

Morphine: Misconception and Moral Distress for Nurses Providing Care to the Dying

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Abstract

The physiological process of active dying may produce variable symptoms of anxiety, restlessness, difficulty breathing, fear, and pain which most would term suffering. For some, these symptoms are blessedly mild or brief, for others more severe and prolonged. Since the inception of hospice care in the United States in the mid 1970s, standards of care have advanced so that pain and suffering may be diminished during the dying process. A major component of that care is the use of morphine to relieve pain and ease respiratory distress. This thesis examines what is understood about the physiology of the dying process; the appropriate and effective use of morphine to ease suffering of the dying; the misconceptions regarding morphine and hastened death; the ethics supporting nurses' actions in administering morphine to dying patients; and how to diminish moral distress to enable nurses' to provide adequate symptom relief in the final days of a patient's life.

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Morphine: Misconception, and Moral Distress for Nurses Providing Care to the Dying

Dying is at once a fact of life, and a profound mystery. Death comes to all, yet each person experiences it in ways that are only partly accessible to the physician or family member, the philosopher, or researcher. In principle, humane care for those approaching death is a social obligation, as well as a personal offering from those directly involved.

In reality, both society and individuals often fall short of what is reasonably—if not simply—achievable. As a result, people have come both to fear a technologically over treated and protracted death and to dread the prospect of abandonment and untreated physical and emotional distress (Institute of Medicine (IOM), 1997, p. 1).

I learned many things during nursing school but received no specific instruction on how to care for a dying patient. Upon finding a patient pulseless and breathless an urgent Code Blue was called, and cardio-pulmonary resuscitation was initiated. Anatomy-Physiology classes focused on the intricacies of the human body but did not address the biological process of death. Nor did it discuss how to manage the symptoms of a dying person. As a nursing novice, I did not understand the process of the body shutting down. The focus was on curative care with little attention given to what happens when the quest for cure fails.

Now, after many years of nursing practice, I have a better understanding of what happens to a person when healing stops and dying begins. Working as a nurse caring for the elderly in long term care, and now in hospice care, has provided me with personal experience caring for the old and dying. On the job training made up for what my nursing education lacked. Caring for a person at the end of life's journey is memorable, and while I cannot say that I remember every experience I have had caring for a dying patient, I believe that I can recall many of them, most in vivid detail. Being present at the

moment of death is an experience that I find a privilege, an opportunity to accompany someone on the final days of their life journey.

Relying on practical experience rather than formal education in end-of-life care, I have become comfortable in caring for dying patients; a comfort level that led me to work as a hospice nurse. Many nurses, however, are uncomfortable and even try to avoid patient care during the final days and hours of life. Lack of formal nursing education on the physiology of dying, and appropriate use of medication to ease pain or respiratory distress, combined with limited practical experience may translate into poor care for the patient and result both in patient suffering during the dying process and a sense of inadequacy or moral distress for the nurse rendering that care.

Competent care at the end of life almost always requires the administration of medication to relieve physical suffering and psychological distress. In the final days of life, most patients benefit greatly from use of pain relieving medication, specifically morphine, to manage discomfort, breathing difficulties, and anxiety or restlessness. Morphine may be given through an intravenous line, by subcutaneous injection, or in a highly concentrated liquid that is absorbed through a patient's oral mucosa, the tissues in the mouth. These options for administration make it the drug of choice when a patient can no longer swallow pills, whether in the hospital, nursing home, or home setting. As a patient's symptoms increase, as their bodies become tolerant, and as death becomes imminent, nurses are often called upon to give increasing doses of morphine to ease suffering.

Nurses are expected to know the purpose, dosing, basic mechanism of action, and potential side effects of medication that they are administering to patients. A basic

understanding of morphine is that it is a highly effective opioid analgesic (pain reliever) but has the side effect of depressing respirations—morphine slows breathing. It is an easy assumption, then, that giving morphine to dying patients who are struggling to breathe would slow their breathing, possibly even resulting in death. While the physician orders morphine, the nurse at bedside must actually give it to the patient. In doing so, the nurse may feel that her actions are hastening the patient's death. Consequently, she may feel moral distress and find reasons not to administer it. As a result, patients may experience unnecessary physical or existential suffering.

The concept of hastening death is addressed by Dr. Ira Byock, a palliative care physician, in his book *The Best Care Possible*. He writes:

In discharging its responsibility to society as a repository of special knowledge and expertise, the profession of medicine as a whole, and the specialty of hospice and palliative care in particular, officially oppose hastening death. In fact, a formal ethical principle and precept of palliative care holds that the practice of palliative care does not intentionally hasten death. (2012, p. 279-280).

Byock, an advocate of compassionate care for the dying patient, makes it clear that intentionally hastening death is never the goal of palliative care. He continues, "...there is no ethical, physiologic, or pharmacologic reason today for any person to die in agony. On the contrary, allowing someone to die suffering is medically and ethically wrong" (p. 165). To find balance between perceived hastening of death and providing compassionate care, physicians who order medication to relieve pain or respiratory distress for a dying patient, and nurses who administer that medication often feel that they are walking a

tightrope between easing suffering and intentionally shortening life (Scanlon, 1998, p. 137). In the end, literally and figuratively, the nurse is the gatekeeper of patient care; it is ultimately her decision to administer or withhold morphine for a dying patient. Nurses, then, feel that they control, through use or avoidance of morphine, the trajectory of their patient's death.

This thesis will review a basic understanding of the physiology of the dying process; dispel myth and misconception surrounding use of morphine during that process; and explore the ethic of morphine administration as an acceptable standard of practice in end of life care. Increased understanding of the dying process as we observe it in the sphere of American medicine; the pharmacodynamics of morphine, its appropriate use as well as its limitations; and the ethical principles that support use of morphine to relieve physical and existential suffering of the dying, empowers nurses to provide compassionate, competent end of life care with diminished moral distress.

Use of Medical Narrative

Perhaps it was personal moral distress that led me to pursue a degree in Medical Humanities. Throughout my nursing career patients' stories have drawn me in and become entwined with my own narrative, particularly when dealing with death. Although I feel competent in the care I have provided to dying patients, certain narratives haunt me, and give me a desire to reach beyond clinical competence to a deeper understanding of humanity and ethics. The beautiful medical narratives shared by writers such as Ira Byock, Abraham Verghese, Sharon Kaufman, Helen Stanton Chapple, and William Carlos Williams, to name a few, serve to illustrate, illuminate, and educate us on the

ethics and morals surrounding medical care and the humans involved, both patients and care providers.

Medical narrative may be used both as a teaching tool to inform nurses about complex ethical concepts, and as a way to clarify a nurse's own feelings. Caring for a dying patient is never routine, each experience has a memorable impact on the nurse providing care. Johna Samir and Simi Rahman note, "The human capacity to understand the meaning and significance of stories is being recognized as critical for effective medical practice" (2011, p. 92). Sharing stories of caring for the dying allows us to "recognize, absorb, interpret, and be moved by stories of illness" (p. 93).

In this thesis I share personal nursing narrative, stories of care provided to dying patients. These narratives illuminate my feelings of moral distress regarding use of Morphine in end of life care. An article on writing as a tool in Medical Humanities asserts:

Stories create memorable and comprehensible structures, using clarifying devices such as causality, and are attentively heard and remembered. Writing narrative opens up wider thoughts, feelings, ideas and insights which, whether we know it or not, are central to human understanding, memory systems, and communication (Bolton, 2008, p. 131).

These narratives reveal personal struggles with ethical questions presented by, and insight into the rationale for care I provided to dying patients, and also attempt to help analyze the moral distress of other nurses involved. Stories about death may provoke deep emotion, but are also invaluablely instructive about the moral dilemmas that nurses face in caring for the dying.

