

PALLIATIVE CARE PAIN MANAGEMENT GUIDELINES  
FOR NURSE PRACTITIONERS

Scholarly Project for the Degree of M. S. N.

MICHIGAN STATE UNIVERSITY

SUSAN GAYLE WIERS

1999

**LIBRARY**  
**Michigan State**  
**University**

PLACE IN RETURN BOX to remove this checkout from your record.  
 TO AVOID FINES return on or before date due.  
 MAY BE RECALLED with earlier due date if requested.

DATE DUE	DATE DUE	DATE DUE
	01 1 1 3	

PALLIATIVE CARE PAIN MANAGEMENT GUIDELINES  
FOR NURSE PRACTITIONERS

By

Susan Gayle Wiers MSN

A SCHOLARLY PROJECT

Submitted to  
Michigan State University  
in partial fulfillment of the requirements  
for the degree of

MASTER OF SCIENCE IN NURSING

College of Nursing

1999



## ABSTRACT

### PALLIATIVE CARE PAIN MANAGEMENT GUIDELINES FOR NURSE PRACTITIONERS

By

Susan Gayle Wiers RN MSN

The health care system has been largely unresponsive to the needs of dying individuals and their families; appropriate end-of-life care or palliative care, is experienced by a small minority of individuals (Hanson, Danis, & Garrett, 1997; Lynn, et al., 1997; SUPPORT Principal Investigators, 1995). A vast amount of lengthy and fragmented information exists on the management of pain in the terminally ill, yet a number of individuals die in pain that could have been more adequately managed. Health care providers often lack education, skills, and experience in managing pain in the terminally ill (Dickey, 1996; Rhymes, 1996; Sachs, et al., 1995). The product of this project is a thorough yet concise set of palliative care practice guidelines for pain. Its development was guided by the Theory for the Peaceful End of Life (Ruland & Moore, 1998). Practice, research, and education implications are discussed.

Copyright by  
SUSAN GAYLE WIERS  
1999

This scholarly project is dedicated to the memory of my father, Allen F. Beaudry, who died from cancer on February 5, 1999. He is in a peaceful place where there is no pain.

## ACKNOWLEDGEMENTS

I would like to express my gratitude to the members of my scholarly project committee, Dr. Joan Wood, chairperson, Dr. George Allen, and Dr. Celia Wills. I have the utmost respect for each of you and consider myself very fortunate to have had the opportunity to learn from you. Your input has resulted in a product that I am very proud of.

The support and time that I received from Dr. Wood was above and beyond what I could have expected. I have learned more from her than she will ever know. I am thankful for her support through the development of this project and through the most difficult moment in my life, when I learned of the death of my father.

As a committee member and an instructor, Dr. Allen demonstrated a dedication to teaching and exemplified professionalism. From him, I have learned the importance of attention to detail. Finally, his ability to integrate humor with instruction truly made graduate school more pleasant.

The kind and diplomatic manner of Dr. Wills cultivated a non-threatening learning environment. Her insight and perspective will benefit me in my future literary endeavors.



## TABLE OF CONTENTS

List of Tables . . . . .	.viii
List of Figures . . . . .	ix
Key to Abbreviations . . . . .	x
Chapter 1: Introduction . . . . .	.1
Statement of problem . . . . .	.1
Purpose of project . . . . .	.3
Chapter 2: Definitions: Conceptual and operational . . . . .	5
Palliative care . . . . .	5
Guidelines . . . . .	.7
Pain . . . . .	.8
Management . . . . .	.9
Nurse Practitioner . . . . .	10
Chapter 3: Theoretical Framework . . . . .	.12
Chapter 4: Review of the literature . . . . .	19
Importance and Incidence of Pain	
In the Terminally Ill . . . . .	.19
Treatment of Pain in Palliative Care . . . . .	24
Current Resources . . . . .	24
Current Recommendations in	
Pain Management . . . . .	.28
Knowledge and Practice of	
Pain Management . . . . .	39
Chapter 5: Development . . . . .	.45
Format . . . . .	46
Introduction . . . . .	47
Definition, Etiology, and Presentation . . . . .	49
Evaluation and Diagnosis . . . . .	50
Management . . . . .	52
Expected Outcome and Follow-up . . . . .	55
Referral . . . . .	56
Resources . . . . .	56
Chapter 6: Implications . . . . .	57
Clinical practice . . . . .	.57
Education . . . . .	.65
Research . . . . .	68

Conclusion . . . . .	71
Appendix: Palliative Care Clinical Practice	
Palliative Care Pain Management Guidelines for	
Nurse Practitioners . . . . .	73
References . . . . .	74

## LIST OF TABLES

Table 1: Recommended Opioid Analgesic Starting Doses for Severe Pain in Patients who are not Opioid Naïve . . . . .	34
---	----

Table 2: Equianalgesic Doses of Opioid Agonist Narcotics . . . . .	37
---	----

## LIST OF FIGURES

Figure 1: Relationships Among the Concepts of the Theory of the Peaceful End of Life . . . . .	13
Figure 2: Revised Descriptive Model for the Relationship Among PCNP, Interventions, Intervention Goals, and the Peaceful End-of-Life . . . . .	17
Figure 3: The WHO Three-Step Analgesic Ladder . . . . .	32



## KEY TO ABBREVIATIONS

AHCPR	Agency for Health Care Policy and Reform
APS	American Pain Society
ANA	American Nurses Association
BID	twice daily
CHF	Congestive Heart Failure
d	day/daily
HCP	health care provider
HELP	Hospitalized Elderly Longitudinal Project
IASP	International Association for the Study of Pain
JAMA	Journal of the American Medical Association
MS	morphine sulfate
NMFS	National Mortality Followback Survey
NP	nurse practitioner
NSAID	non-steroidal anti-inflammatory drug
PCP	primary care provider
PCPMG	palliative care pain management guidelines
po	orally or by mouth
prn	as needed
q	every
QD	daily
SR	Sustained release
TCA	tricyclic antidepressants
ucg	micrograms
WHO	World Health Organization

## CHAPTER 1

### Introduction

Quality end-of-life care has become a central issue in health care as a result of advances in health care over the past half-century. The resulting increase in life expectancy has contributed to greater numbers of older individuals dying of chronic and progressive disorders (Brock & Foley, 1998). Thus, end-of-life care has become more complex and challenging resulting in the development of the specialized area of health care known as palliative care (Rudberg, Teno, & Lynn, 1997).

Miller (1992) states that the greatest needs and fears of the terminally ill include fears of uncontrolled pain, loneliness and abandonment, and loss of control. Appropriate end-of-life care, including pain relief, is not universal in the United States (U.S. Department of Health and Human Services, 1994a). Thus, many individuals receive inappropriate treatment before death in a manner inconsistent with their wishes and die in pain (Hanson, Danis, & Garrett, 1997; SUPPORT Principal Investigators, 1995).

### Problem Statement

Conservative estimates indicate that globally four million people suffer from cancer pain alone, despite the

existence of well-developed pain management technology (World Health Organization, 1990). Palliative care issues including pain and symptom management are not adequately addressed in either medical or nursing programs (Wanzer, et al., 1989; National Council of Hospice Professionals, 1997). According to the U.S. Department of Health and Human Services, (1994a), the failure of health care providers (HCP) to assess pain is a major factor in the undertreatment of pain. Nursing research suggests that nurses do an inadequate job of assessing pain and have inadequate knowledge about opioid pain medications (Dalton, 1989; Ferrell, Eberts, McCaffery, & Grant, 1991, McCaffery, Ferrell, O'Neil-Page, & Lester, 1990; Ryan, Vortherms, & Ward, 1994).

A review of the literature reveals numerous resources on chronic pain management including national guidelines (U.S. Department of Health and Human Services, 1994a, 1994b) and expert national and international recommendations (American Pain Society, 1993; Cherny & Portenoy, 1995; Doyle, Hanks, & MacDonald, 1998; Payne, 1989a, 1989b; World Health Organization, 1990). The majority of currently available palliative care pain management literature was developed for reference, not specifically for use as user-friendly practice guidelines.

The guidelines that do exist are restricted to cancer pain management, are not specific to palliative care, and fail to provide clear and detailed guidance on subjects such medication dosing (U.S. Department of Health and Human Services, 1994a, 1994b). Commonly used patient care guidelines for nurse practitioners (NPs) (Fenstermacher & Hudson, 1997; Hoole, et al., 1995; Uphold & Graham, 1998) do not include palliative care pain management guidelines despite the fact that NPs may assume responsibility for its management. NPs needs adequate guidelines that they can use to reduce the incidence of pain in terminally ill patients.

#### Purpose of Project

As primary care providers (PCP), NPs assume longitudinal responsibility for patients and are accountable for the care of terminally ill patients. Additionally, these practitioners possess advanced assessment skills, interpersonal skills, and case management skills, and thus great potential to promote comfort in the terminally ill population (Solheim, Snyder, & Mirr, 1995; Daly Seuntjens, 1995). However, there are few guidelines related to palliative care pain management to aid them in this process. Because the presence of pain precludes psychological, social, and spiritual well being



(Breitbart, Chochinov, & Passiki, 1998; Carey, 1975; Vachon, 1998), pain management is essential.

The current available state of the art national guidelines (U.S. Department of Health and Human Services, 1994a; 1994b) and expert recommendations (American Pain Society, 1993; Cherney & Portenoy, 1995; Doyle, Hanks, & MacDonald, 1998; Payne, 1989a, 1989b; World Health Organization, 1990) are based on research, thus the literature review of this project does not address this body of knowledge. The purpose of this scholarly project is to summarize and synthesize the vast and complex body of currently accepted expert recommendations and national chronic cancer pain management guidelines into concise, yet complete and user-friendly palliative care pain management guidelines (PCPMG) for the NP in the primary care setting.

## CHAPTER 2

### Definitions: Conceptual and Operational

Several terms require defining prior to the development of the PCPMG for NPs. This section defines key terms, e.g., palliative care, pain, management, guidelines and nurse practitioner from both a conceptual and an operational view.

#### Palliative care

Palliative care is usually directed toward the terminally ill patient. Terminally ill patients are individuals whose disease is not amenable to curative treatment, with death expected whether or not treatment is continued (Conill, et al., 1997; Wanzer, et al., 1989).

The temporal parameters of terminally ill are unclear. Medicare policy stipulates a maximum six-month life expectancy in order to be eligible for hospice (the benchmark for palliative care) benefits (Boling & Lynn, 1998). Boling and Lynn state that the six-month stipulation is arbitrary and does not consistently reflect patient preference or medical appropriateness of care. The review of the literature did not reveal alternative time parameters for terminal illness.

Palliative care is described in a multitude of ways. It is defined as the comprehensive, coordinated, and

intensive management of suffering and pain in terminally or incurably ill patients (Pellegrino, 1998). Ferrell (1998) describes the goal of palliative care as achieving maximum quality of life for patients and their families while optimizing comfort and maintaining dignity. Palliative care reflects a shift in goals from cure and prolongation of life to relieving pain and maximizing quality of life (Hanson, et al., 1997). Ferrell outlines the four dimensions of quality of life as physical, psychological, social, and spiritual well being. Koesters (1996, p.328) describes palliative care as "directed toward promoting a high quality of life, the relief of suffering, and a peaceful death." Doyle, Hanks, & MacDonald (1998) refer to palliative care as the total care of body, mind and spirit.

For the purposes of this project, palliative care reflects a shift in focus from curative to comfort care and is defined as care aimed at the relief of physical, psychological, spiritual, and social symptoms with the expected outcome of a peaceful end-of-life for patients whose disease is expected to result in death with or without medical intervention. Because a time parameter may lend itself to arbitrary application independent of medical appropriateness and patient preferences, the

element of time was not included in the operational definition of palliative care.

### Guidelines

Standards of practice are strict criteria to be followed in virtually all situations with few exceptions (Eddy, 1990). Conversely, guidelines are intended to be more flexible and are applicable to most patients. Deviation from the guidelines is common; they can and should be tailored to fit individual needs (ibid.). According to Field, & Lorh (1990), clinical practice guidelines are systematically developed statements, which assist health care providers with decisions about appropriate health care for specific clinical circumstances. The American Society of Anesthesiologists Task Force on Pain Management (1996, Online) describes practice guidelines as systematically developed recommendations, supported by analysis of the literature, which are designed to assist practitioners and patients with decisions about health care. The recommendations may be utilized, modified, or rejected according to the needs and constraints of the circumstances (American Society of Anesthesiologists Task Force on Pain Management).

For the purposes of this project, guidelines refer to recommendations that are based upon an analysis of the



literature and are designed to assist NPs with pain management decisions for terminally ill patients. They should be tailored to the needs of the patient and their significant others, and modified according to the constraints of the circumstances. For example, limited financial resources may necessitate that the NP select a pharmaceutical agent not recommended as first-line therapy.

### Pain

Pain is defined as "an unpleasant sensation occurring in varying degrees of severity as a consequence of injury, disease, or emotional disorder" (Soukhanov, et al., 1992, p. 1300). According to the International Association for the Study of Pain (IASP) (1999, Online), pain is "an unpleasant sensory and emotional experience associated with actual or potential tissue damage." Pain is a subjective experience, and is thus whatever the person experiencing it feels it is (American Pain Society, 1993; IASP).

Acute pain results from injury to the body and generally disappears when bodily injury heals and is typically accompanied by objectively observable signs such as grimacing, limping, and tachycardia (American Pain Society, 1993).

Chronic pain is defined as a state in which the individual experiences and reports the presence of severe discomfort or an uncomfortable sensation (Johnson & Maas, 1997). Cherney and Portenoy (1995) identify chronic pain as pain which continues for more than three months and Johnson and Maas define chronic pain as pain which persists for six months. In contrast with acute pain, observable signs of chronic pain are typically absent (American Pain Society, 1993).

Breakthrough pain is a transitory exacerbation of severe pain over a baseline, which may occur with or without an identifiable precipitant (Cherney & Portenoy, 1995).

For the purposes of this project, pain is defined as a subjective sensory and emotional experience, and is whatever the person experiencing it feels it is. Chronic pain is defined as pain persisting for at least three months and breakthrough pain is defined as a transient exacerbation of pain over a baseline of chronic pain.

### Management

Manage is defined as "to exert control over" (Soukhanov, et al., 1992, pp. 1091) and management is defined as "the act, manner, or practice of managing" (ibid.).

For the purposes of this project, management is defined as the practice of exerting control over pain.

### Nurse Practitioner

A NP is an individual who has acquired education beyond the basic baccalaureate preparation for a registered nurse. This individual collaborates with a physician, identifies diagnoses, treats minor health deviations, and emphasizes health promotion and health maintenance (Snyder & Yen, 1995; Mirr & Snyder, 1995). According to Snyder and Yen, a NP is an advanced practice nurse. The American Nurses Association (ANA) (1996, p.4) defines a NP as:

" . . . a skilled health care provider who utilizes critical judgment in the performance of comprehensive health assessments, differential diagnosis, and the prescribing of pharmacological and non-pharmacological treatments in the direct management of acute and chronic illness and disease . . . promotes wellness and prevents illness and injury."

This organization states that education for the advanced practice nurse is at the graduate level, which provides registered nurses with additional knowledge and skills. National professional nursing organizations recognize advanced practice as a specialty field and offer the NP certification via examination (ANA, 1996).

NPs may work in a primary care setting. Primary care is defined as the provision of integrated, comprehensive, and longitudinal health care services delivered by clinicians who are accountable for managing the majority of personal health care needs, and are practicing within the context of family and community (Donaldson, Yordy, Lohr, & Vanselow, 1996). The primary care clinician "has direct contact with patients and may be a physician, nurse practitioner, or physician assistant" (Donaldson, et al., 1996).

