day	**Indications**: • Dyspnea, shortness of breath, cough. • Cough or secretions. **Comments**: • First line drugs for management of dyspnea and persistent cough. • May need to titrate to comfort. • Manage side effects (N/V, constipation). • Dose is limited by the ability to manage side effects.
BRONCHODILATORS **Albuterol** Oral: • 2-6 years: 0.1-0.2 mg/kg/dose tid; max 4 mg tid • 6-12 years: 2 mg/dose 3-4 times/day; max 24 mg/d • >12 years: 2-4 mg/dose 3-4 times/day; max: 8 mg qid Nebulized: • 0.01-0.05 ml/kg of 0.5% solution q 4-6 hrs **Beclomethasone** Oral Inhalation: • 1-2 inhalations/day 3-4 times a day; max: 10 inhalations/day	**Indications**: • Dyspnea, wheezing, pulmonary congestion. **Comments**: • May use in conjunction with opioids and other interventions. • Can increase heart rate and sense of anxiety.

Dose	Indications/Comments
ANTICHOLINERGICS **Glycopyrrolate (Robinul)** • 40-100 mcg/kg/dose PO 3-4 times/day • 4-10 mcg/kg/dose IV/SC q 3-4 hrs **Hyoscyamine (Levsin)** • Infant drops (< 2 yrs): 2.3 kg: 3 gtts q 4 hr/ max: 18 gtts/d 3.4 kg: 4 gtts q 4hr; max: 24 gtts/d 5 kg: 5 gtts q 4hr; max: 30 gtts/d 7 kg: 6 gtts q 4hr; max: 36 gtts/d 10 kg: 8gtts q 4hr; max: 48 gtts/d 15 kg: 10 gtts q 4hr; max: 48 gtts/d • 2-12 years: 0.0625-0.125 mg PO q 4hr; max: 0.75 mg/d • > 12 years: 0.125-0.25mg PO q 4 hr; max: 1.5mg/d **Hyoscine Hbr (Scopolamine)** • 6 mcg/kg/dose IV/SC q 6-8 hrs; max: 0.3 mg/dose	**Indications**: • Increased pulmonary congestion, oral secretions. • Dyspnea related to pulmonary congestion or edema. **Comments**: • May use in conjunction with opioids and other interventions. • Assess for dry mouth, decreased sweating, fever and overheating.
SUPPRESSANTS & EXPECTORANTS **Dextromethorphan** • 2-5 years: 15 mg. BID • 6-11 years: 30 mg. BID • > 11 years: 60 mg. BID **Guaifenesin** • < 2 years: 12 mg/kg/d q 4 hrs • 2-5 years: 50-100mg q 4 hrs • 6-11 years: 100-200mg q 4 hrs • >12 years: 200-400 mg q 4 hrs	**Indications**: • Use suppressant with dry, non-productive cough. • Use expectorant with wet, productive cough secondary to infection. **Comments**: • May use suppressant at bedtime with productive coughs to facilitate rest. • Limited effectiveness with expectorant if child is not able to take sufficient fluids.

Dose	Indications/Comments
ANTIBIOTICS **Amoxicillin** • 25-50mg/kg/day q 8 hrs **TMP/SMX** • 6-12 mg TMP/kg/day q 12 hrs (children > 2 months) **Augmentin** • 20-40 mg/kg/day (amoxicillin component) q 8 hrs; or 25-45 mg/kg/day (amoxicillin component) q 12 hrs **Erythromycin** • 30-50 mg/kg/day q 6-12 hrs	**Indications**: • Respiratory infections with common bacterial pathogens. • Discuss use and expected benefit with family. **Comments**: • Rule out viral cause of respiratory infection.
DIURETICS **Furosemide** • 2 mg/kg PO or 1 mg/kg IV/SC adjust to response **Aldactone** • 33 mg/kg/d PO adjusted to response	**Indications**: • Pulmonary edema. **Comments**: • Consider potassium supplementation with furosemide. • Aldactone should be used if patient is on digoxin or if high risk for hypokalemia.
ANXIOLYTICS **Diazepam** • 0.1 to 0.3 mg/kg q 4 to 6 hr PO/IV/SC; max: 10 mg/dose **Lorazepam** • 0.03 to 0.1 mg/kg q 4 to 6 hr PO/IV/SC; max: 2 mg/dose	**Indications**: • Dyspnea, anxiety **Comments**: • Assess for over-sedation if used in conjunction with opioids.

Source: Texas Children's Cancer Center, Texas Children's Hospital. (2000). End of Life Care for Children. Austin, TX: The Texas Cancer Council, pp. 48-49.

Module 3

Table 18: CNS Symptom Medications for Pediatrics

Dose	Indication	Comments
FEVERS		
Acetaminophen		
• 10-15 mg/kg/dose PO/PR q 4-6 hrs	• Fever	
Ibuprofen		
• 10 mg/kg/dose q 6-8 hrs (max 800 mg/dose)	• Fever	• Ibuprofen can cause GI irritation with prolonged use. • Use cautiously in patient with bleeding disorders, decreased platelets.
Indomethacin		
• 1-2 mg/kg/day in 2 to 4 divided doses	• Fever	• Indomethacin available in PR form. Same caution as Ibuprofen.
RESTLESSNESS/AGITATION		
Lorazepam		
• 0.03-0.1 mg/kg q 4-6 hrs PO/IV may titrate to a max of 2 mg/dose	• Generalized anxiety	• May increase sedation in combination with opioids. • Can cause depression with prolonged use.
Diazepam		
• 0.1-0.3 mg/kg q 4-6 hrs PO/PR/IV may titrate to a max of 10 mg/dose • Rectal gel: 0.2-0.5 mg/kg q 4-12 hrs PRN	• Generalized anxiety	• Diazepam also available in long acting form and oral solution.
Haloperidol		
• 0.05 to 0.15 mg/kg/day divide 2-3 times/day PO/SC/IV	• Agitation not responsive to anxiolytics. • Agitation related to terminal restlessness.	• May increase sedation. • Monitor for extra-pyramidal side effects (EPS). • May give hydroxyzine or diphenhydramine in combination with haloperidol to treat EPS.
Midazolam		
• IV/SC: 0.025-0.05 mg/kg; titrate to effectiveness • Rectal: 0.3-1.0 mg/kg (max 20 mg)	• Myoclonus related to prolonged opioid use, neurologic	• Very short acting. • Quickly reversed if overly sedated.
Phenobarbital		

Dose	Indication	Comments
• Consult hospice palliative care physician in regards to use for sedation.	neurologic spasticity. • Refractory restlessness and agitation not responsive to other measures. • Produces sedation.	• For patients with intractable pain or other symptoms causing the child and family distress, sedation may be desirable to patient/family. • Sedation does not provide analgesia, pain medications should be continued.
SEIZURES		
Clonazepam		
• 0.01-0.03 mg/kg/d PO in 3 divided doses	• Absence seizure, akinetic and myoclonic seizures.	• Side effects include sedation, light-headedness, disorientation, agitation, restlessness, headache, and crying.
Lorazepam		
• 0.03-0.1 mg/kg q 4-6 hrs PO/IV/IM; max: 2 mg/dose	• Status Epilepticus	• Repeat twice at 15 to 20 min interval (do not exceed 4 mg/dose).
Gabapentin		
• PO 8-35 mg/kg/day divided every 8 hrs. Round dose to nearest 100 mg.	• Drug refractory partial and secondary generalized seizures.	• Lower side-effect profile. • Side effects include sedation, ataxia, nystagmus, and dizziness.
Phenobarbital		
• Status epilepticus 10-20 mg/kg IV until seizure resolves • Maintenance treatment 3-5 mg/kg/day IV/PO every 12 hrs.	• Treatment of generalized tonic-clonic seizures	• Monitor serum concentration: therapeutic range 20-40 mg/ml
Phenytoin		
• 15-20 mg/kg IV as loading dose for status epilepticus • 5-10 mg/kg/day IV/PO maintenance dosing	• Treatment of generalized tonic-clonic seizures	• Monitor serum concentration: therapeutic range 10-20 mg/ml • Do not give IM
• Diazepam • 0.2-0.5 mg/kg/dose, IV; max: 5 mg/dose	• Status epilepticus	• Monitor serum concentration: therapeutic
Valproic Acid		

Dose	Indication	Comments
• 10-15 mg/kg/day in 1-3 doses	• Simple and complex seizures	range 50-100 mg/ml
SLEEP DISTURBANCES		
Lorazepam		
• 0.03-0.1 mg/kg q 4-6 hrs PO/IV/IM; max: 2 mg/dose	• Insomnia	• Can cause depression with prolonged use
Diphenhydramine		
• 1 mg/kg IV/PO q HS; max: 50 mg/dose		• Diphenhydramine may cause paradoxical excitement
Chloral hydrate		
• 25-50 mg/kg/d q 6-8 hrs; max: 500 mg/dose		
Methylphenidate		
• 2.5-5 mg PO/a.m. and early afternoon	• Sedation due to medications.	• Do not give in late afternoon or evening.
Dextroamphetamine		
• 2.5-5 mg PO/a.m. and early afternoon		

Source: Texas Children's Cancer Center, Texas Children's Hospital. (2000). End of Life Care for Children. Austin, TX: The Texas Cancer Council, p. 52-53.

Module 3
Table 19: Non Drug Lab Equipment

Station	Equipment
1 - Imagery	Poster - Scenic Tennis Balls Fountain Videos - “Scenic” CDs, i.e. “Graceful Passages” & book Aromatherapy Meditation Cassette Tapes
2 - Massage	Baby oil Ben Gay/Icy Hot Massager Massage lotions Handouts from ELNEC Module 2 Supplemental Teaching Materials: • Massage for Relaxation
3 - Diversional Activities	Humor tapes Music tapes/CDs Games - Cards Handouts from ELNEC Module 2 Supplemental Teaching Materials: • Describing Pictures • Sing & Tap Rhythm • Active Listening to Recorded Music
4 - Heat/Cold	Cold Wrap/Hot Wrap Heating Pad Ice Bag Pool Thermometer Water Bottle Ice compresses (Dixie cup/ice bowl/wash cloths) Vicks Fan Handouts from ELNEC Module 2 Supplemental Teaching Materials: • Use of Heat/Use of Cold
5 - Relaxation	Handouts from ELNEC Module 2 Supplemental Teaching Materials: • Relaxation/Imagery Exercise • Deep Breathing Exercise Cassettes/Relaxation Tape Books on Relaxation Techniques
6 - Spiritual	Various religious items/symbols for: • Christianity • American Indian • Buddhism • Catholicism • Judaism

Module 3
Figure 1: Imagery Exercise

Get into a comfortable position (lying or sitting; arms should be at the patient's side or relaxed in the lap if sitting; legs should be uncrossed). Let your jaw drop to relax your facial muscles. I'd like you to begin by taking some deep, slow, cleansing breaths. Breathe in.... Breathe out.... Breathe in.... Breath out.... I'd like you to think about your hands. Feel your hands becoming warm, heavy, and relaxed as you breathe in slowly and deeply and exhale slowly. Breathe in..... Breathe out.... In.... Out.... Feel the warmth and relaxation flow from your hands into the muscles of your forearms and upper arms; feel those muscles become warm, heavy, and relaxed as you breathe in slowly and deeply. Breathe in.... Breathe out.... In.... Out.... Your hands and arms feel warm, heavy, and relaxed.

Now feel the warmth and relaxation flow from your arms into the muscles of your shoulders, neck, and head; feel these muscles become warm, heavy, and relaxed as you breathe in slowly and deeply and exhale slowly. Breathe in.... Breathe out.... Breathe in warmth and relaxation; breathe out tension and pain; the muscles of your head, neck, and shoulders feel warm, heavy, and relaxed. Feel the warmth and relaxation flow from the muscles of your arms, shoulders, head and neck into the muscles of your upper back and chest. Feel these muscles become warm, heavy, relaxed, as you breathe in slowly and deeply and exhale slowly. Breathe in.... Breathe out.... The muscles of your chest and upper back feel warm, heavy, and relaxed.

Now feel the warmth and relaxation flow from your chest and upper back into the muscles of your abdomen and lower back. Feel these muscles become warm, heavy, and relaxed as you breathe in slowly and deeply and exhale slowly. Breathe in.... Breathe out.... The muscles of your abdomen feel warm, heavy, and relaxed.

Now feel the warmth and relaxation flow into the muscles of your pelvis and buttocks. Feel these muscles become warm, heavy, and relaxed as you breathe in slowly and deeply and exhale slowly. Breathe in.... Breathe out.... The muscles of your pelvis and buttocks feel warm, heavy, and relaxed. Now feel the warmth and relaxation flow into the muscles of your legs and feet. Feel these muscles become warm, heavy, and relaxed as you breathe in slowly and deeply and exhale slowly. Breathe in.... Breathe out.... The muscles of your legs and feet feel warm, heavy, and relaxed.

I'd like you to be aware, now, that your whole body is totally relaxed. You feel warm, relaxed, and comfortable. Continue breathing in and out, slowly and deeply. And, while you are feeling relaxed, I'd like you to imagine that your eyelids are a movie screen. See yourself in that special place, the place where you usually feel relaxed and comfortable. It may be indoors or outdoors; you may be alone or with others. Use all of your senses to enter this place of peace, comfort, and relaxation. Be aware of what you see. Be aware of what you feel - are you warm or cool? Be aware of the aromas, the smells associated with this special place. Think about what you hear - hear those sounds now. You are in your special place, feeling comfortable...relaxed... Spend some time there, enjoying this time away... (allow 1 or more minutes to elapse, then continue).