The Institute of Medicine's Committee on Care at End of Life notes the,

Good care at the end of life depends on clinicians with strong interpersonal skills, clinical knowledge, technical proficiency, and respect for individuals, and it should be informed by scientific evidence, values and personal and professional experience. Clinical excellence is important because the frail condition of dying patients leaves little margin to rectify errors. Scientific and clinical knowledge are important, but so are compassion, communication skills, experience, and thoughtful reflection on the meaning of that experience (1997, p. 22).

The reflective narratives shared in this thesis begin with a case from almost thirty years ago, my first experience administering Morphine to an actively dying patient.

Personal Nursing Narrative I—Initiation

My first, intimate experience administering increasing doses of morphine to a dying patient had a profound impact on me and a lasting influence on my nursing practice.

During the clinical component of nursing school, I was never involved in caring for a dying patient. I do not remember any instruction about providing that type of care. During orientation as a new nurse, I learned all about calling a Code Blue to activate the response team of physicians, respiratory therapists, intensive care nurses, and anesthesiologist to resuscitate a person whose heartbeat and breathing had ceased. But I did not receive instruction on how to care for a patient who chose to allow natural death without resuscitative efforts, nor when and how to effectively administer morphine to relieve pain and suffering for that dying patient.

I made it almost to the end of my first year of nursing without having a patient die. At work on a general medical unit in a large community hospital, I received morning report from the night nurse and headed out to check on my assignment fully expecting to find all of my patients awake, alert, and breathing. I'll never forget the heart pounding fear I felt upon discovering one of my patients sitting up in bed, tipped over her breakfast tray, blue, cool, with no heart beat and not breathing. My shaking hand grasped the phone and dialed 0 to call the Code Blue. Yelling for help from nearby nurses, I quickly maneuvered the bed into a flat position, yanked the headboard off and roughly shoved the patient's lifeless body side to side to slide it under her, providing a hard surface on which to begin cardio-pulmonary resuscitation. As the Code Team arrived, the room quickly filled with people. To my relief, I was pushed aside to become an observer as they pumped on her chest, inserted a breathing tube, shoved in an intravenous line, and attempted to restart her heart with various medications. There was no restarting this patient's heart: her time on earth ended and as the code team retreated, I was left with a room full of discarded medical trash and a dead patient.

If care of the dying was not well covered in my nursing education, caring for a dead patient was never even mentioned. Up to that point, I'd managed to avoid the process of preparing a dead body. Experienced colleagues helped me clean up the mess, and then tackle the job of cleaning the body and wrapping it in the plastic shroud for transportation to the morgue. I'll never forget my feeling of helplessness watching the frantic, futile efforts of the code team. I will also never forget the feeling that, during the gentle cleansing and wrapping of that woman's body, I was somehow restoring her to

peace. My first nursing experience with death was awful, yet at the same time awe inducing. I have never forgotten it, and cannot imagine I ever will.

Over the following year, I experienced the death of a patient firsthand several times. In the process, I learned how to navigate a Code Blue and what happens when aggressive treatment stops in order to give the patient a more peaceful death. It was in my third year of nursing that I participated in a case that profoundly affected my view of the dying process and the role that I, as a nurse, could play.

After a year in Connecticut, I returned to Virginia where I'd started my nursing career. I worked as a float nurse filling in on any unit that was short-staffed. One evening, I was assigned to a medical step-down unit where we cared for patients just released from the Intensive Care Unit. The patients were quite sick and required close monitoring. One of the patients assigned to my care was a woman in her late fifties suffering from advanced chronic obstructive pulmonary disease more commonly known as emphysema. Sometimes these patients are called "blue bloaters," since lack of oxygen makes them blue and the steroids required to treat their condition cause both face and abdomen to become distended and round.

For some reason, this patient and I immediately connected. She struggled with each breath, but managed a sweet smile and expressed appreciation for any act of care. She shared with me her frustration with repeated hospitalizations—six times in eight weeks with only a few days at home. She was also frustrated with the loss of privacy and independence, noting that she could not shower alone and even required assistance on and off the toilet. Every small movement made her gasp for air; every tiny effort resulted in severe fatigue.

Over the course of that evening, I administered medication, monitored her IV, and made sure that her oxygen was maintained at the prescribed level. I felt sad and frustrated that I could really do nothing to ease her pain, either physical or psychic. As often as I could manage, I spent time just sitting with her exchanging small talk. When my shift ended, I left hoping I might be assigned to that unit the following evening in order to care for her again.

Indeed, the following evening I was fortunate to be assigned to both the same unit and same patients. My heart dropped, though, when I received shift report and heard that my patient had struggled through a very rough day. She was requiring more and more medication to sustain life as her oxygen level frequently plummeted. When I walked into her room I observed the same sweet smile but with lips that were blue and eyes that were sad. She quickly told me that she had made a decision to stop all medication. Threatened with the need to be put on a ventilator as her oxygen levels dropped, she knew that was something she never wanted to happen. Her quality of life had deteriorated; she was exhausted from the ongoing struggle to breathe; and she was sad knowing that her husband and daughter were spending more time at the hospital with her than at home pursuing their own lives. After many years of care, this patient fully understood that when she stopped taking medication her body would fill with fluid, her already fragile lungs would not be able to compensate, and eventually her heart would be overwhelmed and stop beating. In essence she was choosing to end her life.

I sensed the thought she had put into this decision, her determination, and her understanding of the finality of it. With her husband and daughter by her side, I knew that it was not a decision she had made alone. I was struck by the selflessness in which it had

been made—both on her part and on theirs in allowing her to make it. Her thoughtfulness and courage inspired me; as her nurse I knew I had to take action. Some nurses may have felt that they should dissuade the patient from this life ending decision, but somehow I realized that was not in her best interest, rather would have selfishly eased my own concerns. Instead, I placed a call to her primary physician who had been caring for her over many years who was aware that she was contemplating this choice and had discussed it with her at length. Instead of responding with surprise, he was prepared to accept her choice and to make her death as peaceful as possible.

On the doctor's orders I discontinued all of my patient's medication and started her on a morphine drip. Morphine is an opiate medication that diminishes pain but also works to dilate blood vessels in the lungs and impairs the brain's response to lowering oxygen levels in the blood. In doing so, Morphine relieves the sensation of air hunger—the feeling that a person has when they are not getting enough oxygen. In this way morphine both diminishes the patient's perception of respiratory distress, and provides pain relief at end of life. A side effect of morphine is slowing of the respiratory rate which many believe speeds the dying process.

With the passing of each hour, following doctor's orders, I increased the amount of morphine being administered. At first the patient was awake, able to speak to me, and her family who stayed by her side. With each increase in medication I asked the same question, "Are you sure this is what you want to do?" Each time she responded affirmatively, with no hesitation. After several hours, as oxygen levels dropped and the level of morphine became sedating, she was no longer able to respond. Then I turned to her husband to receive his permission to continue down this challenging road. Though

difficult for him to let her go, he chose to honor her wishes. Near the end of my shift the patient peacefully passed away.

Just as I have never forgotten my first experience losing a patient in a fairly violent, traumatic code blue situation, I will never, ever forget this experience. Although acting fully on the wishes of my patient, under physician orders, I believed it was my direct act of administering morphine that precipitated her death. Did my actions hasten her death, or did my actions allow her to die peacefully rather than drown in her own secretions as she battled for air? Was there something wrong with the sense of relief I felt when she took her final breath? My distress over the course of events that night was enough that I felt it necessary to keep quiet about what had happened in that hospital room. Though it would have been helpful, I did not discuss my concerns with my coworkers, my supervisor, or even my physician husband who might have shared his insight.