For the purpose of this project, a NP is defined as a primary care provider (PCP) who has received a graduate degree from an accredited nursing program, and has received national certification by an advanced practice specialty professional organization.

## CHAPTER 3

### Theoretical Framework

The development of this scholarly project is guided by Ruland & Moore's (1998) Theory of the Peaceful End of Life (See Figure 1). The authors refer to this descriptive model as a mid-range prescriptive theory empirically based in clinical practice; it focuses on the linkages among interventions and outcomes and was derived from 'the standard of care for a peaceful end of life.' This standard of care was developed by nurses possessing a minimum of five years of experience with terminally ill patients and additional education regarding the care of the terminally ill. The standard of care was based on research described in the literature and on the experience of expert practitioners.

The Theory of the Peaceful End of Life is appropriate to guide the development of this scholarly project because it addresses the diverse and complex needs of the terminally ill, their families, and their caregivers. This prescriptive theory encompasses the unique nature and the breadth of palliative care while providing appropriate direction for clinical practice and research.

Ruland & Moore (1998) identify five outcome indicators that constitute the elements contributing to a peaceful

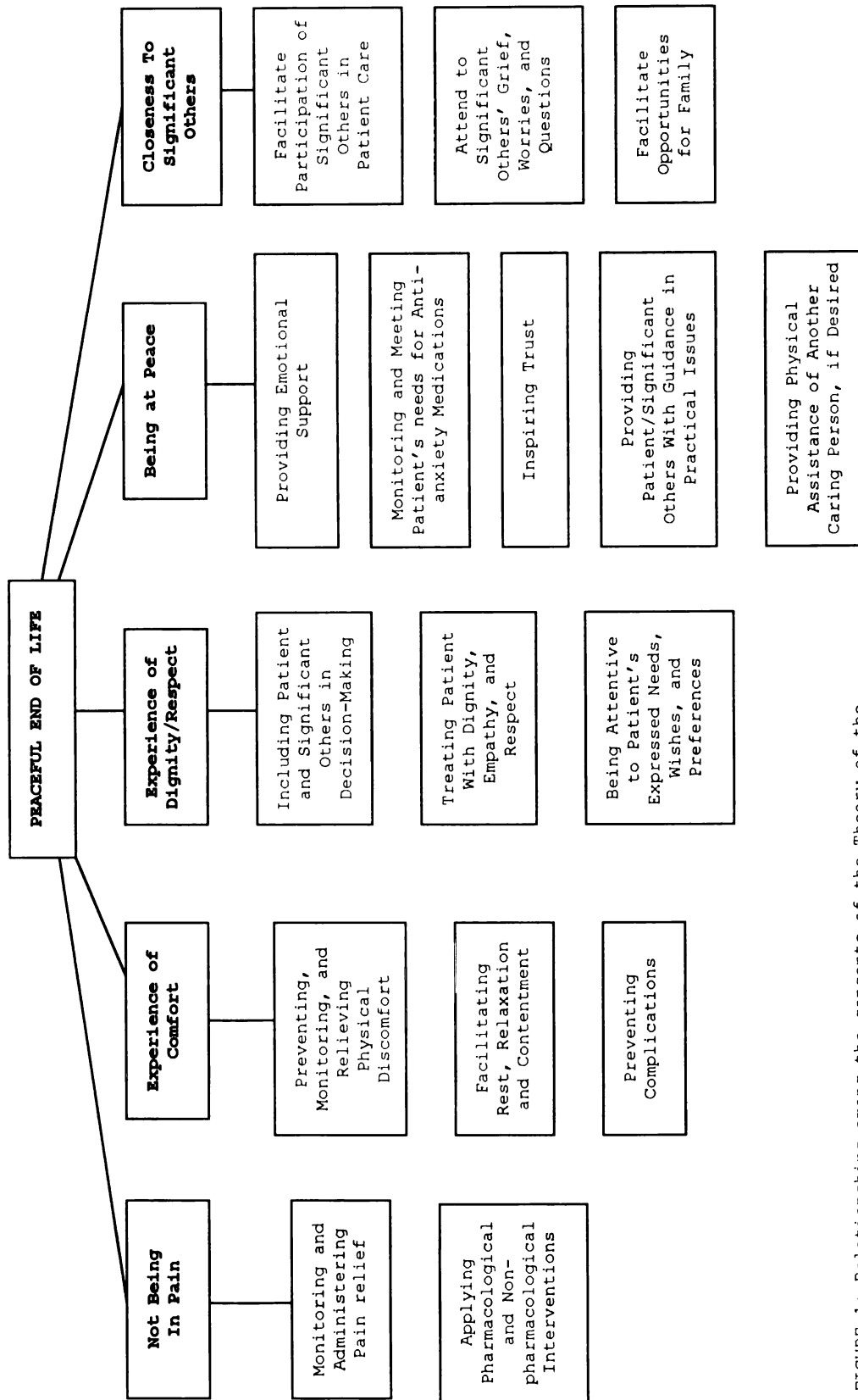


FIGURE 1: Relationships among the concepts of the Theory of the Peaceful End of Life. Adapted from Ruland & Moore (1998)

end-of-life: (a) not being in pain, (b) the experience of comfort, (c) the experience of dignity/respect, (e) being at peace, and (f) closeness to significant others. The authors assume that the dying patient's approach to death is a very personal experience, and thus the outcome indicators are subjective in nature. A description of the outcome indicators and the contributing interventions follow.

Not being in pain is defined as not having the experience of pain. The authors define pain as "an unpleasant, sensory, and emotional experience associated with actual and potential tissue damage or described in terms of such damage" (Ruland & Moore, 1998, p. 172). Ongoing assessment for pain, administration of pharmacological and non-pharmacologic pain interventions, and evaluation of the success of pain relief interventions contribute to the patient's experience of not being in pain.

The experience of comfort is defined as "relief from discomfort, the state of ease and peaceful contentment, and whatever makes life easy or pleasurable" (Ruland & Moore, 1998, p. 172). Managing symptoms, facilitating rest, relaxation and contentment, and preventing complications contribute to the patient's experience of comfort (Ruland &

Moore, 1998).

The experience of dignity/respect is defined as "being respected and valued as a human being" with the notion of worth as a major attribute of the concept (Ruland & Moore, 1998, p. 172). Including the patient and significant others in decision making regarding patient care, treating the patient with dignity, empathy, and respect, and being attentive to the patient's expressed needs, wishes, and preferences are important to the patient's experience of dignity and respect.

Being at peace "involves the feeling of calmness, harmony, and contentment" and the absence of "anxiety, restlessness, worries, and fear" (Ruland & Moore, 1998, p. 172). Providing emotional support, monitoring and meeting the patient's needs for anti-anxiety medications, providing the patient and significant others with guidance about practical issues, and providing physical presence of another caring person if desired, contributes to the patient's experience of being at peace.

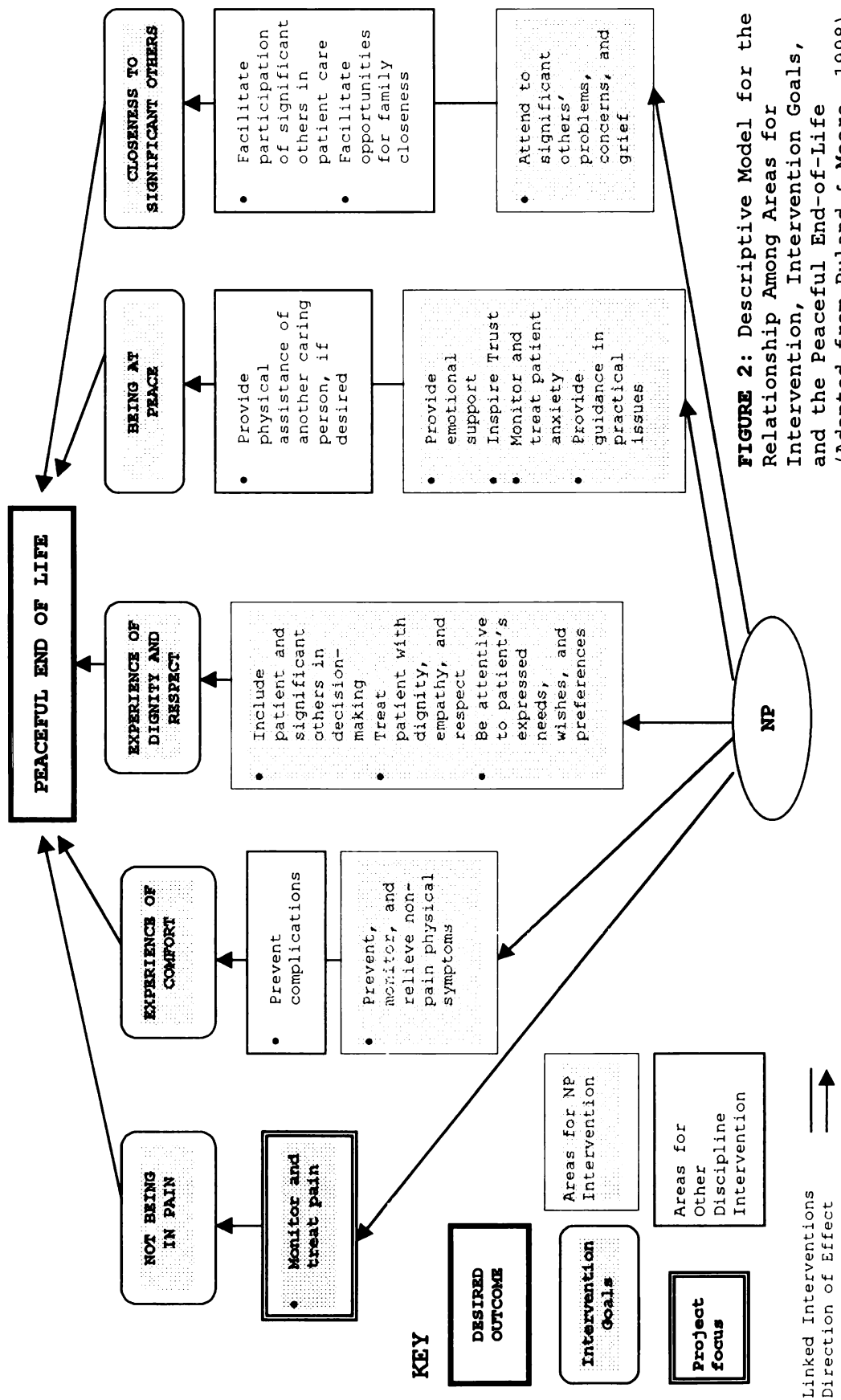
Closeness to significant others is the "feeling of connectedness to other human beings who care" (Ruland & Moore, 1998, p. 172). Encouraging participation of significant others in patient care, attending to the significant other's grief, worries, and questions, and



providing opportunities for family closeness facilitate the patient's experience of closeness to significant others.

#### Modifications to the Framework

While the Theory for the Peaceful End-of-Life (Ruland & Moore, 1998) is generally consistent with the literature review, modifications have been made to the schematic representation (Figure 2). In the interest of conservation of space, NP areas for potential intervention have been consolidated into shaded boxes with bullet points. The NP interventions in the double outlined box with bold print text, Monitor and Treat Pain, represent the focus of this project. Intervention areas viewed as being more appropriately addressed by other disciplines are represented in separate, non-shaded boxes. Preventing complications and facilitating participation of significant others are direct care activities that fall within the domain of a home care, hospice, and/or the staff nurse. In the context of significant psychopathology, facilitating opportunities for family closeness may require skilled counseling for complex unresolved issues, and may be better addressed by a mental health professional. Providing physical assistance of another caring person, e.g. a volunteer or home health aide is an area typically



**FIGURE 2:** Descriptive Model for the Relationship Among Areas for Intervention, Intervention Goals, and the Peaceful End-of-Life (Adapted from Ruland & Moore, 1998)

addressed by community resources such as a hospice or a home care agency.

The interventions under the area of 'Not Being in Pain' were reworded to be more concise. 'Monitoring and administering pain relief' and 'applying pharmacological and non-pharmacological interventions' are comparable and thus reworded as 'monitor and treat pain.' Monitoring pain relief measures is implied in treatment because evaluation is inherent in the nursing process and thus was not identified separately in the modified model.

Under the area of 'Experience of Comfort,' 'preventing, monitoring, and relieving physical discomfort was reworded as 'prevent, monitor, and treat non-pain physical symptoms' to reflect terminology commonly used in palliative care references. The intervention area of 'facilitating rest, relaxation, and contentment' was omitted because facilitating rest and relaxation can be addressed under the treatment of the physical symptoms of asthenia and insomnia.

Under the area of 'being at peace,' 'Monitoring and meeting patient's need for anti-anxiety medications' was reworded as 'Monitor and treat patient anxiety.'

## CHAPTER 4

### Review of the Literature

The review of the literature is based on the results of First Search inquiries with both the CINHALL and Medline databases. With a few exceptions, the searches were limited to dates between 1990 and 1999 to ensure that research findings are currently applicable. Pertinent literature cited in bibliographies and references of reviewed literature were also obtained and reviewed. Articles reflecting opinions from experts in the field of end-of-life issues, palliative care, and pain and current resources in pain management have been included in this literature review.

The literature review is organized under the areas of (a) importance and incidence of pain in the terminally ill and (b) treatment of pain in palliative care.

#### Importance and Incidence of Pain in the Terminally Ill

Current palliative care literature focuses primarily on cancer-related pain. The World Health Organization (WHO) (1990) indicates that at least four million people are currently suffering from cancer pain alone despite the fact that considerable evidence exists that the majority of cancer patients can have their pain reduced considerably or completely. A lack of knowledge by clinicians about

effective assessment and management of pain results in its undertreatment (U.S. Department of Health and Human Services, 1994a). Neglect of symptoms is inappropriate, incompetent practice (Brody, 1992; Curtin, 1996) and is equivalent to malpractice (Pellegrino, 1998). When health care providers fail to adequately address the patient's immediate sources of physical distress, they impair the dying patient's ability to interact with others, and contribute to patient and family isolation and suffering. Pain can also cause a perceived threat to the psychological integrity of the dying patient (Chapman & Gavrin, 1996; Cohen, et al., 1997; O'Connell, 1996; Schonwetter, 1996).

Carey (1975) attempted to analyze the factors related to emotional adjustment of terminally ill patients. Eighty-four participants (50% men) were offered counseling by eleven chaplains. The participants were expected to die within a year and were aware of the seriousness of their illnesses. Data obtained from the patients by the hospital chaplains provided the basis for this qualitative study. Ninety-two percent of the participants had cancer, all except eight percent identified a religious affiliation, 41% were over 60 years old, 68% were married, 45% had completed high school, and 33% had attended college. An important finding for health care providers was that

positive emotional adjustment to a limited life expectancy was negatively correlated with the level of discomfort. In other words, the greater the degree of physical discomfort, the less the likelihood of emotional adjustment. Although a causal relationship cannot be presumed, the apparent reciprocal relationship between physical discomfort and emotional adjustment does warrant adequately addressing pain.

The first major study in nearly 100 years describing the dying experience in the United States was a two-phase research project, funded by the Robert Wood Johnson Foundation (Lynn, et al., 1997). In November of 1995 the Journal of the American Medical Association (JAMA) published the results of this landmark study of 9,000 seriously ill patients, "A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients" (SUPPORT Principal Investigators, 1995). Qualified patients were in the advanced stages of their illness, were 18 years or older in age, and spoke English. Diagnoses were (a) acute respiratory failure, (b) multiple organ system failure with sepsis, (c) multiple organ system failure with malignancy, (d) coma, (e) chronic obstructive lung disease, (f) congestive heart failure (CHF), (g) cirrhosis, (h) metastatic colon cancer, and (i) non-small-cell lung

carcinoma. Data collection methods included concurrent and retrospective medical record review and interviews with patients, patient surrogates, and the patients' physicians. The researchers found that 50% or more of the patients experienced moderate to severe pain at least half the time in the last three days of their lives. The treatment of patients did not improve even when nurses provided physicians with up-to-date information regarding patient pain level. The results of this major study indicate that physicians are resistant to changing their practice patterns and are perhaps unwilling to consider opinions or assessments from nurses.