At the count of three, take a deep breath, let it out slowly, and open your eyes. When you open your eyes, you will feel alert, relaxed, and comfortable. (This last instruction can be modified for subsequent coaching sessions or for an individualized cassette by offering the patient the option of remaining relaxed with eyes closed but advising the patient that your coaching will end.)

Source: Spross, J.A., & Burke, M.W. (1995). Nonpharmacological management of cancer pain. In D.B. McGuire, C.H. Yarbro, & B.R. Ferrell. (Eds.). Cancer Pain Management 2nd edition. p 181. Sudbury, MA: Jones and Bartlett Publishers. Reprinted with permission.

Module 3
Figure 2: Non Drug Relief Methods

Introduction

This educational program was developed based on our years of pain research and clinical experiences. These methods have been used successfully for numerous patients and family members. These educational materials are intended for use as part of a coordinated patient care program. The patient should be encouraged to consult with his or her physician before using any of the techniques that are described.

Also included in the packet is a list of other references and resources about pain management at home. These materials can be used to support your individualized teaching. We recommend that the implementation of these techniques always be under the direction of the physician who is managing the patient's pain. We hope you find this information beneficial in teaching your patients and family caregivers pain management.

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Betty Ferrell, PhD, RN, FAAN   Michelle Rhiner, RN, MSN, OCN

MASSAGE

Method: Hand Massage

Description:
Massage is the stroking or rubbing of the skin surface for pain relief or relaxation.

How Hand Massage Helps:
Massage can be used to decrease pain by soothing the skin and relaxing tense muscles.

Special Considerations/Precautions:
- Do not massage areas being treated with radiation as the skin is very delicate.
- Do not massage an open skin wound or sore or one that is healing.
- Do not massage areas too sensitive to touch or if massage increases pain.
- Massage should not be used directly over an area of a tumor or over any area with bone metastasis.

Equipment:
1. Massage oil or powder
2. A large towel or blanket

Directions:
1. The most common areas for massage are the back and shoulders, but if this is too uncomfortable, a foot or hand rub may be just as relaxing. Choose the area that is best for the patient for the massage.
2. Remove clothing from the area to be massaged.
3. Both the patient and the person giving the massage should be in comfortable positions.
4. For warmth and privacy, cover the parts of the body not being massaged.
5. Use powder or lotion, whichever the patient prefers, just to keep the movement slippery. Friction caused by rubbing the skin without lotion can cause more irritation and discomfort. If lotion is used, warm it first by placing it in the microwave for a few seconds or by placing the bottle in a pan of warm water. Test the lotion first before placing it on the skin.
6. Choose a time that is right for the patient. The patient should try to have a massage before the pain becomes severe. When the patient is tired or starts to get anxious is a good indication. Set aside a time each day for the patient to receive a massage.
7. The length of time for the massage depends on the individual. A few minutes may be all that is necessary to obtain results.
8. Use long, firm strokes in the area being massaged. If the hands and feet are massaged, rub each finger and toe separately.
9. What feels good to the patient? Are softer strokes more relaxing? Firmer strokes? It is important to have the patient tell the person giving the massage what is best.

10. Massage is a time to relax. Just concentrate on how the massage feels to the patient and avoid talking and other noise.
11. To help them relax, some people like to have their favorite music playing while they receive a massage.
12. Be certain to record the massage and its effectiveness in the Self-Care Log.
13. Hand massage is not intended to take the place of pain medication; it is meant to work with pain medication to help achieve better pain relief.

Method: Vibration

Description:
Vibration is a form of electric massage known to soothe skin and muscles.

How Vibration Helps:

- Vibration can relieve a variety of pain problems by causing numbness in the painful area.
- Vibration can also relax tense muscles which may reduce pain.

Special Considerations/Precautions:

- Do not massage areas being treated with radiation as the skin is very delicate.
- Do not massage an open skin wound or sore or one that is healing.
- Do not massage areas too sensitive to touch or if massage increases pain.
- Please follow all the manufacturer's instructions prior to using the electric massager to avoid electrical shock.
- Do not use or recharge electric massager in a room where oxygen in being used.
- Massage should not be used directly over an area of a tumor or over an area with bone metastasis.

Equipment:

- Electric massager

Directions:

1. Choose the area of the body that you think will be the best place to use the massager. If the area is too painful to be touched with the massager, use the massager above or below the painful area. You may also use vibration on the opposite side of the body. For example, if the right hip hurts but is too painful to touch, you can apply the vibration to the left hip.
2. Massaging the trigger area close to the painful area can help to relax the muscles. Trigger points are hypersensitive, tender areas of nerves, tendons, or muscles. The most common areas for trigger points are in the neck, shoulders and back.
3. It is best to remove clothing from the area to be massaged by vibration.
4. Both the patient and the person helping with the use of the massager should be in comfortable positions.

5. For warmth and privacy, cover the parts of the body not being massaged.
6. Choose a time that is right for the patient. The patient should try to have a massage before the pain becomes severe, when the patient is tired or starts to get anxious. Set aside a time each day for the patient to receive a massage.
7. When using a massager, it is best to apply it directly to the painful area. The length of time varies, but the longer the period of vibration, the longer the length of pain relief. Usually 25-45 minutes, twice a day, will provide several hours of pain relief. Intermittent use (off and on) may be the most effective, applying and withdrawing the vibration every few seconds.
8. This is a time to relax; the patient does not have to talk. Just concentrate on how the massage feels to the patient.
9. Be certain to record the massage and its effectiveness in the Self-Care Log.
10. Vibration massage does not take the place of pain medication; it is meant to work with pain medication to help achieve better pain relief.

DISTRACTION

Method: Music

Description:
Distraction is a means of using the senses (hearing, seeing, touch and movement) to focus attention on something other than pain. One method of distraction is the use of music.

How Music Helps:
When distraction is used, pain is more bearable and the patient's mood is better because he/she is not concentrating on the pain. The patient has control over the pain sensation.

Equipment:
1. Cassette player with headphones (for tapes)
2. Tapes of favorite music (country, classical, oldies, etc.)
3. Stereo
4. Records or CDs
5. Radio

Directions:
1. Decide what type of music the patient enjoys the most.
2. Find a comfortable room and a comfortable position.
3. If possible, use distraction when the pain starts, before the pain becomes severe. Have the patient take pain medication and listen to the music as the medication starts to work.
4. Try to have the patient either sing along with the music, or tap his/her fingers and feet to the beat.
5. The more senses used - touch, hearing - the more the patient will think about what he/she is doing and may be able to take his/her thoughts away from the pain.
6. Again, this does not mean that the pain is not severe or real. But research has shown that distraction techniques are powerful in making even severe pain more bearable.
7. Try to use this method of distraction several times a day for best results. If at all possible, hang a sign on the door that says "DO NOT DISTURB" so that full attention can be given to the music.
8. Be certain to record the distraction exercise and its effectiveness in the Self-Care Log.
9. Distraction does not take the place of pain medication; it is meant to work with pain medication to help achieve better pain relief.

Method: Humor

Description:

Distraction is a means of using the senses (hearing, seeing, touch and movement) to focus attention on something other than pain. One method of distraction is the use of humor.

How Humor Helps:

When distraction is used, pain is more bearable and your mood is better because you are not concentrating on the pain. You have control over the pain sensation.

Equipment:

1. Cassette player with headphones (for tapes)
2. Comedy tapes
3. VCR
4. TV
5. Radio

Directions:

1. Decide what type of comedy the patient enjoys the most. Is it a favorite sitcom on TV? A funny movie? A favorite book?
2. Find a comfortable room and a comfortable position.
3. If possible, use distraction when the pain starts, before the pain becomes severe. Have the patient take pain medication and listen or watch as the medication starts to work.
4. Try not to have the patient interrupted while listening or watching his/her favorite comedy.
5. The more senses used - touch, hearing - the more the patient will think about what he/she is doing and may be able to take his/her thoughts away from the pain.
6. Again, this does not mean that the pain is not severe or real. But research has shown that distraction techniques are powerful in making even severe pain more bearable.
7. Try to use this method of distraction several times a day.
8. Be certain to record the distraction exercise and its effectiveness in the Self-Care Log.
9. Distraction does not take the place of pain medication; it is meant to work with pain medication to help achieve better pain relief.

RELAXATION

Method: Imagery

Description:
Relaxation is resting to achieve a reduction in tension. One method of relaxation is the use of imagery. Imagery is using your imagination to help lesson pain. It is a way of "picturing" a thought or image that will distract the patient from his/her pain.

How Imagery Helps:
Relaxation is used to help reduce stress that can cause muscle tension which, in turn, can increase pain. Relaxation itself may not decrease pain, but rather it can help relieve tense muscles that may be contributing to the pain and help the patient cope with all that is happening.

Special Considerations/Precautions:

- Do not use deep breathing/imagery techniques if the patient has difficulty breathing or has other medical problems with the lungs.

Equipment:

- A room that is comfortable and private.

Directions:

1. Find a quiet room where the patient can get into a comfortable position to relax. Have the patient close his/her eyes.
2. Do not have the patient fold arms or cross his/her legs as it may cut off circulation and cause numbness and tingling.
3. Breathe in deeply. Exhale slowly as though whistling out. Do this three times. This will help the patient to relax.
4. Have the patient picture in his/her mind something that is peaceful, or a place that he/she has enjoyed visiting.
5. Think of an image that is pleasant to him/her which symbolizes how the patient pictures pain relief. For example, if the patient thinks of pain as being a large boulder that is on a part of his/her body weighing him/her down, causing pain, perhaps the patient can picture large helium-filled balloons attached to the boulder carrying it away from him/her, releasing the pain. Perhaps the patient may think of the pain as a thunderstorm, complete with lightning and thunder, that rains on his/her body. The patient can imagine how the pain medication is like a gentle breeze that blows the rain and thunderclouds away. Instead of rain and thunder, there is sunshine and warmth. The air smells clean and fresh, the rain has watered all the beautiful flowers and the grass is green and lush. There are swans and ducks on a pond. Only a ripple, caused by the ducks' gentle paddling, disturbs the water's peaceful state.

6. Use imagery at least 20 minutes a day. It is best if this is tried before the pain becomes severe, or while waiting for the pain medication to work.
7. Be certain to record the use of relaxation/imagery and its effectiveness in the Self-Care Log.
8. Imagery is not intended to take the place of pain medication; it is meant to work with pain medication to help achieve better pain relief.

Method: Breathing Exercises

Description:
Relaxation is resting to achieve a reduction in tension. One method of relaxation is the use of breathing exercises.

How Breathing Exercises Help:
Relaxation is used to help reduce stress that can cause muscle tension which, in turn, can increase pain. Relaxation itself may not decrease pain, but rather it can help relieve tense muscles that may be contributing to the pain and help you cope with all that is happening.

Special Considerations/Precautions:

- Do not use deep breathing exercises if the patient has difficulty breathing or has other medical problems with the lungs.

Equipment:

1. Cassette player with headphones
2. Relaxation tapes
3. A room that is comfortable and private

Directions:

1. Find a quiet room where the patient can get into a comfortable position to relax. Have him/her close his/her eyes.
2. Do not have the patient fold arms or cross his/her legs as it may cut off circulation and cause numbness and tingling.
3. Breathe in deeply. Exhale slowly as though whistling out. Do this three times. This will help the patient to relax.
4. Have the patient think of a calm, peaceful setting, or perhaps a place he/she has enjoyed visiting that will help the patient to relax.
5. Have the patient picture his/her body as being very light, floating weightlessly, very limp or comfortably warm. Use any mental picture that will help the patient relax and then begin the breathing exercises.
6. Breathe in deeply. At the same time, have the patient tense muscles or any group of muscles he/she chooses. For example, making a fist, clenching teeth, closing eyes tightly, or drawing arms or legs up as tightly as one can.

7. Have the patient hold his/her breath and keep those muscles tense for a second or two.
8. Then relax those muscles. Breathe out and let his/her body relax.
9. Now start with the muscles in the lower legs, concentrating on one leg at a time and, alternately tightening and releasing, work up by muscle group to the head.
10. If the patient wants a shorter relaxation exercise, he/she may combine muscle groups. For example, think of tensing and relaxing the muscles in both legs together instead of each leg separately.
11. There are audiotapes available that will talk the patient through a series of breathing exercises to help him/her relax. If this method is chosen, try to concentrate on the speaker and what is being said.
12. Use relaxation at least 20 minutes a day. It is best to try this before the pain becomes severe, or while waiting for the pain medication to work.
13. Be certain to record the breathing exercises and their effectiveness in the Self-Care Log.
14. Breathing exercises are not intended to take the place of pain medication; they are meant to work with pain medication to help achieve better pain relief.

Method: Tapes (Music/Sounds)

Description:
Relaxation is resting to achieve a reduction in tension. One method of relaxation is the use of tapes that contain either music or nature sounds.

How Music/Sound Tapes Help:
Relaxation is used to help reduce stress that can cause muscle tension which, in turn, can increase pain. Relaxation itself may not decrease pain, but rather it can help relieve tense muscles that may be contributing to the pain and help you cope with all that is happening.

Special Considerations/Precautions:

- Do not use if the sounds on the relaxation tapes increase anxiety. For example, listening to a tape with sounds of the ocean will not be relaxing for someone who is afraid of water.