In spite of my unsettled, perhaps even guilty, feelings about that experience, I gravitated toward work with dying patients as I moved forward in my nursing career, and never shied away from providing end of life care. Within a few months of that patient's death, I left my hospital job and took my first position as a hospice nurse. Later I moved into work caring for the elderly in a long term care setting, a place where death is no stranger. My comfort level as nurse for the actively dying, which included administering morphine during their final days and hours, caused one administrator to jokingly call me an "Angel of Death." While I appreciated her recognition of my comfort with and ability to care for the dying, it felt troubling to have her imply that my care had any impact on the trajectory of death. Terms such as Angel of Death or Angel of Mercy imply extra

worldly abilities, and have negative connotations that may diminish a nurse's confidence in providing competent, compassionate care to the dying.

The Birth of Palliative and Hospice Care

So what does dying look like in our world today? Over the past fifty years, advances in research and technology have greatly improved the practice of medicine. At one time a sudden heart attack or stroke was often fatal. New treatment modalities such as clot-busting medication, implantable pacemakers and defibrillators, and advanced diagnostic techniques now allow for early intervention, making sudden death less likely (Morhaim, 2012, p. 11). New chemotherapeutic regimens and experimental treatment effectively battle even advanced cancers, allowing patients to live longer. Progress has been made in treatment of disease, yet the inevitable fact of mortality remains; in spite of tremendous medical advances, all humans will eventually die.

As Henry Fielding's Amelia observed, "It hath often been said that it is not death, but dying which is terrible" (1751). Death is the great equalizer, no matter what course our lives take we will all eventually die. In spite of this, dying is a topic that, perhaps outside of the milieu of Medical Humanities and Bioethics, is often avoided. While death is in fact, unavoidable, the course or trajectory of dying has many variables.

According to Ira Byock, "Death is the most inevitable fact of life" (2012, p. 2). Serious, chronic illness is an unexpected but real result of scientific progress of the late twentieth century. Instead of quick death from infection, trauma, or organ failure, we are now able to treat serious, complex illness and prolong life. Prolonged life may also mean prolonged struggles to manage chronic illness, resulting in dependence on others to assist

us with performing basic activities of daily living. At the end, limited mobility along with loss of vision, hearing, diminished taste and touch, and the ultimate indignity of cognitive decline conspire to reduce quality of life. Sudden death may not be desirable, but living to advanced old age may result in an unpleasant end. Byock notes, “It is not easy to die well in modern times” (p. 2).

New medical technology extends life but may also result in a slow decline and, often, a prolonged dying process. In order to provide care to those living with chronic illness, and address the needs of patients approaching death, the medical specialties of palliative and hospice care emerged.

Palliative Medicine was first introduced in the early 1980s. Palliative care focuses on management of the symptoms of illness, addressing physical, as well as psychological, spiritual, and family needs. The goal of care is to minimize physical and psychological stress during the disease trajectory, maximizing a patient’s quality of life. Patients and families are assisted in setting realistic goals of care, understanding that treatment centers on living with, rather than curing illness (Matzo & Sherman (Eds.), 2010, p. 84). All patients, whether suffering from a life-limiting illness or not, benefit from palliative care.

Unlike palliative care, hospice care is solely provided to patients with life-limiting illness. Patients receiving hospice care are no longer pursuing curative treatment and have a life expectancy of six months or less. The goal of hospice is to ease pain and suffering during the dying process. This involves a palliative focus on managing physical and psychological symptoms, while understanding that a cure is no longer attainable.

Hospice care originated in the Middle Ages when pilgrims suffering from physical and mental fatigue in their travels to the Holy Land received assistance from

religious orders who opened their doors and offered care. Based on that model of hospitality (thus the term hospice), the Sisters of Charity in Ireland opened a hospice to care for the ill, in 1879.

The modern day hospice was founded by Dame Cecily Saunders, a nurse who further trained as a social worker and physician. In 1967, she opened St. Christopher's Hospice in London, where she used a multidisciplinary approach to care for dying patients. Dame Saunders's care included around the clock administration of opioid medication, skilled nursing care, counseling for families, and a focus on addressing the spiritual needs of patient and family.

Inspired by the work of Dame Saunders in England, nurse Florence Wald opened an inpatient hospice in Branford, Connecticut in 1974, the first such facility in the United States. In addition to opening the first hospice, Ms. Wald worked tirelessly to promote, "holistic and humanistic care for the dying, and advocating nurses' education regarding care at the end of life" (Matzo & Sherman (Eds.), 2010, p. 84). In 1982, Congress enacted the Medicare hospice benefit as a source of payment for hospice care. The result of this was an exponential growth of hospice programs over the ensuing thirty years. In 1985, there were just over fifteen hundred hospices providing care. By 2009, the number had grown to five thousand with expansion continuing as the United States' population ages (National Hospice and Palliative Care Organization (NHPCO), 2013, p. 8).

Over the past two decades, hospice care and palliative medicine have become accepted models of practice. In 2011, there were 2,513,000 deaths in the United States, with 1,059,000 of those who died receiving hospice care at the end-of-life (NHPCO, p.4). Although acceptance of hospice is on the rise, over a million Americans die each year

without the physical, psychological, spiritual, and bereavement support that hospice care renders. The need for palliative and hospice care will continue to grow in the United States as our population ages (Brody, J., 2009, p. 115).

For nurses, hospice care “is directed toward the prevention and relief of suffering commonly associated with the dying process” (Scanlon, 1998, p. 140). Rather than offering medical care to cure disease or treat illness, nurses must adapt to providing palliative care to ease symptoms as the patient approaches death. Dan Morhaim writes in *The Better End*, “We [medical professionals] have been given a gift: the opportunity to actively participate in the drama of life’s final passage” (2012, p. 122).

The Dying Process

What is the definition of life’s “final passage,” and what does it entail? Prognosis for patients admitted to hospice care must be six months or less, and while that may officially mark the beginning of the dying process, this thesis will use the term “dying process” to refer specifically to the final few days of life, as bodily organ systems shut down and death becomes imminent.

Prognostication is an important tool, necessary to allow patients to receive adequate end of life care, yet there is ongoing difficulty for physicians as they struggle both to make a realistic prognosis, and to communicate that prognosis to patients and their families. Communicating bad news may cause physicians apprehension or distress, yet holding back a bad prognosis will negatively affect the patient and their family’s ability to make informed decisions, and determine end of life goals of care (IOM, 1997, p. 61).

According to Russell Portenoy, a respected palliative care physician and educator, physicians tend to overestimate a patient's prognosis by weeks or months. There is "terrible prognosticating" in the final one to four weeks of life, particularly for patients with diagnoses of congestive heart failure or chronic obstructive pulmonary disease (2012). Perhaps this is because physicians' brief visits with patients allow for them to capture only a snapshot in time. Bedside nurses, especially those in long term care and hospice, see the patient day after day and, thus, have a fuller picture and more realistic view of the patient's dying trajectory. Communication and the "art of prediction" are necessary components to the skill of prognostication (McPhee, Winker, Rabow, Pantilat, & Markowitz (Eds), 2011. P. 303).

In 1997, the Institute of Medicine published an extensive report, *Approaching Death: Improving Care at the End of Life*. Nursing and medical experts in the field of "chronically and severely ill patients, ethics, quality of life, health policy, health services research, law, economics, social services, and related fields" met over the course of a year, gathered data, and presented a report with the goal to improve care of the dying (IOM, 1997, p. vi). Although compiled 16 years ago, the information remains relevant, and is cited in recent writing about the dying process, i.e. Ira Byock's, *The Best Care Possible*, written in 2012. The Institute of Medicine report defines dying as "both a biological process and a psychological and social experience that occurs in a cultural context" (p. 46).