The Hospitalized Elderly Longitudinal Project (HELP) was conducted in conjunction with the SUPPORT study (Lynn et al., 1997). The HELP study examined the experience of a random sample of 1176 patients 80 years of age and older who were hospitalized during 1994. Thirty-four percent of the HELP participants died within one year of the initial hospitalization. The advantage of the HELP findings is that not all of the participants died in an acute care setting, and the results may be more applicable to patients who die at home. However, the findings were not reported according to place of death, thus limiting conclusions about the nature of home deaths vs. hospital deaths. For

the patients who were conscious during the last three days of life and able to communicate with family members, 40% described their pain as severe.

Brock & Foley (1998) discuss their findings from a retrospective study, the 1986 National Mortality Followback Survey (NMFS). The NMFS results are based on the responses from the next of kin or close relatives of 16,598 deceased individuals, and the study was designed to examine the circumstances of death in terms of location of death, transitions among health care settings, circumstances at the time of death, and changes in physical and cognitive function during the last year of life. The NMFS researchers found pain to be present in at least 32.8% of terminally ill patients.

Hanson, Danis, & Garrett (1997) studied family members' and significant others' perceptions of care at the end of life. They identified a representative sample of older people who died from chronic disease by reviewing the death certificates of 12 counties over a three-month period of time. Decedents were considered eligible if they were aged 65 or older at the time of death and had died of chronic lung disease, cancer, hepatic cirrhosis, CHF or stroke. Informants who were listed on the death certificate were considered eligible for participation in



the study if they were a family member or a friend or companion with a prolonged intimate relationship with the deceased. In total, 461 contacts of 700 eligible deceased individuals were interviewed. The respondents believed that 78% of decedents experienced pain during the final month of life.

In summary, currently available research findings primarily focus on the experience of the terminally ill in acute care settings and primarily provide information from the perspective of a patient surrogate. It appears that an inverse relationship also exists between the level of pain and emotional well being. The research clearly demonstrates that many terminally ill patients experience significant pain at the end of life.

### Treatment of Pain in Palliative Care

#### Current Resources

The literature review revealed several key resources on pain management. These resources resulted from a thorough review of research and inclusion of expert opinion. The authors of these references are nationally and internationally respected experts and researchers in the fields of pain management and palliative care.

The Oxford Textbook of Palliative Medicine (Doyle, Hanks, & MacDonald, 1998) is a frequently cited major

reference in the field of palliative care. This 1283-page-22-chapter book is authored by internationally recognized expert clinicians and researchers. Chapter 9 contains 10 sub-chapters and is 180 pages in length and includes an in-depth discussion of pain and its management.

WHO (1990) published Cancer Pain Relief and Palliative Care as a part of a technical report series. This report contains the collective views of an international group of experts, reflects the latest scientific and technical advice on pain and palliative care, and is an internationally recognized document (WHO). The widely adopted WHO three-step analgesic ladder is depicted in this report. This technical report provides a global overview of policies pertinent to cancer pain relief and palliative care. Additionally, the report discusses (a) the nature of and need for palliative care and pain management, (b) the barriers to palliative care implementation, and (c) international morphine distribution and barriers to its use. However, this report did not include (nor was its intent) clinical guidelines for pain management in palliative care.

The Agency for Health Care Policy and Research (AHCPR) was established to enhance the quality, appropriateness, and effectiveness of health care services in the United

States (U.S. Department of Health and Human Services, 1994a). The AHCPR Clinical Practice Guidelines for the Management of Cancer Pain (U.S. Department of Health and Human Services) reflect the current state of knowledge on cancer pain management. These guidelines were developed by a multidisciplinary panel of clinicians and experts and are based on an extensive literature review, peer and field review, and expert recommendations (U.S. Department of Health and Human Services). The Clinical Practice Guidelines for the Management of Cancer Pain (U.S. Department of Health and Human Services) is a 257-page text that includes narrative summarizes, tables, and figures. The accompanying 29-page quick reference guide for clinicians (U.S. Department of Health and Human Services, 1994b) provides general guidelines for pain assessment, but not the specific components of an assessment. For example, while the initial assessment recommendations include a (a) detailed history, (b) physical examination, (c) psychosocial assessment, and (d) diagnostic evaluation, the specific components of these areas are not provided. Also equianalgesic doses of opioids are provided. However, recommended starting doses are not suggested and limited information on switching opioid agonists is provided. Likewise, general information about adjuvant drugs is

presented, but guidelines for dosing are not provided.

Both documents are excellent resources, but only focus on cancer pain.

The American Pain Society (APS) (1993), a national chapter of the IASP, is a not-for-profit educational and scientific organization. Multidisciplinary membership in the APS includes both clinicians and researchers in the field of pain and its treatment (APS). Principles of Analgesic Use in the Treatment of Acute Pain and Cancer Pain (APS) is a 41-page booklet developed by the APS to promote advancing education about pain and its treatment. This publication covers cancer and acute pain, but does not provide information about the treatment of noncancer chronic pain. Because this book is not intended for palliative care use only, information on intramuscular administration is provided which is inconsistent with AHCPH guidelines. This booklet provides limited information for selecting an initial dose of an opioid agonist.

The American Cancer Society publication, The Management of Cancer Pain (Cherny & Portenoy, 1995) is a booklet that is primarily consists of narrative text and tables. This publication thoroughly addresses pain prevalence, etiology, presentation, and its treatment. However, this 47-page booklet is not designed specifically as a quick reference.

Cancer Pain (Abram, 1989) while not considered a major resource, is authored by respected experts in the field of palliative care. The author of the first two chapters, Dr. Richard Payne, was the recipient of a Robert Wood Johnson Foundation award and a National Cancer Institute grant. These chapters (Payne, 1989a, 1989b) contain helpful information on mechanisms and etiology of cancer pain and specific details on the pharmacological management of cancer pain.

In general, there are several excellent current sources on cancer pain management. A few resources address cancer pain management in palliative care. However, none address non-cancer pain management in palliative care. Further, the only true set of practice guidelines are limited to cancer pain and the reference intended for "quick reference" fails to provide sufficient information on subjects such as the detailed components of assessment and the dosing of opioids and adjuvants. Thus, complete, yet concise guidelines focusing on cancer and non-cancer pain management in palliative care is needed.

#### Current Recommendations in Pain Management

Definition and presentation of pain. Uncontrolled pain precludes a satisfactory quality of life and interferes with activities of daily living and psychological, social,

and spiritual well being (Foley, 1998). Pain is a subjective experience and the practitioner is obligated to accept the patient's report of pain; pain is whatever the person experiencing it feels it is (APS, 1992). In palliative care, the pain encountered is usually either chronic or breakthrough in nature. While one source (Johnson & Maas, 1997) described chronic pain as persistent and continuing for more than six months, other experts accept pain persisting for more than three months as being chronic (Cherny & Portenoy, 1995; ISAP, 1979). Breakthrough pain is a transitory exacerbation of pain, which occurs over a baseline of chronic pain (Cherny & Portenoy).

Etiology of pain. Etiologically, pain is categorized as either (a) somatic/nocioceptive which results from direct tissue injury, (b) visceral which results from infiltration, compression, or stretching of viscera, or (c) neuropathic which results from injury to peripheral and/or central neural structures (Cherny & Portenoy, 1995; Payne, 1989a). Treatment options vary based on the type of pain the patient is experiencing.

Evaluation/diagnosis of pain. Evaluation of pain includes a detailed history of the pain including a rating of the pain by the patient (Baumann, 1997; Foley, 1998;

U.S. Department of Health and Human Services, 1994a). The severity of pain is usually measured by asking the patient to rate their pain on a scale of zero (no pain) to ten (the worst pain possible) (APS, 1992; U.S. Department of Health and Human Services). Children under seven years and cognitively disabled adults can be asked to rate their pain on a series of several faces ranging from smiling to crying (APS). Behavioral observation is necessary for babies, very young children, and adults who are unable to communicate (APS). Chronic pain is rarely accompanied by signs of sympathetic nervous system arousal; thus, a lack of objective signs does not preclude the possibility that the patient is experiencing pain (APS). The patient should be evaluated for reversible causes of pain such as fecal impaction and urinary tract infection. The sites of pain and pain radiation should be evaluated and a neurological examination should be performed (U.S. Department of Health and Human Services, 1994a).

Pain assessment also includes a psychosocial assessment including the meaning of pain to the patient and the family, previous experiences, coping mechanisms, concerns of the patient and family, and changes in mood such as anxiety and depression (U.S. Department of Health and Human Services, 1994a). Diagnostic procedures should only be

pursued if the benefits in terms of improved ability to manage symptoms clearly outweigh the inconvenience and discomfort to the terminally ill patient (Breitbart & Jacobsen, 1996; Foley, 1998).

Management. The AHCPR Clinical Practice Guidelines for Chronic Cancer Pain Management (U.S. Department of Health and Human Services, 1994a) include recommendations for the (a) individualization of the treatment to the patient's needs, (b) use of the simplest dosing schedules and the least invasive modalities first, (c) adoption of the WHO Ladder (Figure 3) for titration of therapy, and (d) administration of around-the-clock medications for persistent cancer-related pain with additional as need (prn) doses available for breakthrough pain.

The AHCPR (U.S. Department of Health and Human Services, 1994) recognizes that: (a) Regularly scheduled dosing maintains a constant level of drug in the body and prevents the recurrence of pain, (b) Mixed agonist-antagonist narcotics should not be given to the patient receiving pure or partial agonists to avoid a withdrawal syndrome, (c) Meperidine should not be used for long-term opioid treatment, and (d) Opioid tolerance and physical dependence are expected with long-term opioid use and should not be confused with addiction.



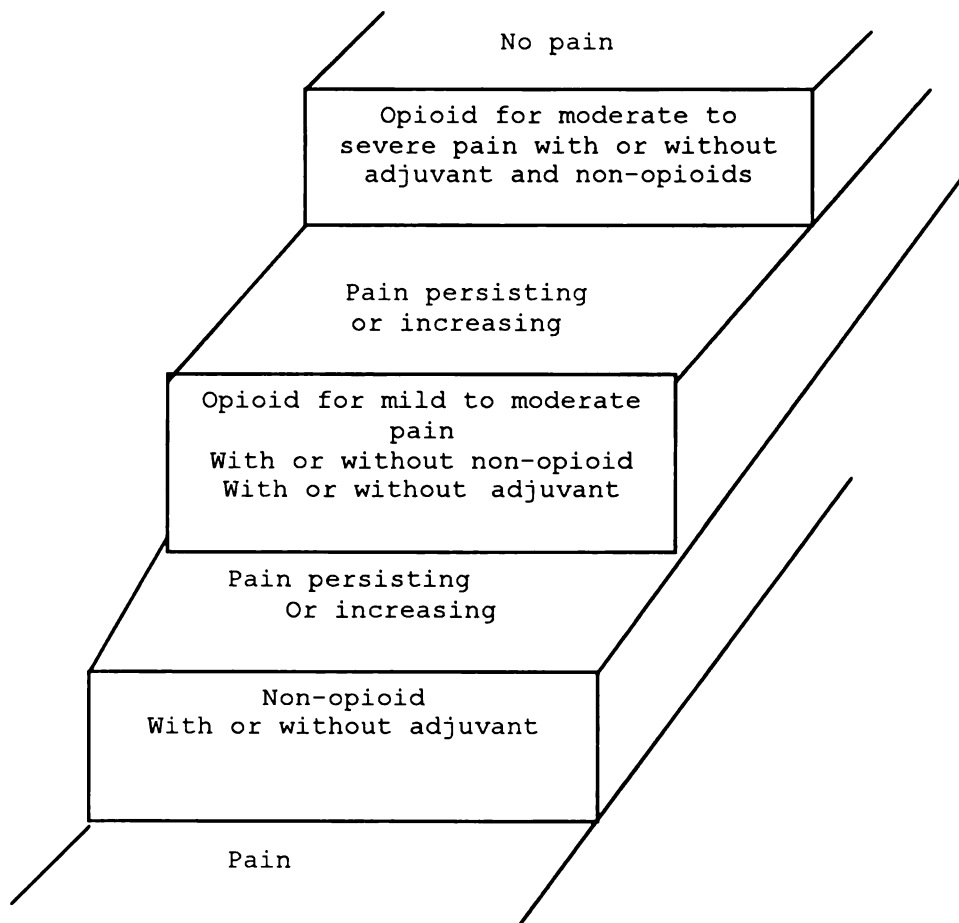


Figure 3: The WHO Three-Step Analgesic Ladder (adapted from WHO, 1990)

Regarding route of administration, the AHCPR (a) designates that the oral (po) route of administration is preferred because it is the most convenient and cost-effective, (b) suggests that the rectal and transdermal routes should be considered only if oral administration is not possible, (c) recommends that intramuscular injections should be avoided because they are painful, and (d) admonishes that intraspinal analgesic systems should only be considered after failure of maximal systemic doses of

opioids and co-analgesics (U.S. Department of Health and Human Services, 1994a).

The AHCPR also recommends monitoring for potential side effects and (a) suggests that great inter-individual variation exists in side effect susceptibility, (b) recognize that constipation is common with opioid use and should be anticipated, treated prophylactically, and monitored closely, (c) recommends that when indicated, Naloxone should be administered for reversal of respiratory depression, but not reversal of analgesia. Finally, the AHCPR guidelines (a) indicate that placebos should not be used, (b) recommend that patients be provided with a written pain management plan and (c) suggest that communication about pain management should occur between settings (U.S. Department of Health and Human Services, 1994a).