Equipment:

1. Cassette player with headphones
2. Relaxation tapes
3. A room that is comfortable and private

Directions:

1. Find a quiet room where the patient can get into a comfortable position to relax. Have the patient close his/her eyes.
2. Do not have the patient fold arms or cross his/her legs as it may cut off circulation and cause numbness and tingling.
3. Breathe in deeply. Exhale slowly as though whistling out. Do this three times to help relaxation.
4. Think of a calm, peaceful setting, or perhaps a place he/she has enjoyed visiting that will help relaxation.
5. Try to have the patient think only of what he/she is listening to on the tapes. If at all possible, use headphones to help the concentration.
6. Try this method of relaxation at least 20 minutes a day. It is best to try this before the pain becomes too severe, or while waiting for the pain medication to work.
7. Be certain to record the relaxation exercise and its effectiveness in the Self-Care Log.
8. Music/sounds are not intended to take the place of pain medication; they are meant to work with pain medication to help achieve better pain relief.

COLD

Method: Ice Bags

Description:
Pain relief may be obtained by applying cold to the painful area. One method of applying cold is by the use of ice bags.

How Ice Bags Help:
When cold is applied to the skin, the cold decreases skin sensations by numbing nerve endings. Cold may also reduce muscle spasms, reduce inflammation and help stop the desire to scratch areas that itch.

Special Considerations/Precautions:
- Do not apply an ice bag to:
  - Skin being treated with radiation therapy;
  - Severe injury;
  - A wound in the healing phase;
  - Areas that have poor circulation.
- Do not use cold if pain increases.

Equipment:
1. Ice bag: (either of the following may be used for an ice bag)
   - Commercial ice bag
   - Self-sealing small plastic bag that won't leak, filled with ice
2. Ice
3. Other sources of cold that can be used are:
   - A bag of frozen corn kernels
   - A bag of frozen peas
4. Towel or pillowcase
5. Menthol-containing products such as Ben Gay®, Icy Hot®, etc.

Directions:
1. Fill the ice bag with ice. The smaller the cubes, the better. Crushed or shaved ice will mold around the area better than large cubes. Push out all the air from the bag.
2. If you are using bags of frozen vegetables, hit the bag on the counter top once or twice to break up the frozen vegetables so the bag will mold to the skin better. Place the plastic bag directly on the skin.
3. If you are using a small plastic bag, be sure it does not leak. Put some water in the bag first to check for holes. Place the ice into the bag. Use same instructions as in #1.
4. Wrap the ice bag in a pillowcase or a towel. If you want it colder, use a wet towel, if you want it less cold, use a dry towel.

5. Be sure the ice bag top is screwed on tightly and that there are no leaks. Hold the bag upside down to be sure the top is on tight.
6. Place the ice bag on the area that is painful. If it is too painful to put the ice bag directly on the area, the ice bag may be placed above or below the painful area, or on the other side of the body that corresponds to where the pain is located. For example, if the right hip hurts but it is too painful to place the ice bag on the right hip, the ice bag can be placed on the left hip.
7. Have the patient in a comfortable position.
8. Leave the ice bag on 10-15 minutes, three or four times a day. The longer it is left in place (up to 1 hour), the longer the pain relief.
9. You may alternate cold with heat. You may have to try either heat/cold several times to find the correct area or temperature that gives the most relief.
10. Products containing menthol such as Ben Gay® or Icy Hot® can be applied to the painful area when using cold, but not with heat, as burns may occur. Wash hands thoroughly after using any product which contains menthol and avoid getting it into eyes. Try a small amount of the menthol product on the inner arm. If, after a few minutes, you do not have any redness or irritation, the product may be used.
11. You may refreeze the bag of vegetables to use again. (Do not cook the vegetables if they have been used as an ice pack.)
12. Be certain to record the cold method and its effectiveness in the Self-Care Log.
13. Ice bags are not intended to take the place of medication; they are meant to work with pain medication to help achieve better pain relief.

Method: Cold Cloths

Description:
Pain relief may be obtained by applying cold to the painful area. One method of applying cold is by the use of cold cloths.

How Cold Cloths Help:
When you apply cold to the skin, the cold decreases skin sensations by numbing nerve endings. Cold may also reduce muscle spasms, reduce inflammation and help stop the desire to scratch areas that itch.

Special Considerations/Precautions:

- Do not apply cold cloths to:
  - Skin being treated with radiation therapy;
  - Severe injury;
  - A wound in the healing phase;
  - Areas that have poor circulation.
- Do not use cold if pain increases.

Equipment:

1. Towels (hand or wash cloth, one for ice, one for drying)
2. Ice
3. Towel or pillowcase
4. Basin
5. Menthol-containing products, such as Ben Gay®, Icy Hot®, etc.

Directions:

1. Fill a basin with about 2 inches of water.
2. Add ice to the water.
3. Soak the towel in the ice water until it is completely wet.
4. Have the patient get into a comfortable position.
5. Wring out the towel and place it directly on the area that hurts.
6. When it becomes warm, remove the towel and rewet it in the ice water.
7. Continue applying cold cloths until relief is achieved.
8. If it is too painful to put the cold cloth directly on the top of the area, the cold cloth may be placed above the painful site or below the area, or on the other side of the body that corresponds to where the pain is located. For example, if the right hip hurts but it is too painful to place the cold cloth on the right hip, you can put the cold cloth on the left hip.
9. Continue changing the towels for 10-15 minutes. This treatment may be used three or four times a day.
10. Alternate cold with heat. You may have to try either heat/cold several times to find the correct area or temperature that gives the most relief.
11. Products containing menthol such as Ben Gay® or Icy Hot® may be applied to the painful area when using cold, but not with heat, as burns may occur. Wash hands thoroughly after using any product which contains menthol to avoid getting it into the eyes. Try a small amount of the menthol product on the inner arm. If, after a few minutes, there is no redness or irritation, the product may be used.
12. Be certain to record the cold method and its effectiveness in the Self-Care Log.
13. Cold cloths are not intended to take the place of pain medication; they are meant to work with pain medication to help achieve better pain relief.

Method: Frozen Gel Packs

Description:

Pain relief may be obtained by applying cold to the painful area. One method of applying cold is by the use of frozen gel packs.

How Frozen Gel Packs Help

When cold is applied to the skin, the cold decreases skin sensations by numbing nerve endings. Cold may also reduce muscle spasms, reduce inflammation and help stop the desire to scratch areas that itch.

Special Considerations/Precautions:

- Do not apply frozen gel packs to:
  - Skin being treated with radiation therapy;
  - Severe injury;
  - A wound in the healing phase;
  - Areas that have poor circulation.
- Do not use cold if pain increases.

Equipment:

1. Gel Pack

   or
2. Homemade pack:
   - Add 1/3 cup of rubbing alcohol and 2/3 cup of water to one self-sealing plastic bag. Place the plastic bag with the mixture in it in the freezer until the mixture resembles slush.
3. Towel or pillowcase
4. Six-inch elastic wrap
5. Menthol-containing products such as Ben Gay®, Icy Hot®, etc.

Directions:

1. Remove the gel pack from the freezer.
2. Wrap the pack in a pillowcase or a towel. If the gel pack is covered in its own elastic wrap, this will be sufficient
3. If using a homemade gel pack, be sure the plastic bag does not leak. Cover the plastic bag with a towel or pillowcase. Place the gel pack on the area that is painful.
4. Have the patient get into a comfortable position.
5. Place the gel pack on the area that is painful.
6. Wrap the gel pack around the area where relief is wanted. The elastic wrap attached to the gel pack can be secured with the Velcro® tape on the wrap. If you are using a homemade gel pack, use a six-inch elastic wrap to hold the gel pack in place.
7. If it is too painful to put the gel pack directly on the area, you may place the gel pack above or below the painful area, or on the other side of the body that corresponds to where the pain is located. For example, if the right hip hurts but it is too painful to place the gel pack on the right hip, you can place the gel pack on the left hip.
8. Leave the gel pack on 10-15 minutes, three or four times a day. The longer it is left in place (up to 1 hour), the longer the pain relief.
9. Alternate cold with heat. Try either heat/cold several times to find the correct area or temperature that gives the most relief.

10. Products containing menthol, such as Ben Gay® or Icy Hot® can be applied to the painful area when using cold, but not with heat, as burns may occur. Wash hands thoroughly after using any product which contains menthol and avoid getting it into the eyes. Try a small amount of the menthol product on the inner arm. If, after a few minutes, there is no redness or irritation, the product may be used.
11. Return the gel pack to the freezer.
12. Be certain to record the cold method and its effectiveness in the Self-Care Log.
13. Gel packs are not intended to take the place of pain medication; they are meant to work with pain medication to help achieve better pain relief.

Method: Ice Massage

Description:

Pain relief may be obtained by applying cold to the painful area. One method of applying cold is by rubbing ice on the painful area.

How Ice Massages Help Your Pain

When applying cold to the skin, it decreases skin sensations by numbing the nerve endings. Cold may also reduce muscle spasms, reduce inflammation and help stop the desire to scratch areas that itch.

Special Considerations/Precautions:

- Do not apply ice massages to:
  - Skin being treated with radiation therapy;
  - Severe injury;
  - A wound in the healing phase;
  - Areas that have poor circulation.
- Do not use cold if pain increases.

Equipment:

1. Ice
2. Towel/bath towel and washcloth
3. Plastic bag or trash bag
4. Paper cups (bathroom size)

Directions:

1. Fill a paper cup halfway with water. Place the cup in the freezer until the water is frozen solid.
2. Peel the paper partly away from the cup to expose the ice.
3. Place the ice cup under cold running water to remove any rough surfaces on the ice.
4. Remove any clothing covering the painful area.

5. Place a plastic bag covered by a bath towel under the area to be massaged. This will help absorb any water that may run off and will help dry the skin as the ice melts.
6. Have the patient get into a comfortable position.
7. Wrap a washcloth around the paper cup to prevent the hand from getting cold.
8. Rub the ice over the painful area in a circular motion. Dry the skin with a towel as the ice melts.
9. Massage the area for four minutes. The skin will be reddened. This is normal. Repeat the ice massage three or four times a day. Alternate cold with heat. Try either heat/cold several times to find the correct area or temperature that gives the most relief.
10. Be sure to keep a supply of paper cups with ice in the freezer so they will be ready when needed.
11. Be certain to record the cold/ice massage and its effectiveness in the Self-Care Log.
12. Ice massages are not intended to take the place of pain medication; they are meant to work with pain medication to help achieve better pain relief.

HEAT

Method: Heating Pad

Description:
Heat is the application of warmth to the skin for the relief of pain. One method of applying heat is by use of a heating pad.

How Heat Helps:
Heat can relieve pain by reducing inflammation and soreness. Heat also decreases sensitivity to pain, relieves joint stiffness and increases blood flow to the skin.

Special Considerations/Precautions:
- Heat can burn if used improperly. Please read the manufacturer's directions before using any heating pad. Please follow all precautions listed to avoid electrical shock.
- Do not apply heat to:
  - Skin being treated with radiation therapy;
  - Any area that is bleeding;
  - Any area with decreased sensation;
  - Any injury within the first 24 hours;
- Do not use with any menthol-containing products (Vicks®, Ben Gay®, Icy Hot®, etc.)
- Do not use if oxygen is being used.

Equipment:
1. Heating pad
2. Manufacturer's cover for the heating pad

Directions:
1. Plug in the heating pad and place the temperature control on low. Adjust to a higher heat if needed.
2. When the heating pad is warm, place the heating pad to the area where you want relief.
3. If the area is too painful to have the heating pad directly on it, place the heating pad on the other side of the body that corresponds to the painful area. For example, if the right hip has pain but it is too painful to put the heating pad on the right hip, put the heating pad on the left hip.
4. Be certain the heating pad has a cover over it to prevent burning the skin.
5. Do not fall asleep on top of the heating pad. Heat is increased with pressure, which may cause burns.
6. Keep the heating pad on for as long as possible to obtain relief, usually 20-30 minutes.

7. Alternate heat and cold (please see the instructional materials on cold) to improve comfort. Try either heat/cold several times to find the correct area or temperature that gives the most relief.
8. If the heating pad is too warm, decrease the temperature to a lower temperature. Adjust the temperature of the heating pad for comfort.
9. Use the heating pad as often as necessary for relief. Try to use the heating pad before the pain becomes severe.
10. Be certain to record the heat method and its effectiveness in the Self-Care Log.
11. The heating pad does not take the place of pain medication; it is meant to work with pain medication to help achieve better pain relief.

Method: Hot Baths

Description:
Heat is the application of warmth to the skin for the relief of pain. One method of applying heat is by use of hot baths.

How Heat Helps:
Heat can relieve pain by reducing inflammation and soreness. Heat also decreases sensitivity to pain, relieves joint stiffness and increases blood flow to the skin.

Special Considerations/Precautions:
- Use heat with caution when feeling to an area is decreased or there is any other irritation to the skin surface.
- Do not take a hot bath if:
  - The painful area is being treated with radiation therapy;
  - The painful area is bleeding;
  - The painful area has been injured.

Equipment:
1. Bath tub
2. Thermometer used for swimming pools and spas
3. Towels

Directions:
1. Fill the bathtub with enough warm water to cover the painful area.
2. Before getting into the tub, take the temperature of the water with the thermometer.
3. The water temperature should be between 98° and 102°.
4. Sit in the hot bath for as long as comfortable.
5. Add more hot water as the water in the tub cools. When adding hot water, be sure to check the temperature of the water.
6. Repeat tub baths as often as needed for relief. Try to take tub baths before the pain becomes severe.

7. If pain becomes worse, if shivering occurs, or the skin becomes irritated, discontinue use of tub baths.
8. Be certain to record the heat method and its effectiveness in the Self-Care Log.
9. Hot baths do not take the place of pain medication; they are meant to work with pain medication to help achieve better pain relief.

Method: Hot Water Bottle

Description:
Heat is the application of warmth to the skin for the relief of pain. One method of applying heat is by use of a hot water bottle.