The biological process of dying elicits psychological and social experience, yet the exact biological processes that occur during active dying are poorly understood. Dr. Russell Portenoy, in a presentation given in May of 2012, states:

What are the physiological changes that occur in these hours before death?

Interestingly enough, when you go to the literature there is very little evidence of this; very few carefully done, rigorously performed observational studies. Most of what's in the literature are clinical observations from experienced clinicians. So I think it's just a framework. If anybody wanted to do research on the actively dying and applied very rigorous observational techniques to the active dying process we probably could learn a lot, because we don't really know that much about the characteristics that are prevalent or less prevalent, and we don't know whether or not different diseases or different populations of patients vary in the way active dying occurs.

As noted in *Approaching Death*, studying phenomena related to a process with uncertain timelines, with the end point being death, which is highly variable, presents challenges in researching the dying process,. Additionally, obtaining informed consent from patients who may lack competence is difficult; as is data collection from patients who may be suffering, weak, confused, or who die before being questioned. All add to the difficulties, and ultimately the lack of rigorous observational study. What we know about what occurs, what patients can expect during the active dying process, is most often obtained from clinical observation. Anecdotal evidence gives us insight into how the dying process is experienced, and provides a guide for nurses assisting patients making end of life care decisions (Winter, Parker, & Schneider, 2007, p. 621).

As a patient is nearing their final days or hours of life, the burden of prognostication for how much time is left falls on the shoulders of the nurse providing care. Nurses use particular language to define stages of the dying process. Patients with a

terminal diagnosis who are still eating and drinking, able to communicate, and participate in activities of daily living are considered to be slowly declining. Sometimes suddenly, but more often gradually, patients' appetites decrease; they become weaker and require more assistance with activities of daily living; and require much more sleep, often more than twelve to fourteen hours of sleep each day. This period is called transition. As patients enter the transition phase of dying, sleep continues to increase; there may be decreased urine output or difficulty controlling urine flow, causing incontinence; little interest in food; and less desire to interact with others. Physical and existential pain may develop, or increase, as the body actively shuts down and the patient comes face to face with the end of their life journey.

The Institute of Medicine report *Approaching Death* outlines four deficiencies that negatively effect care for the dying. The first deficiency is caused by medical pursuit of ineffective, or even harmful, treatment, while failing to provide care that is supportive and relieves distressing symptoms. Second, excellent care at end of life may be impeded by, "legal, organizational, and economic obstacles." These obstacles include laws that negatively impact prescribing of opiates; financial incentives that favor overtreatment rather than palliative care; and organizational failure to provide for continuity of care, along with lack of recognition or support for expansion of palliative care services over more lucrative fields of medicine (p. 264). Third, the education of medical professionals, both physicians and nurses, inadequately prepares them to care well for the dying. Finally, "we still know too little about how people die; how they want to die; and how different kinds of physical, emotional, and spiritual care might better serve the dying and those close to them" (p. 265).

The Journal of Palliative Medicine offers a patient information sheet “Understanding the Dying Process: Transitions during Final Days to Hours” (Moneymaker, 2005, p. 1079). This fact sheet notes that each death, as each person, is unique but offers the following commonalities:

- Social changes, redefining “self” within the context of relationship;
- Emotional changes, addressing the inevitability of death and engages in attempts at “closure”;
- Spiritual changes, “life review,” reflections on “meaning,” addressing forgiveness and reconciliation, making one’s peace;
- Physical changes, physiological processes change as the body prepares to “shut down” and “let go” ...to die.

The social, emotional, and spiritual will all affect the physical process of dying. Nursing care for the patient extends beyond management of physical symptoms, and must also address social, emotional and spiritual needs.

The Visiting Nurse Association of Santa Cruz County published a booklet, *When the Time Comes*, which is utilized by the hospice where I work. It is given to patients and families on admission to our program. The purpose of the booklet is to help them navigate the final journey of dying. It includes this helpful timeline, noting “Because each person’s dying process is unique to him or her, the outline below is only a general guide. People may exhibit some or all of these signs and symptoms at varying times” (2008, p.15).

One to Three Months:

- Withdrawal from people and activities
- Communicating less

- Eating and drinking less
- Sleeping more

One to Two weeks:

- Disorientation and confusion
- Use of symbolic language (“I want to go home”)
- Talking to others not present in the room
- Physical changes:
 - Increase or decrease in pulse
 - Decrease in blood pressure
 - Changes in skin color
 - Irregularities in breathing
 - Changes in body temperature, hot/cold
 - Not eating, taking little or no fluids

Days to Hours:

- Sleeping most of the time
- Surge of energy
- Restlessness
- Difficulty swallowing
- Further discoloration of skin
- Ongoing changes in breathing (long pauses between breaths)
- Rattling breath sounds
- Weak pulse
- Further decrease in blood pressure
- Decreased urine output or no urine
- Eyelids no longer able to close completely

Minutes:

- Shallow breaths with longer pauses
- Mouth open
- Unresponsive (p. 15-16).

Nurses, who regularly care for the dying, whether in the hospital, long term care facility, or hospice, depend on skills of observation, and familiarity with the symptoms of approaching death to ascertain where a patient is in this process at each visit. These skills

are necessary to determine that death is impending; usually precipitated by a “brief, recognizable clinical phenomenon [that] occurs at the conclusion of a terminal illness” (Dendaas, 2002, p. 498).

During active dying, when death is hours or minutes away, the body’s major organ systems are in a cascade of shutting down. Symptoms that occur during the final hours or minutes may include moaning; increased secretions with fluid oozing from the nose, or foaming from the mouth; labored or difficult breathing; bluish coloration around nose and lips; mottled skin color and coolness of hands and feet; loss of bowel and bladder control; muscle jerking or twitching; and an unfocused look in the eyes. At this point most patients are in a deep sleep, seemingly not aware of all that is occurring in their bodies, yet these changes are troubling for loved ones—and often nurses—to observe. In some patients weakening muscles in the throat and chest lose the ability to clear mucus. As mucus accumulates in the back of a patient’s throat it may cause a loud gurgling sound or rattle, commonly referred to as the death rattle (Green, 2008. p.45).

Although little is understood about what actually triggers the physiological shift from living to actively dying, once the dying process has begun the focus of nursing care shifts to alleviation of suffering. Portenoy notes that active dying is both recognizable and actionable; it is necessary to recognize the symptoms of active dying in order to provide appropriate, supportive care to the patient and their family (2012, minute 24). Claire Nunn writes, “The dying process is a complex physiological response to end stage disease, which may be characterized by symptoms that require intensive interventions to ensure comfort for the patient and a sense of well-being for the carers (2010, p. 474). Nunn goes on to note that, “nurses are at the frontline of care and, consequently, make

decisions about, interventions, and administration of prescribed medicines that ensure comfort and dignity for patients at end of life” (p. 480). As a patient nears death, their ability to effectively communicate is often lost. As that occurs, the dying person relinquishes control to those providing care. They, in turn, must strive to respect the wishes of the patient until the moment of death, and by so doing maintain the patient’s comfort and dignity (Seymour, Bellamy, Gott, Ahmedza, & Clark, 2002, p. 289).

Symptom management for actively dying patients, whether in the hospital, at home, or in a long term care facility includes pharmacological and non-pharmacological actions. Simple things such as allowing family to be present around the clock, playing music, gentle massage of the hands and feet, and turning and repositioning every two hours, provide comfort for the dying. The dying process, though, rarely involves just slipping away while listening to music or poetry; often there is pain, respiratory distress, anxiety, and other unpleasant physical effects. If a good death is one that is free from pain and distress, then medical intervention is often required. A romanticized view of good death is not always achievable, rather:

A worthy and more achievable goal is death dignified by care that honors and protects—indeed cherishes—those who are dying, that conveys by word and action that dignity resides in people, not physical attributes, and that helps people to preserve their integrity while coping with unavoidable physical insults and losses (IOM, 1997, p. 25.)