Non-steroidal anti-inflammatory drugs (NSAIDs) are first-line agents for management of mild to moderate pain and have a ceiling effect and are also useful in the treatment of metastatic bone pain (Portenoy, 1998; WHO, 1990). A patient in severe pain should be started on a full opioid agonist (Table 1) (Hanks & Cherny, 1998). Morphine sulfate (MS) is the prototypic agonist narcotic analgesic, has no ceiling effect, and is typically

Opioid Analgesic** Recommended Starting Doses for Severe Pain in Patients who are not Opioid Naive		
DRUG	ADULT STARTING DOSE	
	ORAL (mg)	PARENTERAL (mg)
MS	15-30 q3-4 hr	10 q3-4 hr
MS, sustained release	90-120 q12 hr	NA
Hydromorphone (Dilaudid)	4-8 q3-4 hr	1.5 q3-4 hr
Methadone (Dolophine)	20 q6-8 hr	10 q6-8 hr
Levorphanol (Levo-Dromoman)	2-4 q6-8 hr	2 q6-8 hr
Fentanyl (Duragesic)*** Transdermal		25ucg/hr q72 hr transdermally
Combination Opioid**/Non-opioid Preparations for Mild to Moderate Pain		
Codeine (w/ASA or acetaminophen)	60 q3-4 hr	NA
Oxycodone (Roxicodone, also in Percocet, Percodan, Tylox, others)	30 q3-4 hr	NA
Hydrocodone (in Lorcet, Lortab, Vicodin, others)	30 q3-4 hr	NA

\*Adapted from AHCPR Clinical Practice Guidelines: Management of Cancer Pain (U.S. Department of Health and Human Services, 1994a) and Principles of Analgesic Use in the Treatment of Acute Pain and Cancer Pain (American Pain Society, 1992)

\*\*In the elderly, duration of action of morphine-type drugs is typically prolonged, careful titration is critical (Payne, 1988b)

\*\*\*Transdermal fentanyl (Duragesic) may be started in doses not greater than 25ucg/72 hr in the opioid naïve patient (U.S. Department of Health and Human Services, 1994a). A 60mg po dose of MS q 4 hr over 24 hours (total 360mg po daily dose) is approximately equivalent to 100 ucg Fentanyl transdermally q 72 hr (Kastrup, et al., 1999) or 30mg MS q8 hr is equivalent to 25 ucg Fentanyl q72 hr (American Pain Society, 1992) and a short-acting analgesic should be used for the first 24 hours of fentanyl application until analgesic efficacy with the transdermal system is attained (Kastrup, et al., 1999)

Table 1: Recommended Opioid Analgesic Starting Doses for Severe Pain in Patients who are not Opioid Naive

considered the first-line agent when treating moderate to severe pain (DiPiro, 1998). Initial opioid dosing varies based on whether the patient is opioid naïve (no current or recent routine use of opioids) or not. An optimal analgesic dose varies between individuals, and the dosage should be titrated to the individual's pain (Cherny & Portenoy, 1995; U.S. Department of Health and Human Services, 1994a). The 24-hour (hr) dose requirement is established through titration to pain and then around-the-clock administration is implemented with a sustained release (SR) product (Payne, 1989b). Analgesic therapy is typically not initiated with SR preparations because it is difficult to titrate with these products (Payne, 1989b). Full opioid agonists have no ceiling or maximal recommended dose with the exception of fentanyl which has a recommended maximum dose of 300 micrograms (ucg) per hr transdermally every (q) 72 hr (U.S. Department of Health and Human Services, 1994a). Patients with very severe pain can be managed by repeating parenteral dosing of an opioid narcotic every 15 to 30 minutes, until pain is partially relieved, at which time oral medication can be started (Hanks & Cherny, 1998).

All patients should be provided with a supplemental dose of an opioid given on a prn basis to treat

breakthrough pain (Cherny & Hanks, 1998). An immediate release, fast acting opioid is used for rescue dosing and is typically the same drug administered on a continuous basis with the exception of fentanyl and methadone (op cit). The rescue dose for breakthrough pain should be one-sixth of the 24-hr maintenance dose and may be repeated hourly (op cit). When switching a patient from one opioid to another use an equianalgesic dose (Table 2) (Hanks & Cherny, 1995; op cit). For patients with good pain control, the starting dose of the new opioid should be reduced to 50-75% of the equianalgesic dose due to the possibility of incomplete cross-tolerance (Cherny & Portenoy; Hanks & Cherny). For patients with poor pain control and moderate, unacceptable side effects, the starting dose of the new drug should be between 75-100% of the equianalgesic dose (Cherny & Portenoy; Hanks & Cherny). Experts recommend a conservative approach when switching to methadone, using 66-75% of the equianalgesic dose (Cherny & Portenoy; Hanks & Cherny).

Adjuvant analgesics in pain management include the use of tricyclic antidepressants (TCAs) for the treatment of neuropathic pain in a patient who has inadequate response to opioids and corticosteroids for treatment of metastatic bone pain, neuropathic pain, and painful edema (Portenoy,

Equianalgesic Doses of Opioid Agonist Narcotics				
DRUG	Dose (mg) equianalgesic to 10 mg IM MS		HALF-LIFE (hours)	DURATION OF ACTION (hours)
	PARENTERAL	ORAL		
Combination Opioid\Non-opioid** Drugs Commonly Used to Treat Moderate Pain				
Codeine (w/ASA or acetaminophen)	130 q3-4 hr	180-200 q3-4 hr	2-3	2-4
Oxycodone (Roxicodone), also in Percocet, Percodan, Tylox, others)	NA	30 q3-4 hr	2-3	2-4
Hydrocodone (in Lorcet, Lortab, Vicodin, others)	NA	30 q3-4 hr		
Propoxyphene	-	50	2-3	2-4
Opioid Agonist Drugs Commonly Used to Treat Severe Pain				
MS	10 q3-4 hr	30 q3-4 hr	2-3	3-4
MS Controlled release (MS Contin, Oramorph)	NA	90-120 q12 hr		8-12h
Hydromorphone (Dilaudid)	1.5 q3-4 hr	7.5 q3-4 hr	2-3	2-4
Methadone (Dolophine)	10 q6-8 hr	20 q6-8 hr	15-190	4-8
Oxymorphone	1 q3-4 hr	10 (rectal) q3-4 hr	2-3	3-4
Levorphanol (Levo-Dromoran)	2 q6-8 hr	4 q6-8 hr	12-15	4-8
Fentanyl transdermal (Duragesic)***	25ucg/hr q72 hr	*		48-72

Adapted from AHCPR Clinical Practice Guideline Number 9: Management of Cancer Pain (U.S. Department of Health and Human Services, 1994-a) and Cherney & Portenoy (1995)

\*\* Do not exceed maximum daily doses for non-opioid analgesics

\*\*\* Transdermal fentanyl (Duragesic) may be started in doses not greater than 25-ucg/hr q 72 hr in the opioid naïve patient (U.S. Department of Health and Human Services, 1994-a). A 60mg po dose of MS q 4 hr over 24 hours (total 360mg po daily dose) is approximately equivalent to 100-ucg Fentanyl transdermally q 72 hr (Kastrup, et al., 1999). Or 30 mg MS q 8 hr is equivalent to 25ucg/hr Fentanyl patch q72 hr (American Pain Society, 1992)

Table 2: Equianalgesic Doses of Opioid Agonist Narcotics

1998). Amitriptyline and desipramine are TCAs used in the treatment of neuropathic pain (ibid.). Starting doses of TCAs should be 10 mg per day in the elderly and 25 mg/d in younger adult patients (ibid.). Titration to pain is accomplished by doubling the dose every few days (ibid.). The effective dose range for amitriptyline or desipramine for neuropathic pain is 50-150 mg daily and analgesia onset is typically within one week (ibid.).

Dexamethasone one to two mg daily (QD) to twice daily (BID) has been used with patients with advanced medical illness who continue to have pain due to metastatic bone pain, neuropathic pain, and painful lymphoedema despite optimal dosing of opioid drugs (Portenoy, 1998). The lowest dose that yields therapeutic effects should be used and ineffective regimens should be tapered and discontinued (ibid.). Other symptoms such as nausea or malaise may also be improved with corticosteroids (ibid.).

Non-pharmacological management of pain includes psychosocial interventions and physical modalities. Psychosocial interventions include (a) relaxation and imagery, (b) cognitive distraction and re-framing, (c) patient education, and (d) psychotherapy structured support. Physical modalities include (a) cutaneous stimulation, (b) application of heat and cold, (c)

exercise, (d) repositioning and proper body alignment, (e) immobilization, and (f) counterstimulation (U.S. Department of Health and Human Services, 1994a).

According to the U.S. Department of Health and Human Services (1994a) patient/caregiver teaching should include: (a) Pain is highly individual and variable, (b) Pain can be controlled to a tolerable level, (c) Pain should always be reported, (d) Chronic cancer pain treatment is an appropriate medicinal use of opioid narcotics, (e) Side effects of somnolence and nausea are often transient while tolerance to constipation does occur, (f) Addiction risk is almost nonexistent in the treatment of pain related to cancer, (g) Physiological causes of chronic pain should be described, and (h) Psychosocial and spiritual factors that may contribute to pain should be discussed.

Expected Outcome and Follow-up. Complete resolution of any symptom is the ideal goal; however, it is unwise to expect and promise total relief (Mannix, 1998). Aggressive treatment should minimally pursue the goal of a reduction of pain into a less relevant level in the patient's priority system (Neuenschwander & Bruera, 1998). The U.S. Department of Health and Human Services, 1994a) recommends that follow-up includes pain re-assessment and that patients and families should be educated to report changes



in pain and the emergence of new pain.

### Knowledge and Practice of Pain Management

Despite the existence of well-developed pain management guidelines and technology, pain is not adequately addressed in the terminally ill as evidenced by the findings of the SUPPORT and HELP studies (APS, 1993; Lynn, et al., 1997; SUPPORT Principal Investigators, 1995). Therefore, it is important to examine the gap that exists between available pain management techniques and their application.

In 1986, WHO designated Wisconsin as a demonstration state in the worldwide effort to alleviate the suffering of cancer patients (Diekmann, Engber, & Wassem, 1989). An informal steering committee of the Wisconsin Cancer Pain Initiative found that the problem of inadequate pain control is not due to a lack of effective analgesics, but to the misdiagnosis and mismanagement of pain. WHO recommended that continuing education programs in pain management need to be improved, and should address the need to change attitudes and behaviors of HCPs (Diekmann, et al.). The steering committee concluded that HCPs: (a) lack knowledge about the pathophysiology of cancer pain as well as the clinical pharmacology of analgesics, (b) lack knowledge of the difference between physical dependency and addiction, (c) have excessive concerns about patient

addiction to narcotics and the side effects of narcotic analgesics, (d) believe that patients are not good judges of the severity of their pain, (e) assign a low priority to pain management, and (f) have insufficient formal education in pain management (op cit).

Research studies that examined NPs' knowledge or practices regarding pain management and palliative care were not found. Nor were there studies that examined graduate level nursing education on pain management or graduate level palliative care curriculum content. Thus, it is necessary to draw conclusions from the findings of the studies on nurses, and nursing curriculum to the NP and to graduate level nursing education.

As discussed earlier, pain is a subjective experience. Sufferers of chronic pain rarely experience sympathetic nervous system arousal; thus objective signs such as grimacing and tachycardia are often absent (APS, 1993). The failure of HCPs to assess pain is a major factor in the undertreatment of pain (U.S. Department of Health and Human Services, 1994a). The mainstay of pain assessment of the patient is self-report (APS). However, studies indicate that nurses are often influenced by factors other than the patient's self-report of pain and often do not believe the patient's self-report of pain (Dalton, 1989; Ferrell,

Eberts, McCaffery, & Grant, 1991; Ryan, et al., 1994). As a result, it is likely that pain is underdiagnosed and thus undertreated.

According to Buchan & Tolle (1995, p. 57), "the undertreatment of pain and suffering of the terminally ill is not an acceptable standard of care anywhere in the United States, yet there is significant fear about providing appropriate doses of opioids to dying patients." Despite a stated commitment to pain reduction, nurses often fail to work towards alleviation of pain and have inadequate knowledge about opioid narcotics and pain management (Ferrell, Eberts, McCaffery, & Grant, 1991; McCaffery, Ferrell, O'Neil-Page, & Lester, 1990; Pederson & Parran, 1997; Ryan, Vortherms, & Ward, 1994; Vortherms, Ryan, & Ward, 1992). In general, nurses do an inadequate job assessing pain and pain coping skills, do not teach patients about non-invasive, non-pharmacological pain management strategies, and fail to assess the impact of pain on quality of life (Dalton, 1989; Ferrell, et al., 1991). Nurses have inadequate knowledge about opioids, their side effects, and the frequency of drug addiction with opioids (McCaffery, et al., 1990; Ryan, et al., 1994). In fact, one study found that accurate responses of nurses regarding narcotic vs. non-narcotic classification of major

drugs such as codeine, meperidine, and morphine ranged from 98% to as low as 23% (McCaffery, et al.). These findings indicate that nurses do not possess more knowledge about pain and its management than other HCPs do.

A few of the above cited studies included a small percentage of post-bachelors prepared nurses, but data was not presented according to educational level, so whether masters or doctoral prepared nurses possess more knowledge about pain and its management is not evident.

Research indicates that in baccalaureate schools of nursing, faculty knowledge and belief about pain and the curriculum content related to pain is inadequate (Ferrell, McGuire, & Donovan, 1993). Out of the 498 faculty these investigators surveyed, 84% were prepared at the masters level, and 16% were prepared at the doctoral level. The report of this study does not indicate what type of nursing programs these faculty teach in. However, the results do suggest that if the faculty responsible for educating NP students are not knowledgeable about pain and its management, NPs may not be well prepared in this area.

### Summary

In summary, the topic of palliative care is currently a topic of high interest for HCPs, terminally ill patients, and their significant others. Terminally ill patients need

to have their pain and other physical symptoms controlled to achieve psychological, social, and spiritual well being. However, research indicates that terminally ill patients frequently experience significant pain. Studies demonstrate that nurses have inadequate knowledge about pain and its management. Numerous publications and books address pain management for terminally ill patients. However, available resources are typically lengthy and are not designed to be use as quick-reference user-friendly guidelines for practice. Additionally, different yet complementary information contained in different resources necessitates that the NP needs to review numerous resources to complete information. Thus, a need exists for the summary and synthesis of currently available information on pain management for terminally ill patients into a comprehensive yet concise format.

## CHAPTER 5

This chapter describes the development of PCPMG for NPs. The general format and characteristics of the guidelines are discussed. The product is presented in the appendix.

Review of the literature indicates that one of the greatest fears of the terminally ill patient is pain and that pain interferes with activities of daily life and social functioning and also causes psychiatric symptoms (Chapman & Garvin, 1996). The review also indicates that a gap exists between available information regarding pain management and the implementation of pain management principles by HCPs including nurses. The review of the literature suggests that HCPs, including nurses, typically lack adequate knowledge about pain management for this population, and thus patients die in pain.

Several key resources including complex information on pain management are available. Approaches to pain management in palliative care are generally consistent between sources; however, resources differ in breadth and depth of content. The majority of the pain management literature is in the form of in-depth resources and is not intended as guidelines for practice. Although a quick reference guide for clinicians on management of cancer pain

exists (U.S. Department of Health and Human Services, 1994b), it solely addresses cancer pain, is not specifically intended for palliative care, and lacks detailed information regarding dosing. A thorough yet concise set of palliative care clinical practice guidelines for pain management for the NP is not available. Thus, the development of concise and user-friendly PCPMG to guide NPs with pain management in the terminally ill is warranted.

The challenge was to summarize vast and complex information from numerous resources into a single accessible source that provides current, clinical information for use by the NP in an ambulatory care setting. The PCPMG for NPs are based on expert recommendations found in the literature.

#### Format

The format chosen for the PCPMG includes an introduction and essential elements found in commonly used clinical practices guidelines (Hoole, Pickard, Ouimette, Lohr, & Greenberg, 1995; Uphold & Graham, 1998). The essential elements included are (a) a definition, (c) the etiology, (d) clinical presentation, (e) components of diagnosis including history, examination, and differential diagnosis, (f) management, (e) expected outcome, (f) follow-up, and (g) referral. The definition, etiology, and

clinical presentation are grouped together under an area labeled as 'overview of pain.' The components of the diagnosis were included within an area labeled 'evaluation of pain.' Pain management is described under an area labeled as 'management of pain.' The elements of expected outcome, follow-up, and referral are each discussed in an area labeled as such. Each area is color coded to facilitate recognition. The bright colors chosen delineating the introduction are intended to draw interest. The colors chosen for the guidelines begin with darker colors to symbolize the negative impact of pain and become increasingly brighter to symbolize the positive effect of adequate pain management.

An attempt to present the essential content in the traditional outline format reflected in the commonly used clinical practice guidelines resulted in a complicated and difficult to follow product. Thus, that format was modified to include narrative summaries, bullet points, boxes, and tables for easier reading and use.

### Introduction

A brief introduction provides some basic information for the NP. It includes a definition of palliative care, the responsibility of the PCNP to terminally ill patients, and underlying assumptions. The underlying assumptions are



based on the opinions of experts in the field of palliative care and are included to provide general guiding principles of practice unique to palliative care.