How Heat Helps:
Heat can relieve pain by improving circulation to the muscles, which decreases spasms, and by reducing inflammations. Heat also decreases sensitivity to pain, relieves joint stiffness and increases blood flow to the skin.

Special Considerations/Precautions:

- Use heat with caution when feeling to an area is decreased or there is any other irritation to the skin surface.
- Do not use a hot water bottle if:
  - The painful area is being treated with radiation therapy;
  - The painful area is bleeding;
  - The painful area has been injured.

Equipment:

1. Hot water bottle
2. Towel
3. Thermometer used for swimming pools or spas

Directions:

1. Fill the hot water bottle with hot water from the faucet. Do not put boiling water into the hot water bottle.
2. Use the thermometer made for swimming pools and spas to take the temperature of the water as it runs from the tap into the hot water bottle.
3. Water temperature should be between 104° and 113°.
4. Push all the air out of the hot water bottle and screw cap on tightly. Check to see that it is sealed by holding the hot water bottle upside down.
5. Place the hot water bottle in a towel or pillowcase.
6. Place the hot water bottle on the area where relief is wanted. If it is too painful to place the hot water bottle directly on the painful area, place it above or below the painful site. It also can be placed on the other side of the body that corresponds to

the painful area. For example, if the right hip has pain but it is too painful to put the hot water bottle on the right hip, put the hot water bottle on the left hip.

7. Do not sleep on top of the hot water bottle. Heat is increased with pressure, which may cause burns to the skin.
8. Keep the hot water bottle on for as long as possible to obtain relief, usually between 20-30 minutes. Refill with hot water when the bottle is no longer warm. Recheck temperature.
9. Alternate use of the hot water bottle and switch to cold (please see the instructional materials on cold) to improve comfort. Try either heat/cold several times to find the correct area or temperature that gives you the most relief.
10. Be certain to record the heat method and its effectiveness in the Self-Care Log.
11. Hot water bottles are not intended to take the place of pain medication; they are meant to work with pain medication to help achieve better pain relief.

Method: Moist Heat

Description:
Heat is the application of warmth to the skin for the relief of pain. One method of applying heat is by use of a heating pad that supplies moisture.

How Heat Helps:
Heat can relieve pain by improving circulation to the muscles, which decreases spasms, and by reducing inflammations. Heat also decreases sensitivity to pain, relieves joint stiffness and increases blood flow to the skin. Using moisture with heat may provide a means of getting heat below the skin surface.

Special Considerations/Precautions:

- Use heat with caution when feeling to an area is decreased or there is any other irritation to the skin surface.
- Do not apply to:
  - Skin being treated with radiation therapy;
  - Any area that is bleeding;
  - A painful area which has been injured.
- Do not use if oxygen is being used.

Equipment:

1. Specially-designed heating pad, such as the Sunbeam® Automatic Heating Pad
2. Manufacturer's foam rubber sheet
3. Manufacturer's protective cover for the heating pad

Directions:

1. Plug in the heating pad and place the temperature control on low. Adjust to a higher heat if needed.

2. When the heating pad is warm, place the heating pad on the painful area.
3. If the area is too painful to have the moist heat/heating pad directly on it, you can also place the moist heat/heating pad on the other side of the body that corresponds to the painful area. For example, if the right hip has pain but it is too painful to put the moist heat/heating pad on the right hip, put the moist heat/heating pad on the left hip.
4. Keep the moist heat/heating pad on for as long as possible to obtain relief, usually 20-30 minutes.
5. Alternate heat and cold (please see the instructional materials on cold) to improve comfort. Try either heat/cold several times to find the correct area or temperature that gives the most relief.
6. If the heating pad is too warm, decrease the temperature. Adjust the temperature of the heating pad for comfort.
7. May use the moist heat/heating pad three or four times a day. Try to use the moist heat/heating pad before the pain becomes severe.
8. Be certain to record the heat method and its effectiveness in the Self-Care Log.
9. Moist heat/heating pads are not intended to take the place of pain medication; they are meant to work with pain medication to help achieve better pain relief.

Method: Hot Wrap

Description:
Heat is the application of warmth to the skin for the relief of pain. One method of applying heat is by use of a hot wrap.

How Heat Helps:
Heat can relieve pain by reducing inflammation and soreness. Heat also decreases sensitivity to pain, relieves joint stiffness and increases blood flow to the skin. Heat also helps you to relax.

Special Considerations/Precautions:
- Please follow all manufacturer's directions for use. To avoid burns to the skin when heating the hot wrap, do not leave the hot wrap in the microwave or boiling water too long. To avoid burns, use only the wrap that is included with the hot pack.
- Do not use the hot wrap if:
  - The painful area is being treated with radiation therapy;
  - It is within 24 hours of injury to that area;
  - The painful area has decreased sensation;
  - The painful area has open wounds or sores.

Equipment:
1. Hot wrap such as Champ® Hot Wrap

2. Microwave or boiling water

Directions:

1. The hot wrap can be heated in either a microwave or boiling water.
   - Microwave directions: Unfold the hot wrap and lay it flat in the microwave. Heat with full power for 60 seconds. Note: pack will continue to heat slightly. Test it before use. If it is too warm, set aside until it becomes cooler. If additional heating is required, use five-second intervals to heat the hot pack.
   - Hot water directions: Bring three quarts of water to a boil in a pot. Remove the hot pack from the wrap. Remove the pot from the heat and place the hot pack in the boiled water for no longer than seven minutes. Remove the hot pack with kitchen tongs to prevent burns.
2. When the hot pack is ready, place the hot pack in the wrap that is provided.
3. Place the hot wrap on the area where relief is wanted. If the area is too painful to have the hot wrap directly on it, place the hot wrap on the other side of the body that corresponds to the painful area. For example, if the right hip has pain but it is too painful to put the hot wrap on the right hip, put the hot wrap on the left hip.
4. If possible, secure the hot wrap on the painful area to prevent it from slipping.
5. Do not sleep on top of the hot wrap. Heat is increased with pressure, which may cause burns.
6. Once the hot wrap is cooled, and wish to reuse it, please follow the manufacturer's directions. Do not exceed the recommended heating times, as burns may result. Do not throw the hot wrap away.
7. You may continue to use the hot wrap as long as the patient is comfortable, and the skin under the hot wrap is not reddened or irritated.
8. Occasionally check the skin for any signs of redness or irritation. If either are present, stop using the hot wrap. And if the redness or irritation doesn't disappear within an hour, call the physician.
9. Alternate heat and cold (please see the instructional materials on cold) to improve comfort, or take the hot wrap off for a few minutes. By taking the hot wrap off, the skin will cool quickly giving the contrast between heat and cold.
10. Be certain to record the heat method and its effectiveness in the Self-Care Log.
11. Hot wraps are not intended to take the place of pain medication; they are meant to work with pain medication to help achieve better pain relief.

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Department of Veterans Affairs

Certificate of Training

This certificate is given to

____

License Number ______________________________

for satisfactory completion of the course in

Symptom Management
End of Life

Given at: ***Jerry L. Pettis Memorial VA Medical Center***
Loma Linda, California 92357

This 7th day of March, 2002

VA DESERT PACIFIC HEALTHCARE NETWORK
22

Mary Anne Collins, MSN, RN, C

Mary Anne Collins, MSN, RN,C Educator
Nursing Research & Education Department
Olivia Catolico, MSN, RN, Director

Provider approved by the California Board of Registered Nursing, Provider #02633, for2.5 contact hour(s).

VA FORM 3904, MAR 1989

Symptom Management
End of Life

Target Audience: Nursing Staff
Date: March 7th, 2002, Thursday
Place: Nursing Education Classroom
Times: 0730-1000 & 1500-1730
Presenter: Sheryl Terkildsen
Offerings: 2.5 CEU's

Course Objectives: At the completion of the education program participants will be able to:

1. Identify common symptoms associated with end of life processes.
2. Identify potential causes of symptoms at tend of life.
3. Describe assessment of symptoms at end of life.
4. Describe interventions that can prevent or diminish symptoms at end of life.

"Provider approved by the California Board of Registered Nursing Provider 02633 for 2.5contact hours.

APPENDIX H

NON-DRUG THERAPY LAB

FACILITATOR'S GUIDE

Book List for Non-Drug Therapy Lab Facilitators

(These titles are available for your use at your stations)

MIND, MOOD, & EMOTION

Aromatherapy A Lifetime Guide to Healing with Essential Oils, 1996, Cooksley, V. G., Prentice Hall, Paramus, New Jersey.

The complete illustrated guide to Massage, 1997, Mitchell, S. , Barnes and Nobles Books, New York, NY.

Complete Massage A Visual Guide to Over 100 Techniques, 2001, Maxwell-Hudson, C., DK Publishing, New York, New York.

Creative Visualization to attain your goals and improve your well being, 2001, Drury, Nevill, Barnes and Nobles Books, Singapore.

The Fragrant Art of Aromatherapy, 2000, Doeser, Linda, Barnes & Nobles Books, New York, New York.

The Helper's Journey Working with People Facing Grief, Loss, and Life-Threatening Illness, 1993, Larson, D. G. Research Press, Champaign, IL.

Healing Touch, 1999, Webb, Marcus & Maria. Sterling Publishing, New York, NY.

Learn to Relax A Practical Guide to Easing Tension & Conquering Stress, 1998, George, M., Chronicle Books, San Francisco, CA.

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Module 3
Table 19: Non Drug Lab Equipment

Station	Equipment
1 - Imagery	Poster - Scenic Tennis Balls Fountain Videos - "Scenic" CDs, i.e. "Graceful Passages" & book Aromatherapy Meditation Cassette Tapes
2 - Massage	Baby oil Ben Gay/Icy Hot Massager Massage lotions Handouts from ELNEC Module 2 Supplemental Teaching Materials: • Massage for Relaxation
3 - Diversional Activities	Humor tapes Music tapes/CDs Games - Cards Handouts from ELNEC Module 2 Supplemental Teaching Materials: • Describing Pictures • Sing & Tap Rhythm • Active Listening to Recorded Music
4 - Heat/Cold	Cold Wrap/Hot Wrap Heating Pad Ice Bag Pool Thermometer Water Bottle Ice compresses (Dixie cup/ice bowl/wash cloths) Vicks Fan Handouts from ELNEC Module 2 Supplemental Teaching Materials: • Use of Heat/Use of Cold
5 - Relaxation	Handouts from ELNEC Module 2 Supplemental Teaching Materials: • Relaxation/Imagery Exercise • Deep Breathing Exercise Cassettes/Relaxation Tape Books on Relaxation Techniques
6 - Spiritual	Various religious items/symbols for: • Christianity • American Indian • Buddhism • Catholicism • Judaism

Module 3
Figure 2: Non Drug Relief Methods

Introduction

This educational program was developed based on our years of pain research and clinical experiences. These methods have been used successfully for numerous patients and family members. These educational materials are intended for use as part of a coordinated patient care program. The patient should be encouraged to consult with his or her physician before using any of the techniques that are described.

Also included in the packet is a list of other references and resources about pain management at home. These materials can be used to support your individualized teaching. We recommend that the implementation of these techniques always be under the direction of the physician who is managing the patient's pain. We hope you find this information beneficial in teaching your patients and family caregivers pain management.

We acknowledge the previous research support from the American Cancer Society and the support of our colleagues Marcia Grant, DNSC., FAAN; Margo McCaffery, RN, FAAN and Bruce Ferrell, MD.

Betty Ferrell, PhD, RN, FAAN

Michelle Rhiner, RN, MSN, OCN

Module 2
Figure 4: Selection and Use of Nondrug Pain Treatments

1. Clarify the relationship between the use of nondrug pain treatments and the use of analgesics.
   - In most clinical situations (e.g., postoperative pain or cancer pain) nondrug pain treatments should be used in addition to analgesics.
   - Emphasize to the patient that nondrug therapies do not replace analgesics.
2. Assess the patient's attitude toward and experience with nondrug pain treatments.
   - If the patient has used nondrug methods, find out whether they were successful and what, if any, problems were encountered.
   - Find out whether the patient feels that personal attempts at nondrug therapies have been exhausted and that more conventional pain therapies are now appropriate.
   - Find out whether the patient is using nondrug methods to avoid using analgesics. If analgesics are appropriate, discuss the patient's concerns.
3. Ask the patient what, besides taking pain medicine, usually helps with the pain.
   - Try to identify nondrug treatments that are similar to the patient's coping style.
   - Some patients simply want more information about pain or its management, whereas others want to divert their attention away from pain.
   - Many patients naturally use distraction to cope with pain. For these patients, providing a selection of music or videotapes may be helpful.
4. Assess the patient's level of fatigue, cognitive status, and ability to concentrate and follow instructions.
   - Optimal functioning in these areas is desirable to learn and to use a technique such as relaxation imagery but is unnecessary if a cold pack is used.
   - Some patients barely have enough time to perform required activities of daily living. Adding a lengthy relaxation technique may simply increase stress and decrease the patient's sense of control.
5. Ask the patient's family/friends if they wish to be involved in nondrug pain treatments.
   - In home care the primary caregiver may already be overburdened and have no time or energy to help the patient with a technique such as massage.
   - Some family/friends may welcome a technique like massage that allows them to touch the patient and "do something." However, not all patients or family members are comfortable with techniques that involve touch.
6. Provide the patient and family with adequate support materials.
   - Whenever possible, supply written or audiotaped instructions for even the simplest techniques.
   - Determine whether the appropriate equipment is available. If not, can the patient afford to purchase it? If not, identify less expensive nondrug materials or therapies.