Nurses must utilize all of the tools available to alleviate the physical insults that occur during the dying process. In addition to the non-pharmacological actions outlined above, symptom relief for dying patients most often requires use of medication. Hospices

use a standard symptom relief kit which includes: Scopolamine or atropine to minimize secretions and diminish rattling noise when breathing; lorazepam and haldol to treat restlessness and anxiety; reglan and benadryl for nausea; Tylenol for fever; and morphine for pain and respiratory distress. These medications may be administered in routes that do not require the patient to swallow, either in a highly concentrated liquid which is absorbed sublingually, under the tongue; as a topical gel that is applied to the inner wrist; or as a rectal suppository. It does not take the expertise of a professional nurse to give these medications, family members are taught how to administer the medication to patients being cared for at home. The challenge is not in giving the medication for symptom relief, it is in recognizing the need to give it.

Assessing symptoms such as fever or respiratory distress may be accomplished through objective measures, i.e. temperature or blood oxygen level, making the decision to administer medication straightforward. Pain assessment is subjective, therefore more challenging for the nurse to assess, particularly when caring for patients who can no longer speak. Pain is defined as “a subjective, unpleasant sensory and/or emotional experience that may be exhibited in subtle as well as obvious ways” (Nunn, 2010, p. 475). Dr. Robert L. Fine defines total pain, a term first articulated by Dr. Cicely Saunders. According to Fine, total pain includes not just somatic, visceral, or nerve pain, but also symptoms of nausea, fatigue, difficulty breathing, and sleep disturbance, along with emotional pain—depression, grief, anxiety; social pain from isolation, fear of death, economic worries; and spiritual pain which may include loss of hope, feelings of despair, struggles with the concept of God, or questions about purpose and meaning in life (2007,

p. 7). Managing all aspects of pain—physical, psychological, social, or spiritual—is the goal of compassionate nursing care for the dying patient.

During the earlier stages in the dying process management of psychological, social, and spiritual pain may receive as much, or more, attention as treating physical pain. When a patient moves through transition and is actively dying, management of physical pain comes to the fore. Morphine is the “gold standard” for treating pain and respiratory distress in actively dying patients (Nunn, 2010, p. 476).

Personal Nursing Narrative II – Easing the Pain of Letting Go

Sometimes we learn something we least expect from our patients. Susan was just a few years older than me, yet our lives couldn't have been more different. I was a new mother, just returning to work after maternity leave, while she was battling against the final stages colon cancer.

It was hard to contain my horror as I took the dressing off of her abdomen to reveal the tumor growing through the surface of her skin. Thankfully she turned her head away, not wanting to see such visible evidence of the disease robbing her of life. She was my first young hospice patient. Her body was truly betraying her strong spirit, and her desire to live.

That desire to live was evident to me when she asked me to renew her prescription for birth control pills. Looking at her emaciated body that was essentially bedbound, at first I couldn't fathom why that was important to her—in all honesty I couldn't imagine that she and her husband were still sexually active. It took me awhile to

understand that whether she was sexually active or not, she was not at all ready to surrender her identity as a sexual being.

As Susan's disease rapidly progressed it became apparent that she would also not easily surrender to death. The tumor protruding through her skin was enveloping her internal organs, putting pressure on her belly that caused excruciating pain. She had a small pump that fed a constant stream of morphine through a tiny needle into what little fat was left on her upper thigh. By the time I began caring for her, her tiny body required 50 milligrams of morphine each hour to combat the pain. Even with that, she was often uncomfortable, particularly after she ate or drank. Over the next few weeks, the doctor, Susan, her husband, and I worked to manage the amount of morphine it took to keep her comfortable while not making her too sedated.

It took a team of family and friends to care for Susan during her final weeks. Her husband somehow managed to balance caring for her at night with keeping up at work. During the day Susan's mother or sister would stay with her. Their tiny townhouse that was once a cozy home turned into a crowded combination of home, hotel, and hospice.

As the days slipped by, Susan grew thinner; her strength ebbed until she could no longer get out of bed at all. She slept most of the time. Confusion, perhaps from the disease process, or perhaps from the high doses of morphine, crept in when she was awake. Often she tossed restlessly in the bed, uncomfortable with the weight of tumor pressing down, struggling with pain.

When death neared, Susan confided in me that she wasn't sure she wanted her husband there when she died. She wanted him to remember her as she was before she got sick. On the other hand, it was only when he was at her side that she relaxed into deeper

sleep. I tried to reassure her that her husband was strong enough to be with her when she died, and to be able to have beautiful memories of their life together before she became ill.

Susan's final days were a struggle; she battled death to the bitter end. Without food or fluids, dehydration, a natural anesthetic, set in. Although she had less physical pain, it was sorrow over letting go of her young life that seemed to grip her entire body. We kept her morphine pump flowing, which, along with some sedating medicine and the natural progression of dying, allowed her finally to lapse into unresponsiveness. As her husband cradled her tiny, limp body in his arms she took her final breath.

Susan's death was instructive for me as a young, inexperienced hospice nurse. She reminded me of the need to treat the whole person, not just the sick patient that we see; and of the importance of treating both physical and emotional pain during the dying process. Morphine was not able to miraculously relieve all of her pain and suffering, but I would not have wanted to watch her die without it.

Morphine History

The birth of Morphine may be traced to the poppy fields of the Bengel Province in India, where seeds of the flower were harvested and converted to opium. In 1773, Britain conquered the Bengel Province and seized the opportunity to use opium as currency to pay for goods in trade with China, increasing supply in a country where use of the addictive opiate was already widespread. The dawn of the industrial age in the United States offered work opportunity to many Asians, who brought opium into our country, along with the opium addiction.

In the early 1800s, effort was being made to “preserve the medicinal properties of opium such as pain relief and cough suppression,” while reducing its addictive properties (Mandal, n.d.-a, para.6). In 1806 pharmacy assistant named Friedrich Wilhelm Serturner isolated the “crystalline compound from crude opium after immersing it in ammoniated hot water” (para.6). He followed this with testing of the compound on dogs, with lethal results. After lowering the dose, he bravely tested the drug himself; finding it produced pain relief and euphoria, though in higher doses it caused adverse effects such as nausea, vomiting, cough suppression, slowed breathing, constipation, and psychiatric effects. The pain relieving effect, though, was ten times greater than that from use of opium.

Morpheus, the Greek god of dreams was the namesake for Morphine

Invention of the hypodermic syringe in 1850, allowed for further use of morphine as an adjunct to general anesthetics; its use “reduced the amount of chloroform needed to produce anesthesia” (Brownstein, 1993, p. 539). Experimentation and efforts to produce a less addictive, yet still effective opiate led to synthesis of heroin in the late 1800s, and methadone in the mid-1900s. Experimentation to formulate medically useful opioids resulted in production of codeine, fentanyl, and oxycontin; all widely used today (Institute for Substance Abuse Treatment Evaluation, n.d., para. 5, 7, 8).

Morphine Facts

Morphine is a powerful pain reliever that also produces a sense of euphoria. When introduced into the human body, morphine and other opioids attach, or bind, to proteins referred to as opiate receptors. In binding to these receptors, they “block the transmission of pain messages to the brain and tend to induce euphoria by affecting the brain regions

that mediate pleasure” (Mandal, n.d.-b, p. 1). Morphine attaches to three types of receptors, Mu receptors found in the brain stem and hypothalamus; kappa receptors in the limbic system, the forebrain, the spinal cord, and the brain stem; and delta receptors found throughout the brain, spinal cord, and digestive tract. In addition to pain relief and euphoria, activation of these receptors can produce sedation, and antidepressant effects which would be most likely be considered positive effects, yet also cause the less desirable effects of respiratory depression, constipation, and increased physical dependence (Robertson, n.d., para. 4).