The first stated underlying assumption is that diagnostic considerations should be directed at maintaining the comfort of the patient, not on diagnostic or treatment procedures that are painful or invasive (Breitbart & Jacobsen, 1996; Foley, 1998). This assumption was included to provide the PCNP with a perspective unique to palliative care regarding the judicious use of invasive procedures.

The second assumption is that while a differential diagnosis should always be formulated for the terminally ill patient, diagnostic studies should only be pursued when a suspected etiology can be easily identified and treated (Breitbart & Jacobsen, 1996; Foley, 1998). Thus, the second assumption is an extension of the first assumption, and is designed to provide the PCNP with guidance regarding when diagnostic procedures are warranted in palliative care.

The third assumption provides the NP with information regarding expected outcomes for interventions. While the ideal goal of palliative care is resolution of the symptom (Mannix, 1998), it is more realistic to pursue the goal of a reduction of the symptom to a less relevant level in the

patient's priority symptom profile (Neuenschwander & Bruera, 1998). The outcome criteria of the Standard of Peaceful End of Life (Ruland & Moore, 1998) from which the descriptive model was derived reflects the goal of complete resolution of the symptom. Experts in palliative care (Mannix; Neuenschwander & Bruera) suggest that complete resolution of the symptom, although desirable does not always occur. While not specifically reflected in the literature review, the author included referral to palliative care experts for refractory symptoms.

The fourth stated assumption is that the PCPMG for NPs may not be appropriate for patients seeking curative treatment or for patients not having a limited life expectancy. This assumption was included to preclude the inappropriate application of the guidelines.

#### Definition, etiology, and presentation

The PCPMG for NPs begin with an overview of pain, which includes a definition of pain, derived from the synthesis of definitions by the APS (1992) and the IASP (1999, online). Elements from these definitions reflect the physical and emotional elements of pain and the subjectivity of pain.

Chronic pain and breakthrough pain are terms commonly encountered in the palliative care literature. Thus,



definitions are provided for the NP. The definition of chronic pain incorporates the aspects of duration and intensity. The description of chronic pain as persisting for more than three months (Cherny & Portenoy, 1995) was combined with the Johnson and Maas' (1997) definition to include the presence of severe discomfort or an uncomfortable sensation. A definition of breakthrough pain as a transitory exacerbation over a baseline (Cherny & Portenoy) is also provided.

Finally, the etiology and clinical presentation of the different types of pain, somatic or nociceptive, visceral, and neuropathic is described to assist the NP in evaluating the type of pain the patient is experiencing. This is important because the selection of a pharmaceutical agent is guided by the type of pain the patient experiences. For example, neuropathic pain has a unique clinical presentation and is less responsive to opioid narcotics. Thus, if the patient's presentation indicates pain that is neuropathic in origin, an indicated adjuvant analgesic should be selected (Cherny & Portenoy, 1995).

#### Evaluation and Diagnosis

The guidelines reflect the essential elements of history taking for the patient experiencing pain and are consistent with the classic seven dimensions of a symptom

(Smith, 1996) and those recommended by experts in pain management (Baumann, 1997; Foley, 1998; U.S. Department of Health and Human Services, 1994a). Information regarding a simple pain rating scale of zero to ten is included to reflect the AHCPR Guidelines on cancer pain management (U.S. Department of Health and Human Services). Although children are not the focus of this project, guides for rating pain in children and infants are included because they are also applicable to adults who are disabled or unable to communicate.

The physical examination component is consistent with AHCPR recommendations (U.S. Department of Health and Human Services, 1994a). In addition, the author included evaluation for easily reversible causes of pain such as urinary tract infection and fecal impaction. Although not cited in the literature, evaluating for fecal impaction and urinary tract infection is reflective of good medical and nursing practice.

Since pain is defined as possessing an emotional component and the review of the literature indicated a psychological assessment should be an integral component in the evaluation of pain (Foley, 1998; U.S. Department of Health and Human Services, 1994a), elements of a psychological assessment are included in the guidelines.

## Management

The pain management section includes both pharmacological and non-pharmacological measures. The recommended pharmacological measures are consistent with the AHCPR Clinical Practice Guidelines: Management of Cancer Pain (U.S. Department of Health and Human Services, 1994a) and the WHO Three-Step Analgesic Ladder (WHO, 1990).

The specific management guidelines are preceded by a brief narrative summary including information regarding (a) the use of opioids for persistent or moderate to severe pain, (b) the use of adjuvants to enhance analgesia, (c) the use of morphine sulfate as the first-line agent in treating moderate to severe pain, and (d) the risk of iatrogenic addiction.

General guidelines consistent with AHCPR recommendations (U.S. Department of Health and Human Services, 1994a) are included along with a diagram of the WHO Analgesic Ladder (WHO, 1990). Use of the 'Guidelines for Chronic Cancer Pain Management' (Box 1) and the WHO ladder enables the concise conveyance of a large amount of information.

The pharmacological management of pain includes the subsections of (a) narcotic use in pain management, (b) non-narcotic analgesic use in pain management, and (c)

#### Guidelines for Chronic Cancer Pain Management

- Individualize the regimen to the patient
- Use the simplest dosing schedules and the least invasive modalities first
- Follow the WHO Ladder for titration of therapy
- Administration should be around-the-clock for persistent cancer-related pain with additional as needed (prn) doses available for breakthrough pain because regularly scheduled dosing maintains a constant level of drug in the body and prevents the recurrence of pain
- Mixed agonist-antagonist narcotics should not be given to patients receiving pure or partial agonist to avoid a withdrawal syndrome
- Meperidine should not be used for long-term opioid treatment
- Opioid tolerance and physical dependence are expected with long-term opioid use and should not be confused with addiction
- The oral route of administration is preferred because it the most convenient and cost-effective
- If oral administration is not possible, the rectal and transdermal routes should be considered next
- Intramuscular injections are painful, and should be avoided
- Intraspinal analgesic systems should be considered only after failure of maximal systemic doses of opioids and co-analgesics
- Monitor for potential side effects
- Great inter-individual variation exists in side effect susceptibility
- Constipation is common with opioid use and should be anticipated, treated prophylactically, and monitored closely
- Naloxone, when indicated, should be administered for reversal of respiratory depression but not reversal of analgesia
- Placebos should not be used
- Patient should be provided with a written pain management plan and communication about pain management should occur between settings

\*Adapted from AHCPR Clinical Practice Guidelines: Management of Cancer Pain (U.S. Department of Health and Human Services, 1994-a)

Box 1: Guidelines for Chronic Cancer Pain Management

adjuvant use in pain management. The sub-section on narcotic use in pain management in the PCPMG includes two tables, which convey a large amount of information in a concise format. Table 1 (pp. 34) provides information about recommended starting doses for severe pain with patients who are not opioid naïve and Table 2 (pp. 37) provides equianalgesic doses of opioid agonist drugs. The PCPMG for NPs include recommendations for initial opioid dosing, dose titration, continuous dosing, rescue dosing, and switching opioids.

The sub-section on non-narcotic analgesic use in pain management is brief. Detailed information regarding the use and dose of NSAIDs is not provided, as PCNPs should be familiar with these products because their use is ubiquitous in clinical practice. Thus, only information related to the use of NSAIDs in palliative care is provided. In summary, NSAIDs are considered first-time agents for management of mild to moderate cancer pain and have a ceiling effect (Portenoy, 1998; U.S. Department of Health and Human Services, 1994a). However, NSAIDs are useful in the treatment of metastatic bone pain (Portenoy).

Two adjuvants commonly used in pain management are discussed: TCAs and corticosteroids and information on their indicated use, dose, and titration is included.



The section on non-pharmacological management of pain including psychosocial interventions, physical modalities, and education/teaching is based on AHCPR recommendations (U.S. Department of Health and Human Services, 1994a). Inclusion of psychosocial interventions and education/teaching is important because misconceptions of patients and their families can have a negative impact on pain management (Duggleby, 1991).

#### Expected Outcome and Follow-up

Ideally, total elimination of pain, reflected by the patient report of pain as a zero on a zero to ten scale, is the goal of palliative care pain management. However, total relief of pain is not always realistic (Mannix, 1998); thus, aggressive treatment should pursue a minimum goal of the reduction of pain to an impertinent level in the patient's priority system (Neuenschwander & Bruera, 1998).

Recommended follow-up is based on AHCPR guidelines (U.S. Department of Health and Human Services, 1994a). "Patients and families should be taught to report changes in pain and emergence of new pain" was included because often terminally ill patients are homebound, and patient/family report may be the only mode of evaluation available to the PCNP.

### Referral

Referral to a pain clinic or palliative care experts is recommended for patients with recalcitrant pain or requiring methods other than oral, rectal, or transdermal administration. The latter recommendation is included because therapeutic modes such as radiation or chemotherapy are beyond the scope of practice for the NP.

### Resources

A list of book and website resources for patients and their caregivers is provided at the end of the guidelines. Currently popular references are included. In addition, reputable websites for patients and families and for professionals related to the field of palliative care and/or death and dying are included.

Finally, a list of the cited references and additional recommended readings for the professional are provided. Because these guidelines covered only selected areas of palliative care, references about other aspects of palliative care are included.

## CHAPTER 6

### Implications

The development of the PCPMG has implications for clinical practice, education and research. The significance of these guidelines in these areas is discussed.

#### Clinical Practice

The intent in the development of PCPMG was to create a user-friendly reference for the PCNP in the ambulatory care setting. The guidelines are based on current research and knowledge. The PCPMG for NPs will require periodic revision to reflect advances and research in palliative care pain management. Following appropriate peer review (discussed below) of the PCPMG, they will be submitted for sale and publication. After the sale of the PCPMG, the purchasing organization would be responsible for updating them.

Michigan Nurses Association (MNA) or the ANA could potentially adopt and publish the PCPMG for NPs. The ANA (1994, Online) believes that nurses should not participate in assisted suicide and have an obligation to provide comprehensive and compassionate end-of-life care including pain management. The MNA (undated) states that responsive nurses should respect the patient's request for voluntary

self-termination. However, the MNA admonishes that voluntary self-termination should only be a measure of last resort for those whose suffering cannot be relieved. Thus, the PCPMG for NPs would be appropriate for publication by either organization because they are consistent with their respective position statements on assisted-suicide.

The application of the PCPMG for NPs has implications for the NP as clinician, collaborator, and consultant. The care of the terminally ill including the treatment of pain, falls within the scope of practice of the NP as described by the ANA (1996) to include expert skill in the diagnosis and treatment of complex human responses to actual or potential health problems and the management of chronic illness in various settings throughout the life cycle. However, the PCPMG for NPs are designed for quick reference in an ambulatory care setting and are not intended to be an in-depth reference. It is the responsibility of the NP to consult appropriate references for complete information regarding underlying pathophysiology and pharmacological agents.

The availability and implementation of the PCPMG can benefit the NP's practice in several ways. Their implementation should facilitate the NP's ability to effectively address the frustrating symptom of pain in the

terminally ill, thus resulting in improved quality of care and patient satisfaction. Use of the guidelines may result in cost reduction due to avoidance of unnecessary diagnostic studies and treatment procedures. For example, the guidelines emphasize the use of oral medications in the treatment of pain, which are less costly than the use of morphine pumps requiring the additional expense of equipment. Finally, widespread use of these guidelines should result in improving patient access to appropriate pain management because implementation in a primary care setting would preclude referral to a pain management specialist.

As the NP becomes proficient with pain management for the terminally ill, application of pain management principles could benefit non-terminally-ill patients. Experts suggest that palliative care principles are good practice and can benefit all patients (WHO, 1990; Pellegrino, 1998; Rhymes, 1995). However, some approaches would be inappropriate for non-terminally ill patients. For example, more invasive diagnostic and treatment procedures are indicated for patients who do not have a limited life expectancy and the long-term use of opioids in non-terminally ill patients is typically not appropriate.

Multiple obstacles exist for the use of the PCPMG for

NPs. First, if they are not widely disseminated, their implementation will be limited. Widespread distribution will be more likely if the PCPMG for NPs are adopted by and published by a major nursing organization. However, even with widespread distribution of the PCPMG, barriers to their implementation in practice exist. Authors typically categorize barriers to palliative care and pain management as related to health care professionals, to patients, or to the health care system (institutional barriers) (Dickey, 1996; U.S. Department of Health and Human Services, 1994a). The following discussion focuses on these barriers.

Clinician related barriers to the implementation of the PCPMG for NPs are numerous. First, if NPs do not recognize palliative care pain management as important or pertinent to their practice, they will not have incentive to implement them. Also, as the SUPPORT (SUPPORT Principal Investigators, 1995) study demonstrates, clinicians are resistant to changing their practice patterns even when they are provided with appropriate information.

Implementation of the PCPMG for NPs would require the NP to change practice patterns. The time investment required for the NP to implement the PCPMG would be a barrier to change. Implementation of the PCPMG would require the NP to commit time initially to become familiar

with them. Additionally, the time constraints of a busy ambulatory care setting may be a disincentive for implementation of the PCPMG. Educating NPs about the importance of pain management and the legal ramifications for the failure to do so (negligence of practice) may provide some incentive for implementation of the guidelines. Possible legislative mandates related to the topic of assisted-suicide may obligate HCPs including NPs, to appropriately address palliative care pain management.

Use of the PCPMG for NPs requires the clinician to identify terminally ill patients. Failure to accurately predict prognosis may result in failure to implement palliative care measures in a timely fashion. Education about accurately predicting prognosis and identifying terminally ill patients should accompany any educational program about use of the PCPMG.

Finally, in most states, NPs cannot prescribe opioid narcotics. Thus, implementation of the pain management guidelines will typically require a cooperating physician. The NP concerned with integrating the PCPMG into their practice either needs to assure collaboration with a physician with similar priorities or needs to work to educate the collaborating physician.

Misconceptions of patients and their families may

result in missed diagnosis of pain. For example, patients who believe that their pain is inevitable may fail to report it. Patients may also believe that they should endure pain so they do not develop a tolerance to opioids and will thus have an effective drug 'when they really need it' (Dickey, 1996). Patients in denial may be reluctant to report pain out of fear that increased pain is evidence that the underlying disease is progressing (U.S. Department of Health and Human Services, 1994a). Patients may be reluctant to take pain medications out of fear of addiction or out of concerns about possible side effects (U.S. Department of Health and Human Services, 1994a). Thus, it is essential that NPs educate patients and their families about the importance of pain relief and about faulty beliefs about opioids.

Institutional barriers to the implementation of the PCPMG for NPs include (a) a low priority given to pain treatment by health care systems, (b) inadequate reimbursement for pain medications by insurers, and (c) restrictive regulation of controlled substances (U.S. Department of Health and Human Services, 1994a). These barriers are large-scale and necessitate the unified effort of NPs and other HCPs. NPs could impact these barriers by conducting research to provide evidence to health care



systems (such as managed care organizations) and insurers about cost-effectiveness with quality outcomes with the use of the PCPMG for NPs. Additionally, NPs can educate legislators about appropriate medicinal use of and benefits of opioids in palliative care pain management and lobby for legislative changes to reduce disincentives for appropriate prescribing of opioids.

Palliative care is generally accepted as a collaborative interdisciplinary effort. Application of interventions such as prescribing opioid narcotics will require collaboration with a physician in many states. It is also important for the NP to be able to accurately assess when a problem is beyond his or her scope of expertise and requires collaboration with or referral to experts in palliative care, counselors, or home care agencies. For example, when pain or other symptoms are refractory to the recommended treatments, as evidenced by failure to achieve the recommended outcome, referral to a pain clinic or an expert in palliative care would be indicated. The PCPMG may be difficult for a NP to implement when the patient is homebound and direct observation is not possible.