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Module 2

Figure 5: Nondrug Approaches to Pain Management in Children

General Strategies:

Form a trusting relationship with children and family.

- Express concern regarding their reports of pain.
- Take an active role in seeking effective pain management strategies.

Prepare child before potentially painful procedures but avoid "planting" the idea of pain. For example, instead of saying, "This is going to (or may) hurt," say "Sometimes this feels like pushing, sticking, or pinching, and sometimes it doesn't bother people. Tell me what it feels like to you."

Stay with child during a painful procedure.

- Encourage parents to stay with child if child and parent desire; encourage parent to talk softly to child and to remain near child's head.
- Involve parents in learning specific nonpharmacologic strategies and assisting child in their use.

Educate child about the pain, especially when explanation may lessen anxiety (e.g., that child's pain is expected after surgery and does not indicate something is wrong; reassure child that he or she is not responsible for the pain).

For long-term pain control, give child a doll, which becomes "the patient," and allow child to do everything to the doll that is done to the child; pain control can be emphasized through the doll by stating, "Dolly feels better after the medicine."

Teach procedures to child and family for later use.

Specific Strategies

Distraction

- Involve parent and child in identifying strong distractors.
- Involve child in play; use radio, tape recorder, record player; have child sing or use rhythmic breathing.
- Have child take a deep breath and blow it out until told to stop (French, Painter, Coury, 1994).
- Have child blow bubbles to "blow the hurt away."
- Have child concentrate on yelling or saying "ouch" by focusing on "yelling loud or soft as you feel it hurt; that way I know what's happening."
- Have child look through kaleidoscope (type with glitter suspended in fluid-filled tube) and encourage to concentrate by asking, "Do you see the different designs?" (Vessesy, Carlson, McGill, 1994).
- Use humor, such as watching cartoons, telling jokes or funny stories, or acting silly with child.
- Have child read, play games, or visit with friends.

Relaxation

With an infant or young child:

- Hold in a comfortable, well-supported position, such as vertically against the chest and shoulder.
- Rock in a wide, rhythmic arc in a rocking chair or sway back and forth, rather than bouncing child.
- Repeat one or two words softly, such as "Mommy's here."

With a slightly older child:

- Ask child to take a deep breath and "go limp as a rag doll" while exhaling slowly, then ask child to yawn demonstrate if needed).
- Suggest that the child pretend to float like a balloon.

Imagery for Distraction or Relaxation

- Have child identify some highly pleasurable real or pretend experience.
- Have child describe details of the event, including as many senses as possible (e.g., "feel the cool breezes," "see the beautiful colors," "hear the pleasant music").
- Have child write down or record script.
- Encourage child to concentrate only on the pleasurable event during the painful time; enhance the image by recalling specific details, such as reading the script or playing the record.
- Combine with relaxation.

Cutaneous Stimulation

Includes simple rhythmic rubbing; use of pressure, electric vibrator; massage with hand lotion, powder, or menthol cream; application of heat or cold, such as an ice cube on the site before giving injection or application of ice to the site opposite the painful area (e.g., if right knee hurts, place ice on left knee).

May be duplicated for use in clinical practice. As appears in McCaffery M, Pasero C: Pain: Clinical Manual, p. 422, 1999, Mosby, Inc. Modified from Wong DL: Whaley & Wong's Essentials of Pediatric Nursing, ed 5, p 634, St. Louis, 1997, Mosby. Information from French GM, Painater EC, Courty DL: Blowing away shot pain: A technique for pain management during immunization, Pediatrics 93:384-388, 1994; Vessey JA, Carlson KL, McGill J: Use of distraction with children during an acute pain experience, Nurs Res 43:369, 1994.

Module 2
Figure 13: Communicating Pain Assessment Findings

Unhelpful Communication

"Dr. Jones? This is Jane Brown from 12 West. Your patient, Mrs. Smith has pain. What are you going to do about it?"

Helpful Communication

"Dr. Jones? This is Jane Brown from 12 West. I am concerned about our patient, Mrs. Smith. She has a pain intensity score of 9 on a 0-10 scale; she describes the pain location in her right thigh where we know she has a bone metastasis; the pain is aching and throbbing and is worse when she stands or walks. She was unable to participate in physical therapy today because of the pain. We have been giving her liquid morphine 10 mg every 3 hours, which reduces the pain to about a 7, but this only lasts about one hour. Fortunately, she denies any side effects to the morphine. And looking at her medication list, she is not on any other medications for pain. What do you think we should do?"

"Jane, I'm not sure. Do you have any ideas?"

"Since the morphine works to some degree, I think it is the correct drug. However, 10 mg is only reducing her pain from a 9 to a 7. Because she is tolerating this well, I would like to double the dose to 20 mg. And because she only gets about an hour of relief, I think we should offer it to her every hour. She can always refuse the morphine, and knowing her, she won't take it unless she really needs the medication. So, I think we should order liquid morphine 20 mg po every hour prn. If this works, tomorrow we can talk about converting her to a long acting opioid so she doesn't need to take the drug so often. One more thing, since this is bone pain, and Mrs. Smith denies a history of ulcers, I think adding a nonsteroidal anti-inflammatory drug would be helpful."

Components of Helpful Communication

- Give complete information, including the location, intensity, and quality of the pain.
- Remind colleagues about the probable etiology of the pain, but do not rule out other potential causes.
- Describe the effect of pain on the patient's function (e.g., unable to walk, can't participate in therapy, had to terminate radiation therapy due to discomfort).
- List the medications given for pain, the efficacy of the medication, and any adverse effects.
- Ask for suggestions but be prepared to make recommendations.
- Be objective in the presentation.

- When faced with unhelpful responses, reframe, educate, and normalize. Examples:
    - "I don't think she really has that much pain"
        - "Mrs. Smith is pretty stoic and doesn't usually reveal the pain in her face or posture, but the pain is severely affecting her movement now."
    - "She has lung cancer; I don't want to cause respiratory depression"
        - "Her respiratory rate is 24 and there is no change when she is given the oral morphine. Since she has been on the morphine for three days now, and was on Vicodin for a few weeks, she has likely developed tolerance to the respiratory depressant effect of the opioid."
    - "That seems like a lot of narcotic."
        - "That dose is really not unusual. Plus we know that the correct dose of opioid is the dose that works."

Module 3
Figure 1: Imagery Exercise

Get into a comfortable position (lying or sitting; arms should be at the patient's side or relaxed in the lap if sitting; legs should be uncrossed). Let your jaw drop to relax your facial muscles. I'd like you to begin by taking some deep, slow, cleansing breaths. Breathe in.... Breathe out.... Breathe in.... Breath out.... I'd like you to think about your hands. Feel your hands becoming warm, heavy, and relaxed as you breathe in slowly and deeply and exhale slowly. Breathe in..... Breathe out.... In.... Out.... Feel the warmth and relaxation flow from your hands into the muscles of your forearms and upper arms; feel those muscles become warm, heavy, and relaxed as you breathe in slowly and deeply. Breathe in.... Breathe out.... In.... Out.... Your hands and arms feel warm, heavy, and relaxed.

Now feel the warmth and relaxation flow from your arms into the muscles of your shoulders, neck, and head; feel these muscles become warm, heavy, and relaxed as you breathe in slowly and deeply and exhale slowly. Breathe in.... Breathe out.... Breathe in warmth and relaxation; breathe out tension and pain; the muscles of your head, neck, and shoulders feel warm, heavy, and relaxed. Feel the warmth and relaxation flow from the muscles of your arms, shoulders, head and neck into the muscles of your upper back and chest. Feel these muscles become warm, heavy, relaxed, as you breathe in slowly and deeply and exhale slowly. Breathe in.... Breathe out.... The muscles of your chest and upper back feel warm, heavy, and relaxed.

Now feel the warmth and relaxation flow from your chest and upper back into the muscles of your abdomen and lower back. Feel these muscles become warm, heavy, and relaxed as you breathe in slowly and deeply and exhale slowly. Breathe in.... Breathe out.... The muscles of your abdomen feel warm, heavy, and relaxed.

Now feel the warmth and relaxation flow into the muscles of your pelvis and buttocks. Feel these muscles become warm, heavy, and relaxed as you breathe in slowly and deeply and exhale slowly. Breathe in.... Breathe out.... The muscles of your pelvis and buttocks feel warm, heavy, and relaxed. Now feel the warmth and relaxation flow into the muscles of your legs and feet. Feel these muscles become warm, heavy, and relaxed as you breathe in slowly and deeply and exhale slowly. Breathe in.... Breathe out.... The muscles of your legs and feet feel warm, heavy, and relaxed.

I'd like you to be aware, now, that your whole body is totally relaxed. You feel warm, relaxed, and comfortable. Continue breathing in and out, slowly and deeply. And, while you are feeling relaxed, I'd like you to imagine that your eyelids are a movie screen. See yourself in that special place, the place where you usually feel relaxed and comfortable. It may be indoors or outdoors; you may be alone or with others. Use all of your senses to enter this place of peace, comfort, and relaxation. Be aware of what you see. Be aware of what you feel - are you warm or cool? Be aware of the aromas, the smells associated with this special place. Think about what you hear - hear those sounds now. You are in your special place, feeling comfortable...relaxed... Spend some time there, enjoying this time away... (allow 1 or more minutes to elapse, then continue).

At the count of three, take a deep breath, let it out slowly, and open your eyes. When you open your eyes, you will feel alert, relaxed, and comfortable. (This last instruction can be modified for subsequent coaching sessions or for an individualized cassette by offering the patient the option of remaining relaxed with eyes closed but advising the patient that your coaching will end.)

Source: Spross, J.A., & Burke, M.W. (1995). Nonpharmacological management of cancer pain. In D.B. McGuire, C.H. Yarbro, & B.R. Ferrell. (Eds.). Cancer Pain Management 2nd edition. p 181. Sudbury, MA: Jones and Bartlett Publishers. Reprinted with permission.

MASSAGE

Method: Hand Massage

Description:
Massage is the stroking or rubbing of the skin surface for pain relief or relaxation.

How Hand Massage Helps:
Massage can be used to decrease pain by soothing the skin and relaxing tense muscles.

Special Considerations/Precautions:
- Do not massage areas being treated with radiation as the skin is very delicate.
- Do not massage an open skin wound or sore or one that is healing.
- Do not massage areas too sensitive to touch or if massage increases pain.
- Massage should not be used directly over an area of a tumor or over any area with bone metastasis.

Equipment:
1. Massage oil or powder
2. A large towel or blanket

Directions:
1. The most common areas for massage are the back and shoulders, but if this is too uncomfortable, a foot or hand rub may be just as relaxing. Choose the area that is best for the patient for the massage.
2. Remove clothing from the area to be massaged.
3. Both the patient and the person giving the massage should be in comfortable positions.
4. For warmth and privacy, cover the parts of the body not being massaged.
5. Use powder or lotion, whichever the patient prefers, just to keep the movement slippery. Friction caused by rubbing the skin without lotion can cause more irritation and discomfort. If lotion is used, warm it first by placing it in the microwave for a few seconds or by placing the bottle in a pan of warm water. Test the lotion first before placing it on the skin.
6. Choose a time that is right for the patient. The patient should try to have a massage before the pain becomes severe. When the patient is tired or starts to get anxious is a good indication. Set aside a time each day for the patient to receive a massage.
7. The length of time for the massage depends on the individual. A few minutes may be all that is necessary to obtain results.
8. Use long, firm strokes in the area being massaged. If the hands and feet are massaged, rub each finger and toe separately.
9. What feels good to the patient? Are softer strokes more relaxing? Firmer strokes? It is important to have the patient tell the person giving the massage what is best.

10. Massage is a time to relax. Just concentrate on how the massage feels to the patient and avoid talking and other noise.
11. To help them relax, some people like to have their favorite music playing while they receive a massage.
12. Be certain to record the massage and its effectiveness in the Self-Care Log.
13. Hand massage is not intended to take the place of pain medication; it is meant to work with pain medication to help achieve better pain relief.

Method: Vibration

Description:
Vibration is a form of electric massage known to soothe skin and muscles.

How Vibration Helps:

- Vibration can relieve a variety of pain problems by causing numbness in the painful area.
- Vibration can also relax tense muscles which may reduce pain.

Special Considerations/Precautions:

- Do not massage areas being treated with radiation as the skin is very delicate.
- Do not massage an open skin wound or sore or one that is healing.
- Do not massage areas too sensitive to touch or if massage increases pain.
- Please follow all the manufacturer's instructions prior to using the electric massager to avoid electrical shock.
- Do not use or recharge electric massager in a room where oxygen in being used.
- Massage should not be used directly over an area of a tumor or over an area with bone metastasis.

Equipment:

- Electric massager

Directions:

1. Choose the area of the body that you think will be the best place to use the massager. If the area is too painful to be touched with the massager, use the massager above or below the painful area. You may also use vibration on the opposite side of the body. For example, if the right hip hurts but is too painful to touch, you can apply the vibration to the left hip.
2. Massaging the trigger area close to the painful area can help to relax the muscles. Trigger points are hypersensitive, tender areas of nerves, tendons, or muscles. The most common areas for trigger points are in the neck, shoulders and back.
3. It is best to remove clothing from the area to be massaged by vibration.
4. Both the patient and the person helping with the use of the massager should be in comfortable positions.
5. For warmth and privacy, cover the parts of the body not being massaged.