After it is metabolized in the liver, only about 40-50% of the morphine dosage actually reaches the nervous system, the rest is processed in the kidneys and then eliminated in urine. This means that only 4 to 5 milligrams out of a 10 milligram dose actually impact the nervous system to provide analgesia. Patients who have kidney failure may not eliminate as much morphine therefore requiring close monitoring to titrate adequate dosing without causing greater adverse effects (McPhee, Winker, Rabow, Pantilat, & Markowitz (Eds.), 2011, p. 52). The most common adverse effects of morphine include nausea or vomiting, stomach cramps, sedation, itching due to allergic skin reaction, hallucinations or delirium when given in high doses, and myoclonus (muscle twitching). Levels of morphine peak in the body about thirty minutes after oral administration with a half-life around 120 minutes. It takes about thirty minutes to feel the full effect of a morphine dose, and within two hours it has lost about half of its concentration in the blood. This explains why morphine is given to actively dying patients on an every two hour schedule in order to maintain a steady delivery of pain relief (Robertson, 2014, Mandal, n.d.-b, para. 6).

Morphine is an inexpensive, effective analgesic routinely used to treat pain. It may be administered orally (swallowed), sublingually (under the tongue) or transmucosally (absorbed through tissues in the mouth), subcutaneously (injected into fat), intravenously (directly into the bloodstream through venous access), through spinal injection, or inhaled (McPhee, Winker, Rabow, Pantilat, & Markowitz (Eds.), p. 66.). When a patient is actively dying and no longer able to swallow, morphine is given in a highly concentrated liquid form that allows for a small amount, less than one cubic centimeter (1cc), to be placed under the patient's tongue where it absorbed into the bloodstream through the oral mucosa. Because morphine is available as a generic medication it is the most economically feasible drug for hospices with a daily fixed reimbursement rate to use; it costs just pennies per dose (Nobilette, personal communication, 2014).

Morphine relieves physical and existential (psychological, social, and spiritual) pain, and eases respiratory distress for actively dying patients. It can be easily given to patients who can no longer swallow, through sublingual administration, at minimal cost. It works rapidly yet does not linger in the body so if there is an adverse reaction it will not be prolonged. In spite of these many benefits, and widespread use of morphine to manage symptoms of the dying, many misconceptions remain.

Morphine Misconception

The primary misconception, held by physicians and nurses alike, is that morphine hastens death by depressing, or slowing respirations. In his book, *The Better End*:

Surviving (and Dying) on your own Terms in Today's Modern Medical World, Dan Morhaim, M.D. perpetuates this misconception:

No one wants to suffer needlessly, and modern medicines and pain management techniques have made tremendous progress in relieving pain and discomfort. Still, there are issues to be considered. Some pain medicines can hasten death. For example, narcotics such as morphine, Dilaudid, codeine, and OxyContin are mainstays of pain treatment. But these medicines have side effects, including respiratory depression—reducing the person's ability to breathe. An overdose can lead to death. But it's a fine line in distinguishing when pain relief crosses over to actually speeding the death process along. When does effective pain relief become assisted suicide, which is often a felony? The state has an interest in protecting its citizens' lives, but laws can also have a chilling effect on caregivers. If it were perceived that a doctor "overprescribed" narcotics for pain, even at the request of a patient, then that doctor could face criminal or civil prosecution (2012, p. 59).

Morhaim's statement that "Some medicines can hasten death," is true, of course—any medicine can hasten death if given inappropriately or in excess—yet is a gross oversimplification and misstatement of fact.

Respected medical anthropologist, Sharon Kaufman contributes to the false perception that morphine hastens death by writing:

There are numerous approaches among doctors to the use of morphine for pain control, shortness of breath, and dying...many use morphine more

liberally in its intravenous form and give nurses a great deal of discretion in “turning it up” to relieve symptoms of discomfort, whether those symptoms are actually observed or are imputed... Some physicians will use morphine not only to relieve pain and what they interpret to be suffering but also to hasten death, especially at the request of the family. In addition to the range of individual practices I observed, I was told by doctors and nurses who have worked elsewhere that regions of the United States vary in the use of morphine near the end of life. California is generally considered more liberal. Each physician decides—in the context of local practices and his or her own values—how close the use of morphine, by intravenous drip, comes to assisting death (2005, p. 136.).

This type of rhetoric, based on anecdote rather than evidence based medicine, perpetuates misconceptions about morphine hastening death, and promotes unwarranted fear in caregivers. It negatively affects proper use of morphine to alleviate pain in dying patients.

Lewis M. Cohen’s book, *No Good Deed* (2010), documents the legal case of two nurses accused of homicide. A nursing assistant on their unit observed them administering morphine to a dying patient and felt that their actions precipitated the patient’s death. Ultimately the nurses were exonerated, but their experience resulted in great emotional and professional distress for all involved. Cohen notes, “...accused and accusers are caught in the middle of society’s profound confusion and ambivalence about end-of-life issues and the choices of terminally ill patients...”(p. 234).

In 1998, Ann Alpers studied a marked increase in prosecution over the previous decade, of physicians and nurses accused of administering death hastening medication to dying patients. Her fascinating article, “Criminal Act or Palliative Care: Prosecutions Involving the Care of the Dying,” concludes that lack of a professional standard of care for evidenced based dosing of opioid medication for patients who are actively dying results in “considerable variability” both in cancer pain management, and for treating terminally ill patients (1998, p. 321). Without professional guidelines, the actions of doctors and nurses who administer morphine to dying patients remain vulnerable to misinterpretation, and thereby open to accusations of hastening death.

On the other hand, as long as there is the misconception that morphine hastens death through respiratory depression, doctors and nurses will remain fearful of giving it to dying patients, and they, in turn, will remain vulnerable to unnecessary pain and suffering. Alpers notes that although the *New England Journal of Medicine* published clinical practice guidelines for management of pain in cancer patients, health care providers who practice together still disagree sharply over appropriate doses of opioids (p. 321). She concluded that, “fear of criminal liability or investigation should not deter physicians or nurses from aggressively using opioid analgesics to manage terminal pain, provided that pain has been carefully assessed and treated and communication with families and involved professional caregivers is thorough” (p. 326).

Dr. Robert Fine, referring to a placebo-controlled study of opioids given to cancer patients having difficulty breathing, reported efficacious use of opioids “without significant respiratory depression.” He concluded, “The reality is that respiratory depression with opioids in the setting of life-limiting illness is rare” (2007, p. 9). Fine

suggested that a patient's respiratory rate may be elevated due to pain which is a "potent stimulus to breathe" (p. 9). Pain relief due to morphine allows the patient to relax and respirations to slow. Rather than diminished oxygenation due to respiratory depression, a slower respiratory rate may actually improve the efficiency of the lungs.

J. Bakker, T. Jansen, A. Lima, and E. Kompanje also examined the paradoxical effect of opioid administration to the dying. They posited that respiratory depression from opioids does not hasten death but, in fact, may prolong life (2008, p. 152). Simply explained, remaining alive depends on a balance between oxygen demand and oxygen delivery, or in other words, oxygen consumption and oxygen supply. When a person is dying, their cardiac output decreases, which in turn decreases the flow of oxygen-carrying blood to the lungs. The brain senses low oxygen levels in the arterial blood flow, and stimulates the body to bring in more oxygen by increasing the rate of breathing, as the heart beats faster trying to pump more blood to the lungs. Unfortunately, to beat and breathe at a faster rate, the heart and lungs have to work harder, and harder work increases oxygen demand. Soon this cycle leads to hypoxia, a severe shortage of oxygen circulating in the blood, which causes major organ failure, and ultimately, death. Morphine, by slowing respirations, actually decreases the work of the heart and lungs, reducing oxygen consumption. Less oxygen used by the heart and lungs increases oxygen levels in the blood. Increased blood oxygen provides fuel for other major body organs like the brain and kidneys, thereby prolonging life rather than hastening death (p. 153-154). In addition, morphine, by relaxing respirations, also moderates the reflexive drive to breathe, reducing the dying patient's awareness of the struggle to get enough oxygen

(IOM, 1997, p. 242). In other words, it diminishes the patient's feeling that they can't catch their breath or are suffocating.