The NP as consultant can provide direction to other members of the interdisciplinary team. The NP may have

unique knowledge about the patient and the significant others if a long-standing relationship exists. Sharing information about the patient and the significant others can aid mental health workers, staff and agency nurses, spiritual care personnel, and physicians in their care. As the NP becomes proficient in palliative care pain management, he/she can guide other members of the interdisciplinary team in pain management of the terminally ill.

Although developed for the NP, the palliative care clinical practice guidelines for pain can be utilized by other clinicians such as physicians. Physicians are likely to encounter the same barriers discussed earlier; however, they have fewer legal barriers to prescribing opioid narcotics.

Finally, these guidelines only address one area of the conceptual model of the Theory for the Peaceful End of Life (Ruland & Moore, 1998). The other areas of the model impact practice and require the development of additional palliative care clinical practice guidelines. This might be accomplished by presenting the model to organizations that are interested in improving end-of-life care such as hospice organizations or nursing organizations. Alternatively, the model could be presented to faculty in

graduate nursing programs such as the hospice clinical nurse specialist tract at Madonna University in Michigan so that other students could be encouraged to develop guidelines based on the Theory of the Peaceful End of Life (Ruland & Moore, 1998).

### Education

Implementation of the guidelines would require education of the practicing PCNP. Educating the PCNP on pain management in palliative care could occur through several forums. The easiest method of disseminating the information would be to post the PCPMG for NPs on the world wide web. Once a website was established, publicizing the existence of the website would be necessary. This could be accomplished by notifying appropriate organizations such as the ANA or the MNA and encourage reference to the site. Additionally, other website hosts such as the American Family Physician site and the ANA site, could be encouraged to include the PCPMG for NPs site as a hyperlink. Although a website would be the easiest way to publish the PCPMG for NPs, evaluating the application of the guidelines would be difficult. The website format would also restrict access to the PCPMG to NPs who use the internet.

An educational program targeting NPs in the clinic setting could be offered. Incentives to maximize

attendance would be necessary. For example, approval for continuing education units for PCNPs could be sought. Sponsorship of an educational program by pharmaceutical companies such as Janssen or Roxanne Laboratories (manufacturers of fentanyl patches and morphine products) would be mutually beneficial. Sponsors could subsidize the cost of the inservices while raising awareness of the use of their products in the terminally ill. Alternatively, managed care organizations may chose to sponsor an educational program if cost savings along with quality outcomes are expected to result from the implementation of the guidelines. The example provided earlier regarding the savings associated with the administration of medication orally vs. parenterally demonstrates the potential for reduction in the cost of care.

The program could be developed to teach NPs pain management in a format consistent with the guidelines, e.g., (a) overview, (b) evaluation, (c) plan/management, (d) expected outcome, and (e) follow-up. Initial teaching should be to assist the NP in identifying the appropriate recipients of palliative care. In other words, the NP should be provided with currently available information to assist with accurately predicting prognosis (Christakis, N.A., 1998; Luchins, D.J., Hanrahan, P. & Murphy, K., 1997;

VonGunten & Twaddle, 1996). General principles of palliative care such as the shift from cure to care, avoiding futile treatments and invasive diagnostics, and expected outcomes should be outlined. The program could be conducted in the traditional manner with an instructor in a classroom setting with the use of study guides and overheads. Information on resources for further information and study could be provided. Following the program, the presenter could be available for questions either by phone and/or email.

The most realistic approach would be to develop a teaching module for self-paced independent study. The module would be submitted to the American Nurses Credentialing Center for CEU approval. The content would be the same as described above for an educational program and submitted for publication to major nurse practitioner journals/publications. Alternatively, the teaching module could be submitted to websites that offer online CEUs; however, this approach would limit users to NPs who use the internet. Use of a teaching module submitted to a nurse practitioner journal for CEUs is a realistic goal for the PCPMG because minimal expense would be incurred.

On a more global level, nursing education has been slow to respond to the shifts in health care settings and

societal needs (National Council of Hospice Professionals, 1997). Nursing education programs lack specific course content, nursing competencies, and clinical experience in the care of the dying and the terminally ill and specifically in pain management (National Council of Hospice Professionals). As a result, nurses are inadequately prepared to deliver palliative care.

Death education in nursing curriculum can consist of a specialized course on death and dying or an integrated approach to the content (Kingma, 1994). Formal education on palliative care should include both didactic and practicum experiences. The PCPMG for NPs could be a valuable resource for both advanced practice nursing and medical students by providing guidance for practicum experiences and basic information regarding palliative care. A letter writing campaign outlining the need to quality end-of-life care and reiterating the gap that exists between current knowledge and implementation of pain management could target appropriate faculty such as clinical course chairs.

### Research

As a new and untested product, the PCPMG for NPs need to be carefully evaluated at several levels. The input of palliative care experts on the content of the guidelines is

the essential first step. The PCPMG for NPs require review by palliative care experts and practicing NPs for content, clarity, organization, and usability. Appropriate candidates for peer review would include physicians, nurses, and pharmacists with expertise in palliative care pain management. The guidelines should be altered accordingly prior to implementation. Following the peer-review by experts in pain management, NPs should review the PCPMG for their perspective on clarity, organization, and perceived usability is necessary. If the guidelines are unclear or difficult to use, they are unlikely to be utilized by the NP. Following implementation, clinicians using the guidelines could be surveyed at various points in time for feedback on the same parameters and also for the frequency of use, ease of use, and perceived effectiveness of the interventions.

Research needs to be conducted to evaluate the attainment of the stated expected outcomes and patient/caregiver satisfaction with the outcomes. If the outcomes are not achieved, the PCPMG need to be re-evaluated for possible flaws in clarity and content.

Evaluation of outcomes could be accomplished through a prospective study. A deficiency identified in the literature review was that most studies were retrospective

and that the information was obtained from significant others or caregivers following the death of the patient. A prospective study would result in gaining valuable information from the patient regarding their perspective prior to their death. Ideally, more than a single site should be studied, one for the experimental group and one for the control group in order to prevent cross-fertilization of information. Patients identified as terminally ill would be invited to participate. The participants in an attempt to control for age, gender, prognosis, and diagnosis would be assigned by pair matching. The control group would receive the care that they would have been receiving prior to the initiation of the study. The experimental group would receive pain management guided by the guidelines and participants would not be informed as to whether they are in the control or experimental group. The two groups would be compared on measurements taken prior to implementation and at various intervals during the study. End measurements would include information about outcomes such as pain level. Modifications would be made to the PCPMG for NPs based on the results of NP feedback and results of studies evaluating outcomes.

Two driving forces in the development of guidelines are



cost efficiency and quality of care (Lipson, 1999). Demonstration of reduced pain, patient satisfaction, and reduced costs would be invaluable to managed care organizations. The NP as a researcher could choose markers such as medication, diagnostic, and treatment costs and outcomes such as reduced scores on a pain scale. This study could be in the form of a retrospective review and the costs for those patients receiving care guided by the PCPMG could be compared to the costs of traditional care. Variables such as age, diagnosis, and gender would have to be controlled. If the results of an analysis of patient outcomes demonstrated a reduction in pain while containing costs, the PCPMG for NPs would be of value to managed care organizations. Alternatively, the PCPMG for NPs could be modified to implement alternatives for interventions that proved to be expensive.

### Conclusion

Terminally ill patients require a specialized form of care known as palliative care. However, few terminally ill patients receive appropriate care and thus, die in distress. A guide which is comprehensive and based on currently accepted national and international recommendations for the complex care of these patients is needed by PCNPs and other HCPs in their care of the

terminally ill.

The Theory for the Peaceful End of Life (Ruland & Moore, 1998) is a descriptive model that provides for the delivery and evaluation of palliative care. The proposed PCPMG provide a comprehensive yet concise resource for NPs practicing in an ambulatory care setting. They provide guidance to clinicians based on evidence with the expected outcome of improved care and the potential to promote consistency in care as well as enhance the quality of life for patients and their significant others.

## APPENDIX

**PALLIATIVE CARE PAIN MANAGEMENT GUIDELINES  
FOR NURSE PRACTITIONERS**

**Susan G. Wiers RN, MSN  
Michigan State University College of Nursing  
1999**

**Copyright by  
SUSAN G. WIERS  
1999**

## **Table of Contents**

Introduction. . . . .	2
Overview of Pain. . . . .	3
Evaluation of Pain. . . . .	3
Management of Pain . . . . .	4
Narcotic Use and Initial Dosing . . . . .	6
Dose Titration . . . . .	6
Continuous Dosing . . . . .	7
Breakthrough Pain or Rescue Dosing . . . . .	7
Switching Opioids . . . . .	7
Non-Narcotic Analgesic Use . . . . .	8
Adjuvant Use . . . . .	8
Non-Pharmacological Management . . . . .	8
Expected Outcome . . . . .	9
Follow-up . . . . .	9
Referral . . . . .	9
Recommended Reading List and Web Sites for Patients and Families . . . . .	10
Web Sites for Professionals . . . . .	11
References and Recommended Readings. . . . .	12

## INTRODUCTION

Palliative care reflects a shift in focus from curative to comfort care and is defined as: *care aimed at the relief of physical, psychological, spiritual, and social symptoms with the expected outcome of a peaceful end-of-life for patients whose disease is expected to result in death within six months with or without medical intervention.* Many health care providers have limited education about and experience with end-of-life care. Thus, when a patient's condition requires care rather than cure, the nurse practitioner may feel ill equipped to provide palliative care.

Appropriate pain management is essential to ensure quality of life for the terminally ill patient. These guidelines were developed to provide recommendations to assist nurse practitioners with decisions about the pain management of terminally ill patients and are not intended as an in-depth reference. It is the responsibility of the nurse practitioner to consult appropriate references on subjects such as physical examination, diagnostic studies, differential diagnosis, pathophysiology, and pharmacology. The guidelines should be adapted to the needs of the patient and the family and to the constraints of the circumstances. For example, limited financial resources may influence the selection of pharmacological agents.

The underlying assumptions of these guidelines include:

- Diagnostic considerations for terminally ill patients with pain should be directed at maintaining the comfort of the patient; diagnostic and treatment procedures that are invasive or painful are usually avoided because the focus of palliative care is on comfort. A differential diagnosis should always be formulated; however, studies should be pursued only when a suspected etiology can be easily identified and successfully treated.
- Ideally the goal in palliative care is complete resolution of the symptom. However, it is unwise to expect and promise total relief. Aggressive treatment should minimally pursue the goal of a reduction of pain to an insignificant level in the patient's priority system.
- These guidelines are intended for individuals receiving palliative care and may not be appropriate with patients seeking curative treatment or with those who do not have a limited life-expectancy

## OVERVIEW OF PAIN

Uncontrolled pain precludes a satisfactory quality of life and interferes with activities of daily living, psychological, social, and spiritual well being. Pain is a subjective sensory and emotional experience, and is whatever the person experiencing it says it is; the practitioner must accept the patient's report of pain (American Pain Society, 1992; IASP, 1999, online).

In palliative care, pain is usually chronic or breakthrough in nature. **Chronic pain** is a state in which the individual experiences and reports the presence of severe discomfort or an uncomfortable sensation that continues for more than 3 months. Chronic pain in cancer patients is typically associated with direct tumor infiltration. **Breakthrough pain** is a transitory exacerbation of severe pain over a baseline, which may occur with or without an identifiable precipitant.

Etiologically, pain is categorized as somatic or nociceptive, visceral, or neuropathic. **Somatic (nociceptive pain)** results from tissue injury with resultant stimulation of nociceptors in cutaneous and deep tissues. It includes bone metastasis pain, postsurgical incision pain, myofascial or musculoskeletal pain and is typically well localized.

**Visceral pain** results from infiltration, compression, distention or the stretching of viscera. Visceral pain is poorly localized, described as deep, pressure, or squeezing pain, and is often associated with other symptoms such as nausea, vomiting, and diaphoresis. - **Chronic tumor related visceral pain is often insidious in onset, overt pain behaviors and sympathetic hyperactivity are often absent and affective disturbances such as depression and anxiety may be present.**

**Neuropathic pain** results from injury to the peripheral and/or central neural structures and can result from tumor compression or infiltration, trauma or chemical injury due to surgery, chemotherapy, radiation, spinal cord compression post herpetic neuralgia, and peripheral neuropathy. Neuropathic pain is often severe and described as a constant, dull ache, 'viselike', burning, or shock-like, and is **less responsive to opioid drugs**; effective treatment may require adjuvant analgesics or other approaches such as sympathetic nerve block.

## HISTORY

- Obtain a detailed history including assessment of pain intensity, character, location, radiation, associated signs and symptoms, alleviating and aggravating factors, impact on ADLs, and temporal factors.
- A simple scale rating pain from 0 (no pain) to 10 (the worst pain possible) is commonly utilized for most adults and children over the age of 7 years (American Pain Society, 1992; U.S. Department of Health and Human Services)
- Children under 7 years and cognitively disabled adults can be asked to rate their pain on a series of several faces ranging from smiling to crying
- Behavioral observation is necessary in babies, very young children, and adults who are unable to communicate

## PHYSICAL EXAMINATION

- Chronic pain rarely is accompanied by signs of sympathetic nervous system arousal. Thus, **the lack of objective signs does not preclude the possibility that the patient is experiencing pain** (American Pain Society, 1992)
- Assess for reversible causes of pain such as a fecal impaction and urinary tract infection

- Examine site of pain and sites of pain radiation
- Perform a neurological evaluation:
  - cranial nerve status
  - retina changes
  - motor and sensory function in limbs
  - rectal and urinary sphincter function

### **Psychosocial Assessment** (Adapted from the U.S. Department of Health and Human Services, 1994a)

Evaluate:

- Effect and understanding of diagnosis on the patient and family
- Meaning of pain to the patient and family
- Typical coping mechanisms
- Past experiences with pain
- Concerns of the patient and family about opioids, anxiolytics, and stimulants
- Changes in mood such as anxiety and depression

### **Differential Diagnosis**

Diagnostic studies confirm the clinical diagnosis and define the site and extent of tumor infiltration.

Order and review appropriate diagnostic procedures. Possibilities include:

- CT Scan
- MRI
- Plain radiograph
- Tumor markers such as PSA, CEA

Differential diagnoses include:

- Tumor metastases
- Peripheral neuropathies
- Plexopathies
- Acute and postherpetic neuralgia
- Bowel obstruction and/or constipation
- Occlusion of blood flow to visceral organs
- Thrombosis and engorgement of splenic or renal veins
- Volvulus of the small intestine
- Infection
- Mucositis

Pharmacological pain management should be consistent with the *AHCPR Clinical Practice Guidelines: Management of Cancer Pain* (Box 1) and the WHO Ladder (Figure 1) Presenting pain that is persistent or moderate to severe should be treated with potent opioids such as morphine, hydromorphone, fentanyl, methadone, or levorphanol or by using higher dosages of opioids. Adjuvant drugs such as antidepressants and anticonvulsants may be added at any step to enhance analgesia.

**Morphine sulfate (MS)** is the prototypic agonist narcotic analgesic, has no ceiling effect, and is typically considered the first-line agent when treating moderate to severe pain. The risk of iatrogenic addiction is very small, and should not be a primary concern to practitioners.