6. Choose a time that is right for the patient. The patient should try to have a massage before the pain becomes severe, when the patient is tired or starts to get anxious. Set aside a time each day for the patient to receive a massage.
7. When using a massager, it is best to apply it directly to the painful area. The length of time varies, but the longer the period of vibration, the longer the length of pain relief. Usually 25-45 minutes, twice a day, will provide several hours of pain relief. Intermittent use (off and on) may be the most effective, applying and withdrawing the vibration every few seconds.
8. This is a time to relax; the patient does not have to talk. Just concentrate on how the massage feels to the patient.
9. Be certain to record the massage and its effectiveness in the Self-Care Log.
10. Vibration massage does not take the place of pain medication; it is meant to work with pain medication to help achieve better pain relief.

Module 2

Figure 12: Massage for Relaxation

Massage is an age-old method of helping someone relax. Some examples are:

1. Brief touch or massage (e.g., handholding or briefly touching or rubbing a person's shoulder). These are so common and quickly done that we sometimes forget they are methods of helping someone relax.
2. Warm foot soak in a basin of warm water, or wrap the feet in a warm, wet towel.
3. Massage (3 to 10 minutes) may consist of whole body or be restricted to back, feet, or hands. If the patient is modest or cannot move or turn easily in bed, consider massage of the hands or feet.

Use a warm lubricant (e.g., a small bowl of hand lotion may be warmed in the microwave-oven, or a bottle of lotion may be warmed by placing it in a sink of hot water for about 10 minutes).

Massage for relaxation is usually done with smooth, long, slow strokes. (Rapid strokes, circular movements, and squeezing of tissues tends to stimulate circulation and increase arousal.) However, try several degrees of pressure along with different types of massage (e.g., kneading, stroking, and circling). Determine which is preferred.

Especially for the elderly person, a back rub that effectively produces relaxation may consist of nor more than 3 minutes of slow, rhythmic stroking (about 60 stokes/minute) on both sides of the spinous process from the crown of the head to the lower back. Continuous hand contact is maintained by starting one hand down the back as the other hand stops at the lower back and is raised.

Set aside a regular time for the massage. This gives the patient something to look forward to and depend on.

May be duplicated for use in clinical practice. From McCaffery M, Pasero C: Pain: Clinical Manual, p. 421. Copyright © 1999, Mosby Inc.

DISTRACTION

Method: Music

Description:
Distraction is a means of using the senses (hearing, seeing, touch and movement) to focus attention on something other than pain. One method of distraction is the use of music.

How Music Helps:
When distraction is used, pain is more bearable and the patient's mood is better because he/she is not concentrating on the pain. The patient has control over the pain sensation.

Equipment:
1. Cassette player with headphones (for tapes)
2. Tapes of favorite music (country, classical, oldies, etc.)
3. Stereo
4. Records or CDs
5. Radio

Directions:
1. Decide what type of music the patient enjoys the most.
2. Find a comfortable room and a comfortable position.
3. If possible, use distraction when the pain starts, before the pain becomes severe. Have the patient take pain medication and listen to the music as the medication starts to work.
4. Try to have the patient either sing along with the music, or tap his/her fingers and feet to the beat.
5. The more senses used - touch, hearing - the more the patient will think about what he/she is doing and may be able to take his/her thoughts away from the pain.
6. Again, this does not mean that the pain is not severe or real. But research has shown that distraction techniques are powerful in making even severe pain more bearable.
7. Try to use this method of distraction several times a day for best results. If at all possible, hang a sign on the door that says "DO NOT DISTURB" so that full attention can be given to the music.
8. Be certain to record the distraction exercise and its effectiveness in the Self-Care Log.
9. Distraction does not take the place of pain medication; it is meant to work with pain medication to help achieve better pain relief.

Method: Humor

Description:

Distraction is a means of using the senses (hearing, seeing, touch and movement) to focus attention on something other than pain. One method of distraction is the use of humor.

How Humor Helps:

When distraction is used, pain is more bearable and your mood is better because you are not concentrating on the pain. You have control over the pain sensation.

Equipment:

1. Cassette player with headphones (for tapes)
2. Comedy tapes
3. VCR
4. TV
5. Radio

Directions:

1. Decide what type of comedy the patient enjoys the most. Is it a favorite sitcom on TV? A funny movie? A favorite book?
2. Find a comfortable room and a comfortable position.
3. If possible, use distraction when the pain starts, before the pain becomes severe. Have the patient take pain medication and listen or watch as the medication starts to work.
4. Try not to have the patient interrupted while listening or watching his/her favorite comedy.
5. The more senses used - touch, hearing - the more the patient will think about what he/she is doing and may be able to take his/her thoughts away from the pain.
6. Again, this does not mean that the pain is not severe or real. But research has shown that distraction techniques are powerful in making even severe pain more bearable.
7. Try to use this method of distraction several times a day.
8. Be certain to record the distraction exercise and its effectiveness in the Self-Care Log.
9. Distraction does not take the place of pain medication; it is meant to work with pain medication to help achieve better pain relief.

Module 2
Figure 10: Patient Information: Describing Pictures for Distraction

Use:

- The use of pictures may help with a brief period of pain, that is, pain that last a few minutes up to an hour.
- Use this activity along with your pain medicine.

Instructions:

1. **Obtain pictures** that interest you.
    - Types of pictures, such as pictures from magazines; photographs of friends, family, or vacation; merchandise catalogs; or books with pictures of a specific subject such as airplanes or civil war. You may want pictures on the same subject or different subjects. Avoid any pictures that you find disturbing or that remind you of your discomfort.
    - Number of pictures. The number of pictures you need will depend on several factors, such as how long your discomfort will last, how much detail you describe, and how fast you talk.
2. You may need **assistance**. If you do not have much time or energy, you may consider asking a friend to obtain the pictures for you (e.g., cut out magazine pictures). You may also want someone to hold the pictures up for you to see as you describe them and help you with your descriptions by asking you for some of the details discussed below.
3. **Look at the pictures and describe them** in any manner that interests you. Usually it is best to continue looking at the pictures while you describe them (as opposed to looking at the picture briefly, hiding it, and then trying to remember the details of the picture). Ways of describing or talking about the pictures include the following – to help you keep your attention focused on the pictures, you may want a friend to have this list and ask you about these items:
    - Pretend you are in the picture. What would you do?
    - Count the number of items in the picture.
    - Name each item in the picture.
    - Name the colors.
    - What is happening in the picture? Make up a story about the picture.
4. If this is **not effective enough, try adding or changing** one or more of the following: try different pictures or different questions; reverse the procedure and ask questions of the person who is assisting you; include at random some surprise pictures that may be difficult to describe but have novel value (e.g., simple cartoons or scantily clad figures); if the discomfort increases, try changing the pictures more rapidly; if you feel self-conscious talking aloud, try describing the pictures to yourself silently.

This technique may be an ideal way to involve someone who has extra time and wants to help you with your pain. A friend or nurse may gather pictures in his or her spare time and give them to you before a painful event, or the person might be there to show you the pictures and ask questions.

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Module 2
Figure 8: Patient Information: Sing and Tap Rhythm for Distraction

1. Keep your **eyes open and focus** steadily on one stationary spot or object. If you wish to close your eyes, picture something about the song you will be singing.
2. **Select a song** that you know the words to (at least four or more lines), such as a hymn, nursery rhyme, popular song, or commercial jingle.
3. **Sing the song.** To avoid disturbing others or feeling self-conscious, most adults choose to sing silently. You may emphatically mouth the words silently or whisper the words.
4. **Mark time to the song** (e.g., tap out the rhythm with your finger or nod your head). This helps you concentrate on the song instead of your discomfort.
5. Begin singing slowly. **Sing faster if the pain increases;** sing slower when the pain decreases.
6. If this is **not effective enough, try adding or changing** one or more of the following: massage your body in rhythm to the song; try another song; ask someone to sing with you; or mark time to the song in more than one manner (e.g., nod your head at the same time you tap your finger).

Additional points: This technique is easy to learn, but if you are already tired, you may find it physically exhausting if you do it for more than a few minutes. You may also feel self-conscious when you first do this, but you may find you do not mind as long as the technique helps you get through your discomfort.

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Module 2

Figure 9: Patient Information: Active Listening to Recorded Music for Distraction

Use:

- The following suggestions may help you with a brief period of pain, that is, pain that lasts from a few minutes up to an hour.
- Use these suggestions along with your pain medicine.

Instructions:

1. Obtain the following:
    - A cassette player or tape recorder. (Small, battery-operated ones are more convenient.)
    - Earphone or headset. (This is a more demanding stimulus than a speaker a few feet away, and it avoids disturbing others.)
    - Cassette of music you like. (Most people prefer fast, lively music, but some select relaxing music. Other options are comedy routines, sporting events, old radio shows, or stories.)
2. **Listen to the music** at a comfortable volume. **If the discomfort increases, try increasing the volume**; decrease the volume when the discomfort decreases.
3. **Mark time to the music** (e.g., tap out the rhythm with your finger or nod your head). This helps you concentrate on the music rather than you discomfort.
4. Keep your **eyes open and focus** steadily on one stationary spot or object. If you wish to close your eyes, picture something about the music.
5. If this is **not effective enough, try adding or changing** one or more of the following: massage your body in rhythm to the music; try other music; mark time to the music in more than one manner (e.g., tap your foot and finger at the same time).

Additional points: Many patients have found this technique helpful. It tends to be very popular among patients, probably because the equipment is usually readily available and is a part of daily life - you see many people exercising and listening to a recording through a headset. Other advantages are that it is easy to learn and is not physically or mentally demanding. For these reasons, it may be used for up to an hour. If you are very tired, you may simply listen to the music and omit marking time or focusing on a spot.

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Module 2
Figure 6: Patient Information: Use of Cold

Cold may relieve the following types of pain, and it often works better than heat:

- Muscle aches or spasms, such as neck or low back pain
- Joint pain
- Headache
- Surgical incision
- Itching

Precautions:

- Do not use cold over areas of poor circulation or skin being treated with radiation therapy.
- Do not use cold if pain increases.
- Think cool, not cold. Keep the sensation of cold at a cool, comfortable level.
- Cover the cold pack with a towel.
- Remember that moisture increases the intensity of cold.
- Remove the cold pack if your skin becomes numb.
- Do not freeze your skin.

Equipment for cold can be any of the following:

- Ice bag
- Gel pack
- Ice and water in a plastic bag
- A bag of frozen peas or frozen corn kernels (Hit the bag on the countertop to break up the frozen vegetables so it will mold to your skin.)
- Slush pack made by freezing in a sealed plastic container (e.g., plastic bag) 1/3 alcohol and 2/3 water.
- Towel soaked in water and ice chips and wrung out
- Flexible cold pack made with a damp cloth or towel, folded in the desired shape, sealed in a plastic bag, and placed in the freezer

Application of cold:

- Cover ice pack with a pillowcase or one or more towels.
- Keep it at a comfortably cool intensity.
- Apply to painful area for 10 to 20 min. You may use cold for any length of time if it remains at a comfortable level of coolness that does not irritate your skin.
- If you cannot get to the area that hurts, apply the cold pack to any or all of the following sites:
    - Opposite side of the body corresponding to the pain (e.g., left leg if the right leg hurts)
    - Above the pain (e.g., over upper arm if your lower arm hurts)
    - Below the pain (e.g., over the lower arm if your upper arm hurts)

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Module 2

Figure 7: Patient Information: Use of Heat

Heat may relieve the following types of pain:

- Muscle aches or spasms, such as neck or low back pain
- Joint pain
- Itching
- Rectal pain

Precautions:

- Do not use heat if pain increases.
- Think warm, not hot. Keep the sensation at a warm, comfortable level.
- Cover the heat source with a towel.
- Remember that moisture increases the intensity of heat.
- Do not use heat over skin where menthol ointment or an oil substance has been applied.
- Do not use over an area that is bleeding or recently injured.

Equipment for heat application can be any of the following:

- Hot water bottle
- Electric heating pad
- Hot moist compresses (e.g., towel)
- Immersion in water (e.g., tub, basin, whirlpool)
- Retention of body heat with plastic wrap (e.g., Saran Wrap, plastic dry cleaner bag taped to itself). Be careful to wash and dry your skin well at least once a day if you are using this method.

Application of heat:

- Cover heat source with a pillowcase or one or more towels.
- Keep it at a comfortably warm intensity.
- Do not fall asleep on top of an electric heating pad.
- Apply to painful area for 10 to 20 min. You may use warmth for any length of time if it remains at a comfortable level that does not irritate your skin.
- If you cannot get to the area that hurts, apply the heat pack to any or all of the following sites:
  - Opposite side of body corresponding to the pain (e.g., left leg if the right leg hurts)
  - Above the pain (e.g., over upper arm if your lower arm hurts)
  - Below the pain (e.g., over the lower arm if your upper arm hurts)

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COLD

Method: Ice Bags

Description:
Pain relief may be obtained by applying cold to the painful area. One method of applying cold is by the use of ice bags.

How Ice Bags Help:
When cold is applied to the skin, the cold decreases skin sensations by numbing nerve endings. Cold may also reduce muscle spasms, reduce inflammation and help stop the desire to scratch areas that itch.

Special Considerations/Precautions:
- Do not apply an ice bag to:
  - Skin being treated with radiation therapy;
  - Severe injury;
  - A wound in the healing phase;
  - Areas that have poor circulation.
- Do not use cold if pain increases.

Equipment:
1. Ice bag: (either of the following may be used for an ice bag)
   - Commercial ice bag
   - Self-sealing small plastic bag that won't leak, filled with ice
2. Ice
3. Other sources of cold that can be used are:
   - A bag of frozen corn kernels
   - A bag of frozen peas
4. Towel or pillowcase
5. Menthol-containing products such as Ben Gay®, Icy Hot®, etc.