A retrospective study completed in 1998, reviewed the records of 453 patients who received morphine while residing in an inpatient hospice setting. Of those patients, fifty-five received high doses of morphine, more than 299 milligrams per day, some took almost 600 milligrams over a twenty four hour period. There was no statistically significant difference in survival time among all groups. In addition, "The absence of clinical respiratory depression in all patients receiving high dose morphine provides strong evidence that the possibility of inducing this complication and hastening a patients' demise has been exaggerated. This should encourage physicians who are still reluctant to use higher dose morphine..." (Bercovitch, Waller, & Adunsky, 1999, p. 873-875). A study undertaken in 2006, explored the relationship between opioid use and survival among hospice patients, analyzing data from over one thousand patients to determine the effect of increasing doses of morphine on length of time until death. Results showed little risk of opioid toxicity when administered to dying patients. The authors conclude that under treatment of pain is of far greater concern than the risk of hastened death, and urge physicians to use opioids to relieve suffering in dying patients (Portenoy, et al 2006, p. 538-539.)

Fear of addiction is often mentioned in connection with morphine use. For patients who are actively dying, this concern is ill-placed. If a patient has pain, physical or existential, use of morphine to alleviate that pain is strongly indicated; any concern over development of dependence or compulsive use is misconceived. Diversion of the

patient's morphine by family members with addiction should be of greater concern (Fine, 2007, p. 8.).

Patients who take morphine over a period of time to control pain may develop dependence on, and tolerance to morphine. The patient's brain and body become physiologically adapted to morphine over time. Abrupt cessation of morphine for patients who have been regularly taking it causes unpleasant physical withdrawal symptoms such as sweating, headaches, and return of pain. This adaptation diminishes morphine's effect. This diminution may be to both side effects from the medication, and to the medications efficacy (Fine, 2007, p. 8). Tolerance and dependence are expected effects of morphine, but are not indicators of addiction and therefore should not be used as reasons to avoid administering it to patients.

It is important, across all healthcare settings, for there to be consistency in morphine administration once it is initiated as part of patient care, particularly when used to manage pain in actively dying patients. Around the clock dosing allows for better pain relief by keeping plasma levels of morphine stable (Matzo & Sherman, (Eds.) 2010, p. 375). It is important to observe patients for tolerance to morphine and increase dosing accordingly.

The best medical care follows evidence based practice. As such, it seems imperative for physicians and nurses to accept morphine administration as a standard of practice and utilize it to provide effective, compassionate care to the dying.

Personal Nursing Narrative III—Good Death Bad Death

Nurses who care for the dying understand the concept of good death and bad death. A good death is more than just dying with limited pain and physical suffering, although that is important. Good death may also mean the patient is able to have closure; to say goodbye to loved ones and express that they're ready to die.

Conversely, a bad death may be characterized by physical symptoms that cause distress for the patient and/or the family such as pain, respiratory distress, and death rattle breathing. It might also be a bad death because the dying person is struggling psychologically, either with a longing to remain alive or with a desire for the dying process to end more quickly. Sometimes when death is imminent terminal agitation, a sudden burst of physical and psychic energy exhibited through restless, almost frantic, movement, accompanied by vivid dreams, hallucinations, anxiety, or frustration sets in.

Nurses who accompany patients on their death journey come away with the feeling that they have had an impact on whether that death is good or bad; and thus, can view their own experience as good or bad. For the patient, bad death ends with the last heartbeat, but for the nurse, a bad death lingers and haunts future experience. I struggle to tell Jenny's story because my shortcomings as her hospice nurse remain so upsetting to me.

I thought Jenny would have a good death. When the doctor diagnosed advanced, inoperable pancreatic cancer, she accepted it with the same graciousness in which she had lived all her life. She went home, packed up her apartment, and moved to the assisted living unit to receive hospice care with barely a word of fear or regret over her new circumstance.

I felt so fortunate to be one of her hospice nurses. We'd known each other for a decade; often engaging in conversation ranging from the quality of food in the café, to deep discussion of theology. I appreciated Jenny's intellect and pragmatism; I knew that she would use that pragmatism to deal with dying just as she lived.

Jenny was given a prognosis of three to six months, and so, just a few weeks later, we were all surprised when she had a very rapid turn for the worse. She suddenly went from walking, talking, and eating, to bedridden, in pain, and struggling to breathe. It didn't matter what caused this quick decline, it only mattered that we get her symptoms under control so she could be comfortable. The assisted living nurses and I reviewed the medication orders and started giving her morphine every two to four hours to manage pain, along with lorazepam every six hours to keep her mildly sedated and relaxed.

Her grown children and grandchildren were called, at her request, and arrived over the next day to sit vigil with her. We all expected death to come quickly and easily since Jenny told everyone she was ready to go. Her room had the air of a subdued family reunion with Jenny reigning over it all from her bed. Day one rolled into day two, then, day three. Jenny and her family members began to feel impatient with the dying process; things were just taking too long. On top of that, the nights were very difficult. Jenny's daughter stayed with her, trying to sleep in the chair at bedside. The overnight nurse was reluctant to administer morphine to Jenny even every four hours. Jenny's daughter requested it on her mother's behalf, but when the nurse checked Jenny's blood pressure she said it was too low to safely give the morphine.

This incident was the first thing I heard about when I made a hospice visit that morning. Sure enough, the nurse documented her actions in Jenny's medical record,

noting that she held the morphine because the patient had very low blood pressure. She also documented that the patient was “sleeping” so didn’t have pain. Jenny was actively dying; low blood pressure was to be expected. She needed steady dosing of morphine to keep her comfortable and to decrease any perception of a struggle to breathe.

The relationship between hospice nurses, who visit a few times a week for an hour or so, and the nurses who staff long term care facilities, is complicated. The facility nurses care for the patient day after day, therefore they know the patients well. Facility nurses provide the round the clock hands on delivery of care; hospice nurses provide intermittent hands on care but are available round the clock to recommend actions to be taken by the facility staff to maintain the patient’s comfort. The very nature of hospice nursing requires hospice nurses to develop a close relationship with the patient and family quickly in order to provide compassionate, individualized care during a stressful time. It’s natural for there to be some territoriality, and for nurses to struggle to work collaboratively. It is imperative, though, to focus on the patient’s needs, and strive to set aside barriers to good patient care.

Unfortunately for Jenny, barriers to care were erected. I visited during the day so I didn’t speak directly with the nurse to ask why she’d made the poor decision to withhold morphine in the middle of the night. Instead, I spoke to the administrative nurse, and the nurse providing care that day, to stress the need to give morphine around the clock. I also spent time with Jenny and her daughter, first calming them down about the overnight upset, then reassuring them that all was set for that night. In fact, I felt so confident that Jenny would be well cared for, I told her exhausted daughter to go sleep at home for the night.

Instead of assuming that all would go well, I should have called Jenny's doctor for an order to change the morphine from being given prn, as needed, to a standing order, to be given every two hours around the clock. Because I didn't change morphine to a standing order, the overnight nurse had discretion in deciding when, and if, to medicate Jenny. She went against the urging of the other nurses, the recommendation I had written in the chart, and Jenny's obvious need to stay on morphine regularly to keep her pain and suffering. She did not give Jenny any morphine from midnight on. When the day shift nurse arrived at 7 a.m., she found Jenny restless, uncomfortable, breathing rapidly, and frightened. The nurse quickly gave her a dose of morphine, just as Jenny's daughter arrived.