## BOX 1\*

- Individualize the regimen to the patient
- Use the simplest dosing schedules and the least invasive modalities first
- Follow the WHO Ladder for titration of therapy
- Administration should be around-the-clock for persistent cancer-related pain with additional as needed (pm) doses available for breakthrough pain because regularly scheduled dosing maintains a constant level of drug in the body and prevents the recurrence of pain
- Mixed agonist-antagonist narcotics should not be given to patients receiving pure or partial agonists to avoid a withdrawal syndrome
- Meperidine should not be used for long-term opioid treatment
- Opioid tolerance and physical dependence are expected with long-term opioid use and should not be confused with addiction
- The oral route of administration is preferred because it is the most convenient and cost-effective
- If oral administration is not possible, the rectal and transdermal routes should be considered next
- Intramuscular injections are painful and should be avoided
- Intraspinal analgesic systems should be considered only after failure of maximal systemic doses of opioids and co-analgesics
- Monitor for potential side effects
- Great inter-individual variation exists in side effect susceptibility
- Constipation is common with opioid use and should be anticipated, treated prophylactically, and monitored closely
- Naloxone, when indicated, should be administered for reversal of respiratory depression but not reversal of analgesia
- Placebos should not be used
- Patients should be provided with a written pain management plan and communication about pain management should occur between settings

\*Adapted from AHCPR Clinical Practice Guidelines: Management of Cancer Pain (U.S. Department of Health and Human Services, 1994a)

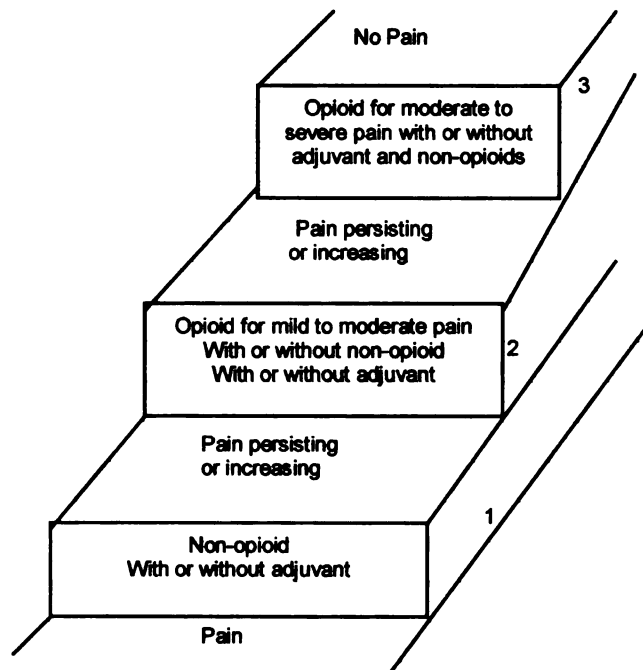


Figure 1: The WHO three-step analgesic ladder adapted from the World Health Organization (1990).



## Continuous dosing

- Establish 24-hour dose requirement through titration to pain. Once daily dosing requirements are established, around-the-clock administration should be implemented preferably with a sustained-release (SR) product
- Analgesic therapy typically is not initiated with SR preparations because it is difficult to titrate with these products

## Breakthrough Pain or Rescue Dosing

- All patients should be provided with a supplemental dose of an opioid given on a prn basis to treat pain that breaks through the regular schedule
- Typically the rescue drug is the same drug administered on a continuous basis with the exception of fentanyl and methadone
- An immediate release, fast acting opioid is used
- Oral rescue doses can be administered every hour
- The rescue dose should be one-sixth of the 24 hour maintenance dose

## Switching opioids

- When switching a patient from one opioid to another, use an equianalgesic dose (Table 2). For patients with good pain control, the starting dose of the new opioid should be reduced to 50-75% of the equianalgesic dose due to the possibility of incomplete cross-tolerance

**Table 2\***

DRUG	Dose (mg) equianalgesic to 10 mg IM MS		HALF-LIFE (hours)	DURATION OF ACTION (hours)
	PARENTERAL	ORAL		
Codeine (w/ASA or acetaminophen)	130 q3-4 hr	180-200 q3-4 hr	2-3	2-4
Oxycodone (Roxicodone, also in Percocet, Percodan, Tylox, others)	NA	30 q3-4 hr	2-3	2-4
Hydrocodone (in Lorcet, Lortab, Vicodin, others)	NA	30 q3-4 hr		
Propoxyphene	-	50	2-3	2-4
MS	10 q3-4 hr	30 q3-4 hr	2-3	3-4
MS Controlled release (MS Contin, Oramorph)	NA	90-120 q12 hr		8-12h
Hydromorphone (Dilaudid)	1.5 q3-4 hr	7.5 q3-4 hr	2-3	2-4
Methadone (Dolophine)	10 q6-8 hr	20 q6-8 hr	15-190	4-8
Oxymorphone	1 q3-4 hr	10 (rectal) q3-4 hr	2-3	3-4
Levorphanol (Levo-Dromoran)	2 q6-8 hr	4 q6-8 hr	12-15	4-8
Fentanyl transdermal (Duragesic)***	25ucg/hr q72 hr	*		48-72

Adapted from AHCPR Clinical Practice Guideline Number 9: Management of Cancer Pain (U.S. Department of Health and Human Services, 1994a) and Cherny & Portenoy (1995)

\*\* Do not exceed maximum daily doses for non-opioid analgesics

\*\*\* Transdermal fentanyl (Duragesic) may be started in doses not greater than 25-ucg/hr q 72 hr in the opioid naïve patient (U.S. Department of Health and Human Services, 1994a). A 60mg po dose of MS q4 hr over 24 hours (total 360mg po daily dose) is approximately equivalent to 100mcg Fentanyl transdermally q 72 hr (Kastrup, et al., 1999). Or 30 mg MS q 8 hr is equivalent to 25 ucg/hr Fentanyl patch q72 hr (American Pain Society, 1992)

- For patients with poor pain control and moderate, unacceptable side effects, the starting dose of the new drug should be between 75-100% of the equianalgesic dose
- Experts recommend a conservative approach when switching to methadone, using 66-75% of the equianalgesic dose

### **Non-narcotic Analgesic Use in Pain Management**

- NSAIDs are first-line agents for management of mild to moderate cancer pain (Portenoy, 1998), but have a ceiling effect
- NSAIDs are used for the treatment of metastatic bone pain

### **Tricyclic Antidepressant Management**

**Tricyclic antidepressants (TCAs)** are indicated for treatment of neuropathic pain in a patient who has inadequate response to opioids.

- Starting doses should be 10mg/day in the elderly and 25 mg/day in younger patients
- Titrate to pain by doubling the dose every few days
- Effective dose range for amitriptyline or desipramine is 50-150 mg
- Analgesia onset is typically within one week

**Corticosteroids** may be administered for metastatic bone pain, neuropathic pain due to compression or infiltration, and painful lymphoedema.

- Other symptoms such as nausea or malaise may also be improved with these products
- **Dexamethasone** 1-2mg qd or bid has been used for patients with advanced medical illness who continue to have pain despite optimal dosing of opioid drugs
- The lowest dose that yield therapeutic effects should be used
- Ineffective regimens should be tapered and discontinued

### **Non-pharmacologic Pain Management Options**

**Psychosocial Interventions** (From the U.S. Department of Health and Human Services, 1994a)

- Relaxation and imagery
- Cognitive distraction and reframing
- Patient education
- Psychotherapy and structured support
- 

**Physical Modalities** (U.S. Department of Health and Human Services, 1994a)

- Cutaneous stimulation; acupuncture
- Heat (Avoid burns by wrapping heat source in a towel. Contraindicated on irradiated tissue. Diathermy and Ultrasounds are not recommended for use over tumor sites)
- Cold (Do not exceed 15 minutes and avoid use in patients with peripheral vascular disease or on tissue damaged by radiation.)
- Massage, pressure, and vibration
- Exercise (PROM and AROM for bed bound patients by therapists or trained family members. Avoid weight bearing exercises when bone fracture is likely.)
- Repositioning and proper body alignment
- Immobilization (To manage acute pain and stabilize fractures. Avoid prolonged immobilization.)
- Counterstimulation (TENS and acupuncture)

## Education/Teaching

- Pain is highly individual and variable
- Pain can be controlled to a tolerable level
- It is essential to report all pain
- Treatment of chronic cancer pain is an appropriate medicinal use of opioid narcotics
- Side effects of somnolence and nausea are often transient while tolerance to constipation does not occur
- The risk of addiction is almost nonexistent in the treatment of pain related to cancer
- Chronic pain lacks anticipated resolution of the underlying physiologic cause
- Describe possible physiological causes of chronic pain
- Discuss possible psychosocial and spiritual factors that may contribute to pain

## EXPECTED OUTCOME

Ideally, total elimination of pain as reflected by the patient report of pain level as a 0 on a 0-10 scale, is the goal of palliative care pain management. However, total relief of pain is not always realistic; thus, aggressive treatment should pursue a minimum goal of reduction of pain to an impertinent level in the patient's priority system (Neuenschwander & Bruera, 1998).

## FOLLOW-UP

Patients and families should be taught to report changes in pain and emergence of new pain (U.S. Department of Health and Human Services, 1994a).

## REFERRAL

Referral to a hospice, pain clinic, or a clinician experienced in pain management should be made for patients requiring methods other than oral, rectal, or transdermal administration and for those experiencing recalcitrant pain.

## Recommended Book and Website for Terminally Ill Patients and Caregiver

### BOOKS

Albom, M. (1997). Tuesdays with Morrie: An old man, a young man, and life's greatest lesson. New York: Doubleday.

Buscaglia, L. (1982). The fall of Freddie the leaf. New York: Henry Holt.

Callanan, M. & Kelley, P. (1997). Final gifts. New York: Bantam Books.

Freemantle, Francesca, Trungpa, & Chogyam. (1975). The Tibetan book of the dead. Boston: Shambhala Publications. (A translation and commentary on the Buddhist teachings about death)

Houts, P.S. (Ed.). (1994). American college of physicians home care guide for cancer. Philadelphia: American College of Physicians.

Kubler-Ross, E. (1974). Questions and answer on death and dying. New York: Collier Books.

Kubler-Ross, E. (1975). Death: The final stage of growth. New York: Simon & Schuster, Touchstone.

Kubler-Ross, E. (1999). The tunnel and the light. New York: Marlowe & Company.

LeShan, E. (1976). Learning to say goodbye. New York: Macmillan.

LeShan, E. (1986). When a parent is very sick. Boston: Little, Brown.

Moody, R. (1975). Life after life. New York: Bantam Books.

Stein, S.B. (1974). About dying. New York: Walker and Company.

Viorst, J. (1986). Necessary losses. New York: Ballantine Books.

## **WEBSITES:**

Americans for Better Care of Dying: <http://www.abcd-caring.com/>

Choice in Dying (includes downloadable advanced directives for all 50 states:  
<http://www.choices.org/>

Death and Dying: <http://www.death-dying.com/>

The End of Life: Exploring Death in America, National Public Radio:  
<http://www.npr.org/programs/death/>

National Hospice Foundation: <http://www.nho.org/foundati.htm>

Project on Death in America: <http://www.soros.org/death/index.htm>

## **Recommended Websites for Professionals**

American Academy of Hospice and Palliative Medicine: <http://www.aahpm.org/>

**20 Improvements in End of Life Care - Changes Internists Could Do Next Week!**  
*Don Berwick, MD*, Institute for HealthCare Improvement, at the ACP-ASIM Annual Meeting, April 22, 1999 (prepared by Americans for Better Care of the Dying)  
<http://www.abcd-caring.com/tools/intern.htm>

Hospice and Palliative Nurses Association: <http://www.hpna.org/index.htm>

National Hospice Foundation: <http://www.nho.org/foundati.htm>

National Hospice Organization: <http://www.nho.org/>



## REFERENCES AND ADDITIONAL RECOMMENDED READINGS

American Pain Society (1993). Principles of analgesic use in the treatment of acute pain and cancer pain (3rd ed.). Skokie, Illinois: Author.

Baumann, T.J. (1997). Pain management. In J.T. DiPiro, R.L. Talbert, G.C. Yee, G.R. Matzke, B.G. Wells, & L.M. Posey (Eds.), Pharmacotherapy: A pathophysiologic approach (3rd ed., pp. 1259-1292). Stamford, CT: Appleton & Lange.

Bertman, S. (1998). Ars moriendi: Illuminations on 'the good death' from the arts and humanities. In J.K. Harrold & J. Lynn (Eds.), A good dying: A shaping of health care for the last months of life (pp. 5-28). Binghampton, N.Y.: The Haworth Press.

Breitbart, W. & Jacobsen, P.B. (1996). Psychiatric symptom management in terminal care. Clinics in Geriatric Medicine, 12, 329-347.

Cherny, N.I. & Portenoy, R.K. (1995). The management of cancer pain. Atlanta, Georgia: The American Cancer Society, Inc.

DiPiro, J.T., Talbert, R.L., Yee, G.C., Matzke, G.R., Wells, B.G., & Posey, L.M. (Eds.). (1997). Pharmacotherapy: A pathophysiologic approach (3rd ed.). Stamford, Connecticut: Appleton & Lange.

Doyle, D., Hanks, G.W.C., & MacDonald, N. (Eds.). (1998). Oxford textbook of palliative medicine (2nd ed.). New York: Oxford University Press.

DuFault, K. Sr., Cannell-Firsch, S., Gardner, A., Jones, M., Reynolds-Moseley, J., & Stone, S. (Eds.). (1985). Guidelines for cancer nursing practice. Orlando, Florida: Grune & Stratton.

Foley, K. (1998). Pain assessment and cancer pain syndromes. In D. Doyle, G.W.C. Hanks, & N. MacDonald (Eds.), Oxford textbook of palliative medicine (2nd ed., pp. 310-331). New York: Oxford University Press.

Hanks, G. & Cherny, N. (1998). Opioid analgesic therapy. In D. Doyle, G.W.C. Hanks, & N. MacDonald (Eds.), Oxford textbook of palliative care (2<sup>nd</sup> ed., pp. 331-355). New York: Oxford University Press.

Johnson, M. & Maas, M. (Eds.). (1997). Nursing outcomes classification (NOC). St. Louis: Mosby-Year Book, Inc.

Kastrup, E.K., Hebel, S.K., Rivard, R., Burnham, T.H., Short, R.M., Belle, W.L., Schweain, S.L., & Snitker, J.A. (Eds.). (1999). Drug facts and comparisons: 1999 edition. St. Louis: Facts and Comparisons.

Kubler-Ross, E. (1969). On death and dying. New York: Simon & Schuster, Touchstone.

Kyle, M. (1995). Collaboration. In M. Snyder & M.P. Mirr (Eds.), Advanced practice nursing: A guide to professional development (pp. 169-182). New York: Springer Publishing Company.

Larson, D.G. (1993). The helper's journey: Working with people facing grief, loss, and threatening illness. Champaign, IL: Research Press

Mannix, K.A. (1998). Gastrointestinal symptoms. In D. Doyle, G.W.C. Hanks, & N. MacDonald (Eds.), Oxford textbook of palliative medicine (2nd ed., pp. 489-499). New York: Oxford University Press.

Neuenschwander, H. & Bruera, E. (1998). Asthenia. In D. Doyle, G.W.C. Hanks, & N. MacDonald (Eds.), Oxford textbook of palliative medicine (2nd ed., pp. 573-581). New York: Oxford University Press.

Payne, R. (1989a). Cancer pain mechanisms and etiology. In S.E. Abram (Ed.), Cancer pain (pp. 1-10). Boston: Kluwer Academic Publishers.

Payne, R. (1989b). Oral and parenteral drug therapy for cancer pain. In S.E. Abram (Ed.), Cancer pain (pp. 11-32). Boston: Kluwer Academic Publishers.

Portenoy, R.K. (1998). Adjuvant analgesics in pain management. In D. Doyle, G.W.C. Hanks, & N. MacDonald (Eds.), Oxford textbook of palliative medicine (2nd ed., pp. 361-390). New York: Oxford University Press.

Rosen, E.J. (1998). Families facing death: A guide for health care professionals. San Francisco: Josey-Bass, Inc.

Soukhanov, A.H., et al. (Eds.). (1992). The American heritage dictionary of the English language (3rd ed.). Boston: Houghton Mifflin Company.