Directions:
1. Fill the ice bag with ice. The smaller the cubes, the better. Crushed or shaved ice will mold around the area better than large cubes. Push out all the air from the bag.
2. If you are using bags of frozen vegetables, hit the bag on the counter top once or twice to break up the frozen vegetables so the bag will mold to the skin better. Place the plastic bag directly on the skin.
3. If you are using a small plastic bag, be sure it does not leak. Put some water in the bag first to check for holes. Place the ice into the bag. Use same instructions as in #1.
4. Wrap the ice bag in a pillowcase or a towel. If you want it colder, use a wet towel, if you want it less cold, use a dry towel.

5. Be sure the ice bag top is screwed on tightly and that there are no leaks. Hold the bag upside down to be sure the top is on tight.
6. Place the ice bag on the area that is painful. If it is too painful to put the ice bag directly on the area, the ice bag may be placed above or below the painful area, or on the other side of the body that corresponds to where the pain is located. For example, if the right hip hurts but it is too painful to place the ice bag on the right hip, the ice bag can be placed on the left hip.
7. Have the patient in a comfortable position.
8. Leave the ice bag on 10-15 minutes, three or four times a day. The longer it is left in place (up to 1 hour), the longer the pain relief.
9. You may alternate cold with heat. You may have to try either heat/cold several times to find the correct area or temperature that gives the most relief.
10. Products containing menthol such as Ben Gay® or Icy Hot® can be applied to the painful area when using cold, but not with heat, as burns may occur. Wash hands thoroughly after using any product which contains menthol and avoid getting it into eyes. Try a small amount of the menthol product on the inner arm. If, after a few minutes, you do not have any redness or irritation, the product may be used.
11. You may refreeze the bag of vegetables to use again. (Do not cook the vegetables if they have been used as an ice pack.)
12. Be certain to record the cold method and its effectiveness in the Self-Care Log.
13. Ice bags are not intended to take the place of medication; they are meant to work with pain medication to help achieve better pain relief.

Method: Cold Cloths

Description:
Pain relief may be obtained by applying cold to the painful area. One method of applying cold is by the use of cold cloths.

How Cold Cloths Help:
When you apply cold to the skin, the cold decreases skin sensations by numbing nerve endings. Cold may also reduce muscle spasms, reduce inflammation and help stop the desire to scratch areas that itch.

Special Considerations/Precautions:

- Do not apply cold cloths to:
  - Skin being treated with radiation therapy;
  - Severe injury;
  - A wound in the healing phase;
  - Areas that have poor circulation.
- Do not use cold if pain increases.

Equipment:

1. Towels (hand or wash cloth, one for ice, one for drying)
2. Ice
3. Towel or pillowcase
4. Basin
5. Menthol-containing products, such as Ben Gay®, Icy Hot®, etc.

Directions:

1. Fill a basin with about 2 inches of water.
2. Add ice to the water.
3. Soak the towel in the ice water until it is completely wet.
4. Have the patient get into a comfortable position.
5. Wring out the towel and place it directly on the area that hurts.
6. When it becomes warm, remove the towel and rewet it in the ice water.
7. Continue applying cold cloths until relief is achieved.
8. If it is too painful to put the cold cloth directly on the top of the area, the cold cloth may be placed above the painful site or below the area, or on the other side of the body that corresponds to where the pain is located. For example, if the right hip hurts but it is too painful to place the cold cloth on the right hip, you can put the cold cloth on the left hip.
9. Continue changing the towels for 10-15 minutes. This treatment may be used three or four times a day.
10. Alternate cold with heat. You may have to try either heat/cold several times to find the correct area or temperature that gives the most relief.
11. Products containing menthol such as Ben Gay® or Icy Hot® may be applied to the painful area when using cold, but not with heat, as burns may occur. Wash hands thoroughly after using any product which contains menthol to avoid getting it into the eyes. Try a small amount of the menthol product on the inner arm. If, after a few minutes, there is no redness or irritation, the product may be used.
12. Be certain to record the cold method and its effectiveness in the Self-Care Log.
13. Cold cloths are not intended to take the place of pain medication; they are meant to work with pain medication to help achieve better pain relief.

Method: Frozen Gel Packs

Description:
Pain relief may be obtained by applying cold to the painful area. One method of applying cold is by the use of frozen gel packs.

How Frozen Gel Packs Help
When cold is applied to the skin, the cold decreases skin sensations by numbing nerve endings. Cold may also reduce muscle spasms, reduce inflammation and help stop the desire to scratch areas that itch.

Special Considerations/Precautions:

- Do not apply frozen gel packs to:
  - Skin being treated with radiation therapy;
  - Severe injury;
  - A wound in the healing phase;
  - Areas that have poor circulation.
- Do not use cold if pain increases.

Equipment:

1. Gel Pack

or

2. Homemade pack:
   - Add 1/3 cup of rubbing alcohol and 2/3 cup of water to one self-sealing plastic bag. Place the plastic bag with the mixture in it in the freezer until the mixture resembles slush.
3. Towel or pillowcase
4. Six-inch elastic wrap
5. Menthol-containing products such as Ben Gay®, Icy Hot®, etc.

Directions:

1. Remove the gel pack from the freezer.
2. Wrap the pack in a pillowcase or a towel. If the gel pack is covered in its own elastic wrap, this will be sufficient
3. If using a homemade gel pack, be sure the plastic bag does not leak. Cover the plastic bag with a towel or pillowcase. Place the gel pack on the area that is painful.
4. Have the patient get into a comfortable position.
5. Place the gel pack on the area that is painful.
6. Wrap the gel pack around the area where relief is wanted. The elastic wrap attached to the gel pack can be secured with the Velcro® tape on the wrap. If you are using a homemade gel pack, use a six-inch elastic wrap to hold the gel pack in place.
7. If it is too painful to put the gel pack directly on the area, you may place the gel pack above or below the painful area, or on the other side of the body that corresponds to where the pain is located. For example, if the right hip hurts but it is too painful to place the gel pack on the right hip, you can place the gel pack on the left hip.
8. Leave the gel pack on 10-15 minutes, three or four times a day. The longer it is left in place (up to 1 hour), the longer the pain relief.
9. Alternate cold with heat. Try either heat/cold several times to find the correct area or temperature that gives the most relief.
10. Products containing menthol, such as Ben Gay® or Icy Hot® can be applied to the painful area when using cold, but not with heat, as burns may occur. Wash hands

thoroughly after using any product which contains menthol and avoid getting it into the eyes. Try a small amount of the menthol product on the inner arm. If, after a few minutes, there is no redness or irritation, the product may be used.

11. Return the gel pack to the freezer.
12. Be certain to record the cold method and its effectiveness in the Self-Care Log.
13. Gel packs are not intended to take the place of pain medication; they are meant to work with pain medication to help achieve better pain relief.

Method: Ice Massage

Description:

Pain relief may be obtained by applying cold to the painful area. One method of applying cold is by rubbing ice on the painful area.

How Ice Massages Help Your Pain

When applying cold to the skin, it decreases skin sensations by numbing the nerve endings. Cold may also reduce muscle spasms, reduce inflammation and help stop the desire to scratch areas that itch.

Special Considerations/Precautions:

- Do not apply ice massages to:
  - Skin being treated with radiation therapy;
  - Severe injury;
  - A wound in the healing phase;
  - Areas that have poor circulation.
- Do not use cold if pain increases.

Equipment:

1. Ice
2. Towel/bath towel and washcloth
3. Plastic bag or trash bag
4. Paper cups (bathroom size)

Directions:

1. Fill a paper cup halfway with water. Place the cup in the freezer until the water is frozen solid.
2. Peel the paper partly away from the cup to expose the ice.
3. Place the ice cup under cold running water to remove any rough surfaces on the ice.
4. Remove any clothing covering the painful area.
5. Place a plastic bag covered by a bath towel under the area to be massaged. This will help absorb any water that may run off and will help dry the skin as the ice melts.
6. Have the patient get into a comfortable position.
7. Wrap a washcloth around the paper cup to prevent the hand from getting cold.
8. Rub the ice over the painful area in a circular motion. Dry the skin with a towel as the ice melts.
9. Massage the area for four minutes. The skin will be reddened. This is normal. Repeat the ice massage three or four times a day. Alternate cold with heat. Try either heat/cold several times to find the correct area or temperature that gives the most relief.

10. Be sure to keep a supply of paper cups with ice in the freezer so they will be ready when needed.
11. Be certain to record the cold/ice massage and its effectiveness in the Self-Care Log.
12. Ice massages are not intended to take the place of pain medication; they are meant to work with pain medication to help achieve better pain relief.

HEAT

Method: Heating Pad

Description:
Heat is the application of warmth to the skin for the relief of pain. One method of applying heat is by use of a heating pad.

How Heat Helps:
Heat can relieve pain by reducing inflammation and soreness. Heat also decreases sensitivity to pain, relieves joint stiffness and increases blood flow to the skin.

Special Considerations/Precautions:

- Heat can burn if used improperly. Please read the manufacturer's directions before using any heating pad. Please follow all precautions listed to avoid electrical shock.
- Do not apply heat to:
  - Skin being treated with radiation therapy;
  - Any area that is bleeding;
  - Any area with decreased sensation;
  - Any injury within the first 24 hours;
- Do not use with any menthol-containing products (Vicks®, Ben Gay®, Icy Hot®, etc.)
- Do not use if oxygen is being used.

Equipment:

3. Heating pad
4. Manufacturer's cover for the heating pad

Directions:

12. Plug in the heating pad and place the temperature control on low. Adjust to a higher heat if needed.
13. When the heating pad is warm, place the heating pad to the area where you want relief.
14. If the area is too painful to have the heating pad directly on it, place the heating pad on the other side of the body that corresponds to the painful area. For example, if the right hip has pain but it is too painful to put the heating pad on the right hip, put the heating pad on the left hip.
15. Be certain the heating pad has a cover over it to prevent burning the skin.
16. Do not fall asleep on top of the heating pad. Heat is increased with pressure, which may cause burns.
17. Keep the heating pad on for as long as possible to obtain relief, usually 20-30 minutes.

18. Alternate heat and cold (please see the instructional materials on cold) to improve comfort. Try either heat/cold several times to find the correct area or temperature that gives the most relief.
19. If the heating pad is too warm, decrease the temperature to a lower temperature. Adjust the temperature of the heating pad for comfort.
20. Use the heating pad as often as necessary for relief. Try to use the heating pad before the pain becomes severe.
21. Be certain to record the heat method and its effectiveness in the Self-Care Log.
22. The heating pad does not take the place of pain medication; it is meant to work with pain medication to help achieve better pain relief.

Method: Hot Baths

Description:
Heat is the application of warmth to the skin for the relief of pain. One method of applying heat is by use of hot baths.

How Heat Helps:
Heat can relieve pain by reducing inflammation and soreness. Heat also decreases sensitivity to pain, relieves joint stiffness and increases blood flow to the skin.

Special Considerations/Precautions:
- Use heat with caution when feeling to an area is decreased or there is any other irritation to the skin surface.
- Do not take a hot bath if:
  - The painful area is being treated with radiation therapy;
  - The painful area is bleeding;
  - The painful area has been injured.

Equipment:
4. Bath tub
5. Thermometer used for swimming pools and spas
6. Towels

Directions:
10. Fill the bathtub with enough warm water to cover the painful area.
11. Before getting into the tub, take the temperature of the water with the thermometer.
12. The water temperature should be between 98° and 102°.
13. Sit in the hot bath for as long as comfortable.
14. Add more hot water as the water in the tub cools. When adding hot water, be sure to check the temperature of the water.
15. Repeat tub baths as often as needed for relief. Try to take tub baths before the pain becomes severe.

16. If pain becomes worse, if shivering occurs, or the skin becomes irritated, discontinue use of tub baths.
17. Be certain to record the heat method and its effectiveness in the Self-Care Log.
18. Hot baths do not take the place of pain medication; they are meant to work with pain medication to help achieve better pain relief.

Method: Hot Water Bottle

Description:
Heat is the application of warmth to the skin for the relief of pain. One method of applying heat is by use of a hot water bottle.

How Heat Helps:
Heat can relieve pain by improving circulation to the muscles, which decreases spasms, and by reducing inflammations. Heat also decreases sensitivity to pain, relieves joint stiffness and increases blood flow to the skin.

Special Considerations/Precautions:

- Use heat with caution when feeling to an area is decreased or there is any other irritation to the skin surface.
- Do not use a hot water bottle if:
  - The painful area is being treated with radiation therapy;
  - The painful area is bleeding;
  - The painful area has been injured.

Equipment:

4. Hot water bottle
5. Towel
6. Thermometer used for swimming pools or spas

Directions:

12. Fill the hot water bottle with hot water from the faucet. Do not put boiling water into the hot water bottle.
13. Use the thermometer made for swimming pools and spas to take the temperature of the water as it runs from the tap into the hot water bottle.
14. Water temperature should be between 104° and 113°.
15. Push all the air out of the hot water bottle and screw cap on tightly. Check to see that it is sealed by holding the hot water bottle upside down.
16. Place the hot water bottle in a towel or pillowcase.
17. Place the hot water bottle on the area where relief is wanted. If it is too painful to place the hot water bottle directly on the painful area, place it above or below the painful site. It also can be placed on the other side of the body that corresponds to

the painful area. For example, if the right hip has pain but it is too painful to put the hot water bottle on the right hip, put the hot water bottle on the left hip.

18. Do not sleep on top of the hot water bottle. Heat is increased with pressure, which may cause burns to the skin.
19. Keep the hot water bottle on for as long as possible to obtain relief, usually between 20-30 minutes. Refill with hot water when the bottle is no longer warm. Recheck temperature.
20. Alternate use of the hot water bottle and switch to cold (please see the instructional materials on cold) to improve comfort. Try either heat/cold several times to find the correct area or temperature that gives you the most relief.
21. Be certain to record the heat method and its effectiveness in the Self-Care Log.
22. Hot water bottles are not intended to take the place of pain medication; they are meant to work with pain medication to help achieve better pain relief.

Method: Moist Heat

Description:
Heat is the application of warmth to the skin for the relief of pain. One method of applying heat is by use of a heating pad that supplies moisture.

How Heat Helps:
Heat can relieve pain by improving circulation to the muscles, which decreases spasms, and by reducing inflammations. Heat also decreases sensitivity to pain, relieves joint stiffness and increases blood flow to the skin. Using moisture with heat may provide a means of getting heat below the skin surface.

Special Considerations/Precautions:

- Use heat with caution when feeling to an area is decreased or there is any other irritation to the skin surface.
- Do not apply to:
  - Skin being treated with radiation therapy;
  - Any area that is bleeding;
  - A painful area which has been injured.
- Do not use if oxygen is being used.

Equipment:

4. Specially-designed heating pad, such as the Sunbeam® Automatic Heating Pad
5. Manufacturer's foam rubber sheet
6. Manufacturer's protective cover for the heating pad

Directions:

10. Plug in the heating pad and place the temperature control on low. Adjust to a higher heat if needed.

11. When the heating pad is warm, place the heating pad on the painful area.
12. If the area is too painful to have the moist heat/heating pad directly on it, you can also place the moist heat/heating pad on the other side of the body that corresponds to the painful area. For example, if the right hip has pain but it is too painful to put the moist heat/heating pad on the right hip, put the moist heat/heating pad on the left hip.
13. Keep the moist heat/heating pad on for as long as possible to obtain relief, usually 20-30 minutes.
14. Alternate heat and cold (please see the instructional materials on cold) to improve comfort. Try either heat/cold several times to find the correct area or temperature that gives the most relief.
15. If the heating pad is too warm, decrease the temperature. Adjust the temperature of the heating pad for comfort.
16. May use the moist heat/heating pad three or four times a day. Try to use the moist heat/heating pad before the pain becomes severe.
17. Be certain to record the heat method and its effectiveness in the Self-Care Log.
18. Moist heat/heating pads are not intended to take the place of pain medication; they are meant to work with pain medication to help achieve better pain relief.

Method: Hot Wrap

Description:
Heat is the application of warmth to the skin for the relief of pain. One method of applying heat is by use of a hot wrap.

How Heat Helps:
Heat can relieve pain by reducing inflammation and soreness. Heat also decreases sensitivity to pain, relieves joint stiffness and increases blood flow to the skin. Heat also helps you to relax.

Special Considerations/Precautions:

- Please follow all manufacturer's directions for use. To avoid burns to the skin when heating the hot wrap, do not leave the hot wrap in the microwave or boiling water too long. To avoid burns, use only the wrap that is included with the hot pack.
- Do not use the hot wrap if:
  - The painful area is being treated with radiation therapy;
  - It is within 24 hours of injury to that area;
  - The painful area has decreased sensation;
  - The painful area has open wounds or sores.

Equipment:

3. Hot wrap such as Champ® Hot Wrap

4. Microwave or boiling water

Directions:

12. The hot wrap can be heated in either a microwave or boiling water.
    - Microwave directions: Unfold the hot wrap and lay it flat in the microwave. Heat with full power for 60 seconds. Note: pack will continue to heat slightly. Test it before use. If it is too warm, set aside until it becomes cooler. If additional heating is required, use five-second intervals to heat the hot pack.
    - Hot water directions: Bring three quarts of water to a boil in a pot. Remove the hot pack from the wrap. Remove the pot from the heat and place the hot pack in the boiled water for no longer than seven minutes. Remove the hot pack with kitchen tongs to prevent burns.
13. When the hot pack is ready, place the hot pack in the wrap that is provided.
14. Place the hot wrap on the area where relief is wanted. If the area is too painful to have the hot wrap directly on it, place the hot wrap on the other side of the body that corresponds to the painful area. For example, if the right hip has pain but it is too painful to put the hot wrap on the right hip, put the hot wrap on the left hip.
15. If possible, secure the hot wrap on the painful area to prevent it from slipping.
16. Do not sleep on top of the hot wrap. Heat is increased with pressure, which may cause burns.
17. Once the hot wrap is cooled, and wish to reuse it, please follow the manufacturer's directions. Do not exceed the recommended heating times, as burns may result. Do not throw the hot wrap away.
18. You may continue to use the hot wrap as long as the patient is comfortable, and the skin under the hot wrap is not reddened or irritated.
19. Occasionally check the skin for any signs of redness or irritation. If either are present, stop using the hot wrap. And if the redness or irritation doesn't disappear within an hour, call the physician.
20. Alternate heat and cold (please see the instructional materials on cold) to improve comfort, or take the hot wrap off for a few minutes. By taking the hot wrap off, the skin will cool quickly giving the contrast between heat and cold.
21. Be certain to record the heat method and its effectiveness in the Self-Care Log.
22. Hot wraps are not intended to take the place of pain medication; they are meant to work with pain medication to help achieve better pain relief.

RELAXATION

Method: Imagery

Description:
Relaxation is resting to achieve a reduction in tension. One method of relaxation is the use of imagery. Imagery is using your imagination to help lesson pain. It is a way of "picturing" a thought or image that will distract the patient from his/her pain.

How Imagery Helps:
Relaxation is used to help reduce stress that can cause muscle tension which, in turn, can increase pain. Relaxation itself may not decrease pain, but rather it can help relieve tense muscles that may be contributing to the pain and help the patient cope with all that is happening.

Special Considerations/Precautions:
- Do not use deep breathing/imagery techniques if the patient has difficulty breathing or has other medical problems with the lungs.

Equipment:
- A room that is comfortable and private.

Directions:
9. Find a quiet room where the patient can get into a comfortable position to relax. Have the patient close his/her eyes.
10. Do not have the patient fold arms or cross his/her legs as it may cut off circulation and cause numbness and tingling.
11. Breathe in deeply. Exhale slowly as though whistling out. Do this three times. This will help the patient to relax.
12. Have the patient picture in his/her mind something that is peaceful, or a place that he/she has enjoyed visiting.
13. Think of an image that is pleasant to him/her which symbolizes how the patient pictures pain relief. For example, if the patient thinks of pain as being a large boulder that is on a part of his/her body weighing him/her down, causing pain, perhaps the patient can picture large helium-filled balloons attached to the boulder carrying it away from him/her, releasing the pain. Perhaps the patient may think of the pain as a thunderstorm, complete with lightning and thunder, that rains on his/her body. The patient can imagine how the pain medication is like a gentle breeze that blows the rain and thunderclouds away. Instead of rain and thunder, there is sunshine and warmth. The air smells clean and fresh, the rain has watered all the beautiful flowers and the grass is green and lush. There are swans and ducks on a pond. Only a ripple, caused by the ducks' gentle paddling, disturbs the water's peaceful state.

14. Use imagery at least 20 minutes a day. It is best if this is tried before the pain becomes severe, or while waiting for the pain medication to work.
15. Be certain to record the use of relaxation/imagery and its effectiveness in the Self-Care Log.
16. Imagery is not intended to take the place of pain medication; it is meant to work with pain medication to help achieve better pain relief.

Method: Breathing Exercises

Description:
Relaxation is resting to achieve a reduction in tension. One method of relaxation is the use of breathing exercises.

How Breathing Exercises Help:
Relaxation is used to help reduce stress that can cause muscle tension which, in turn, can increase pain. Relaxation itself may not decrease pain, but rather it can help relieve tense muscles that may be contributing to the pain and help you cope with all that is happening.

Special Considerations/Precautions:
- Do not use deep breathing exercises if the patient has difficulty breathing or has other medical problems with the lungs.

Equipment:
4. Cassette player with headphones
5. Relaxation tapes
6. A room that is comfortable and private

Directions:
15. Find a quiet room where the patient can get into a comfortable position to relax. Have him/her close his/her eyes.
16. Do not have the patient fold arms or cross his/her legs as it may cut off circulation and cause numbness and tingling.
17. Breathe in deeply. Exhale slowly as though whistling out. Do this three times. This will help the patient to relax.
18. Have the patient think of a calm, peaceful setting, or perhaps a place he/she has enjoyed visiting that will help the patient to relax.
19. Have the patient picture his/her body as being very light, floating weightlessly, very limp or comfortably warm. Use any mental picture that will help the patient relax and then begin the breathing exercises.
20. Breathe in deeply. At the same time, have the patient tense muscles or any group of muscles he/she chooses. For example, making a fist, clenching teeth, closing eyes tightly, or drawing arms or legs up as tightly as one can.

21. Have the patient hold his/her breath and keep those muscles tense for a second or two.
22. Then relax those muscles. Breathe out and let his/her body relax.
23. Now start with the muscles in the lower legs, concentrating on one leg at a time and, alternately tightening and releasing, work up by muscle group to the head.
24. If the patient wants a shorter relaxation exercise, he/she may combine muscle groups. For example, think of tensing and relaxing the muscles in both legs together instead of each leg separately.
25. There are audiotapes available that will talk the patient through a series of breathing exercises to help him/her relax. If this method is chosen, try to concentrate on the speaker and what is being said.
26. Use relaxation at least 20 minutes a day. It is best to try this before the pain becomes severe, or while waiting for the pain medication to work.
27. Be certain to record the breathing exercises and their effectiveness in the Self-Care Log.
28. Breathing exercises are not intended to take the place of pain medication; they are meant to work with pain medication to help achieve better pain relief.

Method: Tapes (Music/Sounds)

Description:
Relaxation is resting to achieve a reduction in tension. One method of relaxation is the use of tapes that contain either music or nature sounds.

How Music/Sound Tapes Help:
Relaxation is used to help reduce stress that can cause muscle tension which, in turn, can increase pain. Relaxation itself may not decrease pain, but rather it can help relieve tense muscles that may be contributing to the pain and help you cope with all that is happening.

Special Considerations/Precautions:
- Do not use if the sounds on the relaxation tapes increase anxiety. For example, listening to a tape with sounds of the ocean will not be relaxing for someone who is afraid of water.

Equipment:
4. Cassette player with headphones
5. Relaxation tapes
6. A room that is comfortable and private

Directions:

9. Find a quiet room where the patient can get into a comfortable position to relax. Have the patient close his/her eyes.
10. Do not have the patient fold arms or cross his/her legs as it may cut off circulation and cause numbness and tingling.
11. Breathe in deeply. Exhale slowly as though whistling out. Do this three times to help relaxation.
12. Think of a calm, peaceful setting, or perhaps a place he/she has enjoyed visiting that will help relaxation.
13. Try to have the patient think only of what he/she is listening to on the tapes. If at all possible, use headphones to help the concentration.
14. Try this method of relaxation at least 20 minutes a day. It is best to try this before the pain becomes too severe, or while waiting for the pain medication to work.
15. Be certain to record the relaxation exercise and its effectiveness in the Self-Care Log.
16. Music/sounds are not intended to take the place of pain medication; they are meant to work with pain medication to help achieve better pain relief.

Module 2

Figure 11: Patient Information: Deep Breathing for Relaxation with the Option of Peaceful Imaging

1. Breathe in slowly and deeply.
2. As you breathe out slowly, feel yourself beginning to relax; feel the tension leaving your body.
3. Now breathe in and out slowly and regularly, at whatever rate is comfortable for you.
4. To help you focus on your breathing and breathe slowly and rhythmically:
   Breathe in as you say silently to yourself, "in, two, three."
   Breathe out as you say silently to yourself, "out, two, three."
   or
   Each time you breathe out, say silently to yourself a word such as peace or relax.
5. You may imagine that you are doing this in a place you have found very calming and relaxing for you, such as laying in the sun at the beach.
6. Do steps 1 through 4 only once or repeat steps 3 and 4 for up to 20 minutes.
7. End with a slow, deep breath. As you breathe out you may to yourself, "I feel alert and relaxed."

Additional points:

- This technique for relaxation has the advantage of being very adaptable. You may use it for only a few seconds or for up to 20 minutes. For example, you may do this regularly for 10 minutes twice a day. You may also use it for one or two complete breaths any time you need it throughout the day or when you awaken in the middle of the night.
- If you use this technique for more than a few seconds, try to get in a comfortable position in a quiet environment.
- A very effective way to relax is to add peaceful images once you have performed steps 1through 4 above. Following are some ideas about finding your own peaceful memories. Something may have happened to you a while ago that can be of use to you now. Something may have brought you deep joy or peace. You may be able to draw on that past experience to bring you peace or comfort now.

Think about these questions. Can you remember any situation, even when you were a child, when you felt calm, peaceful, secure, hopeful, or comfortable?

Do you get a dreamy feeling when you listen to music?
Do you have any favorite music?
Do you have any favorite poetry that you find uplifting or reassuring?

Are you now or have you ever been religiously active? Do you have favorite readings, hymns, or prayers? Even if you haven't heard or thought of them for many years, childhood religious experiences may still be very soothing. Very likely some of the things you think of in answer to these questions can be tape-recorded for you, such as your favorite music or a prayer ready by your clergyman. Then you can listen to the tape whenever you wish. Or, if your memory is strong, you may simply close your eyes and recall the events or words.

May be duplicated for use in clinical practice. From McCaffery M, Pasero C: <u>Pain: Clinical Manual</u>, p. 420. Copyright © 1999, Mosby Inc.

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