Thomas, C.L. (Ed.). (1977). Taber's cyclopedic medical dictionary. Philadelphia: F.A. Davis Company.

U.S. Department of Health and Human Services (1994a). Management of cancer pain: Adults (AHCPR Publication No. 94-0593). Rockville, MD.

U.S. Department of Health and Human Services (1994b). Management of cancer pain: Adults. Quick reference guide for clinicians, no. 9. (AHCPR Publication No. 94-0593). Rockville, MD.

Vachon, M.L.S. (1998). Emotional problems of the patient. In D. Doyle, G.W.C. Hanks, & N. MacDonald (Eds.), Oxford textbook of palliative medicine (2nd ed., pp. 883-907). New York: Oxford University Press.

World Health Organization, (1990). Cancer pain relief and palliative care: Report of a WHO expert committee. Geneva: World Health Organization.

## REFERENCES

## References

Abram, S.E. (Ed.). (1989). Cancer pain. Boston: Kluwer Academic Publishers.

American Nurses Association (1994). Position statements: Assisted suicide, (Online). Available: <http://www.nursingworld.org/readroom/position/ethics/etsuic.htm>

American Nurses Association (1996). Scope and standards of advanced practice registered nursing. Washington, D.C.: American Nurses Publishing.

American Pain Society (1993). Principles of analgesic use in the treatment of acute pain and cancer pain (3<sup>rd</sup> ed.). Skokie, IL: Author.

American Society of Anesthesiologists task force on pain management, cancer pain section (1996). Anesthesiology, 84, 1243-1257 (Online). Available: <http://.asahq.org/Practice/Cancer.html>

Baumann, T.J. (1997). Pain management. In DiPiro, J.T., Talbert, R.L., Yee, G.C., Matzke, G.R., Wells, B.G., & Posey, L.M. (Eds.), Pharmacotherapy: A pathophysiologic approach (3rd ed., pp. 1259-1292). Stamford, CT: Appleton & Lange.

Boling, A. & Lynn, J. (1998). Hospice: Current practice, future possibilities. In J.K. Harrold & J. Lynn (Eds.), A good dying: Shaping health care for the last months of life (pp. 28-32). New York: The Haworth Press, Inc..

Breitbart, W. & Jacobsen, P.B. (1996). Psychiatric symptom management in terminal care. Clinics in Geriatric Medicine, 12(2), 329-347.

Breitbart, W., Chochinov, H.M., & Passik, S. (1998). Psychiatric aspects of palliative care. In D. Doyle, G.W.C. Hanks, & N. MacDonald (Eds.), Oxford textbook of palliative medicine (2nd ed., pp. 933-954). New York: Oxford University Press.

Brock, D.B. & Foley, D.J. (1998). Demography and epidemiology of dying in the U.S. with emphasis on deaths of older persons. In J. K. Harrold & J. Lynn (Eds.), A good dying: A shaping health care for the last months of life, (pp. 49-60). Binghamton, N.Y.: The Haworth Press, Inc.

Brody, H. (1992). Assisted death-A compassionate response to medical failure. The New England Journal of Medicine, 327(19), 1384-1388.

Buchan, M.L. & Tolle, S.W. (1995). Pain relief for dying persons: Dealing with physicians' fears and concerns. The Journal of Clinical Ethics, 6(1), 53-61.

Carey, R.G. (1975). Living until death: A program of service and research for the terminally ill. In E. Kubler-Ross (Ed.), Death: The final stage of growth (pp.75-86). New York: Simon & Schuster.

Chapman, R.C. & Gavrin, J. (1996). Suffering and the dying patient. Journal of Pharmaceutical Care in Pain and Symptom Control, 3(3/4) 67-89.

Cherny, N.I. & Portenoy, R.K. (1995). The management of cancer pain. Atlanta, Georgia: The American Cancer Society, Inc.

Christakis, N.A. (1998). Predicting patient survival before and after hospice enrollment. In J. K. Harrold & J. Lynn (Eds.), A good dying: A shaping health care for the last months of life, (pp. 71-87). Binghamton, N.Y.: The Haworth Press, Inc.

Cohen, S.R., Bultz, B.D., Clarke, J., Kuhl, D.R., Poulson, M.J., Kjerstin Baldwin, M., & Mount, B.M. (1997) Well-being at the end of life: Part 1. A research agenda for psychosocial and spiritual aspects of care from the patient's perspective. Cancer Prevention & Control, 1(5), 334-342.

Conill, C., Verger, E., Henriquez, I., Saiz, N., Espier, M., Lugo, F., & Garriogos, A. (1997). Symptom prevalence in the last week of life. Journal of Pain and Symptom Management, 14(6), 328-331.

Curtin, L.L. (1996). First you suffer, then you die: Findings of a major study on dying in U.S. hospitals. Nursing Management, 27(5), 56-60.

Dalton, J.A. (1989). Nurses' perceptions of their pain assessment skills, pain management practices, and attitudes toward pain. Oncology Nursing Forum, 16(2), 225-231.

Daly Suentjens, A. (1995). Case management/care management. In M. Snyder & M. P. Mirr (Eds.), Advanced practice nursing: A guide to professional development (pp. 135-152). New York: Springer Publishing Company, Inc.

Dickey, N.D. (1996). Pain management at the end of life. JOSPT, 24(4), 237-239.

Diekmann, J.M., Engber, D., & Wassem, R. (1989). Cancer pain control: One state's experience. Oncology Nursing Forum, 16(2), 219-223.

DiPiro, J.T., Talbert, R.L., Yee, G.C., Matzke, G.R., Wells, B.G., & Posey, L.M. (Eds.). (1997). Pharmacotherapy: A pathophysiologic approach (3rd ed.). Stamford, Connecticut: Appleton & Lange.

Doyle, D., Hanks, G.W.C., & Macdonald, N. (Eds.). (1998). Oxford textbook of palliative medicine (2nd ed.). New York: Oxford University Press.

Duggleby, W. (1991). Pain beliefs affect pain management. AARN Newsletter, 47(10), 17.

Eddy, D.M. (1990). Designing a practice policy: Standards, guidelines, and options. JAMA, 263(22), 3077-3084.

Fenstermacher, K. & Hudson, B.T. (1997). Practice guidelines for family nurse practitioners. Philadelphia: W.B. Saunders Company.

Ferrell, B.R. (1998). How can we improve care at the end of life? Nursing Management, 29(9), 41-3.

Ferrell, B.R., Eberts, M.T., McCaffery, M., & Grant, M. (1991). Clinical decision making and pain. Cancer Nursing, 14(6), 289-297.

Ferrell, B.R., McGuire, D.B., & Donovan, M.I. (1993). Knowledge and beliefs regarding pain in a sample of nursing faculty. Journal of Professional Nursing, 9(2), 79-88.

Field, M.J. & Lohr, K.N. (Eds). (1990). Clinical practice guidelines: Directions for a new program. Washington, D.C.: National Academy Press.

Foley, K. (1998) Pain assessment and cancer pain syndromes. In D. Doyle, G.W.C. Hanks, & N. MacDonald (Eds). Oxford textbook of palliative medicine (2<sup>nd</sup> ed., pp. 310-331). New York: Oxford University Press.

Hanks, G. & Cherny, N. (1998). Opioid analgesic therapy. In D. Doyle, G.W.G. Hanks, & N. MacDonald (Eds.). Oxford textbook of palliative care (2<sup>nd</sup> ed., pp. 331-355). New York: Oxford Press.

Hanson, L.C., Danis, M., & Garrett, J. (1997). What is wrong with end-of-life care? Opinions of bereaved family members. Journal of the American Geriatrics Society, 45(11), 1339-1344.

Hoole, A.J., Pickard, C.G., Jr., Ouimette, R.M., Lohr, J.A., & Greenberg, R.A. (1995). Patient care guidelines for nurse practitioners (4<sup>th</sup> ed.). Philadelphia: J.B. Lippincott Company.

IASP (1999). Pain terms (On-line). Available: <http://www.halcyon.com/iap/terms-p.html>

Johnson, M. & Maas, M. (Eds.). (1997). Nursing outcomes classification (NOC). St. Louis: Mosby-Year Book, Inc..

Kastrup, E.K., Hebel, S.K., Rivard, R., Burnham, T.H., Short, R.M., Belle, W.L., Schweain, S.L., & Snitker, J.A. (Eds.). (1999). Drugs facts and comparisons: 1999 edition. St. Louis: Facts and Comparisons.

Kingma, R. (1994). Spotlight on revising death education. Nurse Educator, 19(5), 15-16.

Koesters, S. (1996). Hospice care. In: J. V. Hickey, R. M. Ouimette, & S. L. Venegoni (Eds). Advanced practice nursing: Changing roles and clinical applications (pp. 327-333). Philadelphia: Lippincott.

Lipson, S.T. (1999) Clinical practice guidelines. Managed Solutions: Interactive Journal of Managed Care. Online. Available: <http://www.medconnect.com/finalhtm/mc/featured/fea.html>

Luchins, D.J., Hanrahan, P. & Murphy, K. (1997). Criteria for enrolling dementia patients in hospice. Journal of the American Geriatrics Society, 45, 1054-1059.

Lynn, J., Teno, J.M., Phillips, R. S., Wu, A.W., Desbiens, N., Harrold, J., Claessens, M.T., Wenger, N., Kreling, B., & Connors, A.F. for the SUPPORT Investigators (1997). Perceptions by family members of the dying experience of older and seriously ill patients. Annals of Internal Medicine, 126(2), 97-106.

Mannix, K.A. (1998). Gastrointestinal symptoms. In D. Doyle, G.W.C. Hanks, & N. MacDonald (Eds.), Oxford textbook of palliative medicine (2<sup>nd</sup> ed., pp. 489-499). New York: Oxford University Press.

McCaffery, M., Ferrell, B, O'Neil-Page, E., Lester, M. (1990). Nurses' knowledge of opioid analgesic drugs and psychological dependence. Cancer Nursing, 13(1), 21-27.

Miller, R.J. (1992). Hospice care as an alternative to euthanasia. Law, Medicine, & Health Care, 20(1-2), 127-132.

Mirr, M.P. & Snyder, M. (1995). Evolution of the advanced practice nurse role. In M. Snyder & M. P. Mirr (Eds.), Advanced practice nursing: A guide to professional development (pp.13-32). New York: Springer Publishing Company, Inc.

Michigan Nurses Association (undated). Position Statement on Assisted Voluntary Self-Termination (Available from the Michigan Nurses Association, 2310 Jolly Oak Road, Okemos, MI 48864-4599)

National Council of Hospice Professionals (1997). Guidelines for curriculum development on end-of-life and palliative care in nursing education. National Hospice Organization: Arlington, Virginia.



Neuenschwander, H. & Bruera, E. (1998). Asthenia. In D. Doyle, G.W.C. Hanks, & N. MacDonald (Eds.), Oxford textbook of palliative medicine (2<sup>nd</sup> ed., pp. 573-581). New York: Oxford University Press.

O'Connell, L. J. (1996). Changing the culture of dying: A new awakening of spirituality in America heightens sensitivity to the needs of dying persons. Health Progress, 77(6), 16-20.

Payne, R. (1989a). Cancer pain mechanisms and etiology. In S.E. Abram (Ed.), Cancer pain (pp. 1-10). Boston: Kluwer Academic Publishers.

Payne, R. (1989b). Oral and parenteral drug therapy for cancer pain. In S.E. Abram (Ed.), Cancer pain (pp. 11-32). Boston: Kluwer Academic Publishers.

Pederson, C. & Parran, L. (1997). Bone marrow transplant nurse' knowledge, beliefs, and attitudes regarding pain. Oncology Nursing Forum, 24(9), 1563-1571.

Pellegrino, E.D. (1998). Emerging ethical issues in palliative care. JAMA, 279, 1521-1522.

Portenoy, R.K. (1998). Adjuvant analgesics in pain management. In D. Doyle, G.W.C. Hanks, & N. MacDonald (Eds.), Oxford textbook of palliative medicine (2<sup>nd</sup> ed., pp. 361-390). New York: Oxford University Press.

Rhymes, J.A. (1995). Hospice care-Too little, too late? Journal of the American Geriatrics Society, 43, 557-558.

Rudberg, M.A., Teno, J.M., & Lynn, J. (1997). Developing and implementing measures of quality care at the end of life: A call for action. Journal of the Gerontological Society, 45, 528-530.

Ruland, C.M. & Moore, S.M. (1998). Theory construction based on standards of care: A proposed theory for the peaceful end of life. Nursing Outlook, 46, 169-175.

Ryan, P., Vortherms, R., & Ward. (1994). Cancer pain: Knowledge, attitudes of pharmacologic management. Journal of Gerontological Nursing, 20(1), 7-16.

Sachs, G.A., Aronheim, J.C., Rhymes, J.A., Volicer, L., & Lynn, J. (1995). Good care of dying patients: The alternative to physician-assisted suicide and euthanasia. Journal of the American Geriatric Society, 43(5), 553-562.

Schonwetter, R.S. (1996). Care of the dying geriatric patient. Clinics in Geriatric Medicine, 12(2), 253-265.

Smith, R.C. (1996). The patients story: Integrated patient-doctor interviewing. New York: Little, Brown, and Company.

Snyder, M. & Yen, M. (1995). Characteristics of the advanced practice nurse. In M. Snyder & M. P. Mirr (Eds.), Advanced practice nursing: A guide to professional development (pp.3-12). New York: Springer Publishing Company, Inc.

Solheim, K., Snyder, M., & Mirr, M. (1995). Settings for care. In M. Snyder & M. P. Mirr (Eds), Advanced practice nursing: A guide to professional development (pp. 55-68). New York: Springer Publishing Company, Inc.

Soukhanov, A.H., et al. (Eds.). (1992). The American heritage dictionary of the English language (3<sup>rd</sup> ed.) Boston: Houghton Mifflin Company.

SUPPORT Principal Investigators. (1995). A controlled trial to improve care for seriously ill hospitalized patients. Journal of the American Medical Association, 274(19), 1380-1384.

Uphold, C.R. & Graham, M.V. (1998). Clinical guidelines in family practice (3<sup>rd</sup> ed.). Gainesville, Florida: Barmarrae Books.

U.S. Department of Health and Human Services (1994-a). Management of cancer pain: Adults (AHCPR Publication No. 94-0593). Rockville, MD.

U.S. Department of Health and Human Services (1994-b). Management of cancer pain: Adults quick reference guide No. 9 (AHCPR Publication No94-0593). Rockville, MD.

Vachon, M.L.S. (1998). Emotional problems of the patient. In D. Doyle, G.W.C. Hanks, & N. MacDonald (Eds.), Oxford textbook of palliative medicine (2<sup>nd</sup> ed., pp.883-907). New York: Oxford University Press.

VonGunten, C.F. & Twaddle, M.L. (1996). Terminal care for noncancer patients. Clinics in Geriatric Medicine, 12, 349-357.

Vortherms, R., Ryan, P., & Ward, S. (1992). Knowledge of, attitudes toward, and barriers to pharmacologic management of cancer pain in a statewide random sample of nurses. Research in Nursing & Health, 15, 459-466.

Wanzer, S.H., Federman, D.D., Adelstein, S.J., Cassel, C.K., Cassem, E.H., Cranford, R.E., Hook, E.W., Lo, B., Moertel, C.G., Safar, P., Stone, A., & VanEys, J. (1989). The physician's responsibility toward hopelessly ill patients. The New England Journal of Medicine, 320(13), 844-849.

World Health Organization (1990). Cancer pain relief and palliative care: Report of a WHO expert committee. Geneva: World Health Organization.



MICHIGAN STATE UNIVERSITY LIBRARIES



3 1293 02374 9991