When I made a visit a short time later, Jenny was resting comfortably, but her daughter was justifiably furious with me. We had a long discussion about the situation in which she said that Jenny's prolonged dying process was inhumane; that we treat dogs better than that. I couldn't defend the actions of the night nurse; I could only suggest that something in her moral code kept her from giving morphine, perhaps believing that it would hasten Jenny's death.

That was the last time I saw Jenny. When I left that morning, Jenny's daughter called my supervisor and requested a different hospice nurse to manage care. Jenny passed away a short time later. Regret over my role in her struggles during the dying process, and the lack of peace she and her family felt at the end remains troubling for me. It was a lesson on the need to work harder to disabuse nurses of misconceptions about morphine; and to communicate with nurses about the ethics of morphine administration

in order to diminish moral distress and allow appropriate administration of morphine to dying patients.

The Ethics of Morphine Administration to the Dying

The Code of Ethics for Nurses includes the following interpretive statement:

Nurses are leaders and vigilant advocates for the delivery of dignified and humane care. Nurses actively participate in assessing and assuring the responsible and appropriate use of interventions in order to minimize unwarranted or unwanted treatment and patient suffering. The acceptability and importance of carefully considered decisions regarding resuscitations status, withholding and withdrawing life-sustaining therapies, forgoing medically provided nutrition and hydration, aggressive pain and symptom management and advance directives are increasingly evident. The nurse should provide interventions to relieve pain and other symptoms in the dying patient even when those interventions entail risks of hastening death. However, nurses may not act with the sole intent of ending a patient's life even though such action may be motivated by compassion, respect for patient autonomy and quality of life considerations. Nurses have invaluable experience, knowledge, and insight into care at the end of life and should be actively involved in research, education, practice, and policy development (American Nurses Association (ANA), 2001, p. 12).

It is challenging for nurses to discern what is ethically reasonable in providing interventions that might even entail hastening death. Understanding that many nurses

have a misconception that morphine hastens death, it is important to look at the ethics that guide nursing practice in care for the dying.

Merriam-Webster Dictionary defines ethic as “rules of behavior based on what is morally good and bad.” Ethics, then, is the study of those rules; often a within a philosophical or theoretical domain. A moral is a particular belief of what is right or wrong, and morality refers to the practice of those morals which guide our actions. To differentiate the two: ethics is the process of examining and weighing our thoughts and beliefs; morality is how we act on those beliefs. An ethical dilemma occurs when there is question over which course of action is the right, or good, course of action. An ethical dilemma that is unresolved causes moral distress (Highfield, n.d.).

In the hierarchy of healthcare, nurses’ actions are guided by physician orders, orders that often leave room for interpretation. Most physician orders to treat pain, using morphine or other analgesics, are written as prn (pro re nata), to be given as needed. Nurses, then, must assess the patient to determine if, when, and how much medication to give the patient. Even if an order is written as a standing order, to be given in specific doses at specified times, nurses may override those instructions with documented cause. Nurses are almost always responsible for determining when and if a patient needs to be given morphine, and then for actually administering it to the patient. A nurse who believes that giving morphine will hasten death, yet observes the patient suffering from pain or respiratory distress if she does not give it, faces an ethical dilemma which may induce moral distress.

Dispelling moral distress over use of morphine should simply be accomplished by dissemination of research that indicates that use of morphine does not, in fact, hasten

death. The article, “High Dose Morphine Use in the Hospice Setting” concludes that even high doses of morphine do not affect patient survival” (Bercovitch, Waller, & Adunsky, 1999, p. 871). The United States Conference of Catholic Bishops acknowledges that “many doctors hesitate to give dying patients adequate pain relief,” because they lack knowledge about the “medically appropriate use of analgesic drugs” (Doerflinger & Gomez, n.d., para. 8). They also note that doctors need not hesitate to increase doses of morphine, with the maximum dose being that which relieves the patient’s pain.

Still, myth and misconception about morphine remains widespread. The current web page for the New Jersey Hospice and Palliative Care Organization (NJHPO) includes this from their question and answer page:

Q: They’ll give the patient extra morphine to “push him over the edge” near the end, right?

A: Hospice seeks to reduce the patient’s physical pain, often through the use of morphine. A patient on morphine often develops a natural tolerance to the morphine over time, requiring the hospice to use larger doses of morphine to keep pain to a tolerable level. Larger doses of morphine may depress respiration (breathing) as a side effect, sometimes to the point where a patient stops breathing. This is called the “double effect,” which is accepted medical practice, widely accepted by religious groups, and in keeping with hospice philosophy, which seeks to ease a patient’s suffering while neither hastening, nor delaying death through artificial means (NJHPO, n.d., para. 3).

Given the widespread misconception about morphine hastening death, simple reassurance that morphine does not hasten death will be ineffective. It is important to take an

encompassing look at the ethical argument in favor of morphine use in care of the dying, even if it were to hasten death.

The ethical principle of double effect is widely used to support the use of morphine for those who believe that it hastens death. This long standing ethical argument is attributed to Thomas Aquinas. The “doctrine” of double effect is often cited in articles about use of morphine in end of life care. Perhaps because the myth that morphine hastens death has been perpetuated for years, it requires a years old doctrine to appease the conscience of misinformed medical professionals. Yet use of this argument feels inadequate and misguided to me. Allison McIntyre suggests that, “...the myth that pain relief hastens death might have persisted and perpetuated itself because it expresses the compassionate thought behind the second assumption: that the hastening of death may be a welcome side effect of administering pain relief to patients at the end of life” (2011, para. 36). There are stronger ethical arguments to dispel moral distress over morphine administration to dying patients.

Tom Beauchamp and James Childress authored the first edition of *Principles of Bioethical Ethics* in 1977, providing a much needed framework for the ethical practice of medicine in the United States. Patient autonomy is one of the main principles of modern day bioethics. According to Beauchamp and Childress, autonomous patients act intentionally, with understanding of the expected outcome from their actions (choices), and make choices without controlling influences (2013, p. 104). When patients are actively dying their autonomy may or may not be compromised, depending on whether they are cognitively able to understand their situation and make reasonable decisions. If patients are unable to act autonomously, a health care proxy may function in their stead.

This frequently occurs during end of life care when family members sit vigil with their loved ones. As the patient becomes less responsive, or less able to communicate, the family members often act to ensure that they continue to receive adequate medication to relieve pain.

Beneficence, another of the principles of bioethics that Beauchamp and Childress identify, falls into the realm of good nursing practice. Beneficence requires the nurse to act for the benefit of the patient. This extends beyond mere acts of kindness or mercy, but becomes a moral obligation to the patient (p. 203). Beneficent nursing, in its truest form, requires nurses to administer morphine to patients who exhibit pain, whether that pain is physical or existential (i.e. the thought of impending death causes the patient emotional distress), even if the nurse struggles with her personal intuition or belief that morphine hastens death. Additionally, when the patient is unable to make his needs known, the nurse must respond to the requests of family members who speak for the patient.

Nurses, just as well as physicians, may be guilty of acting in a paternalistic fashion when providing care. It is important for nurses to understand that any use of their influence to restrict autonomous choice is unethical. If a nurse has a strong bias against administration of morphine to active dying patients then it would be wise to find work in a setting that does not require her to do so. A more insidious paternalistic act occurs when a nurse shares her personal bias against the use of morphine with a patient and/or the family, perhaps even sharing a story of a time when she felt morphine hastened a patient's death. This is an attempt to override the patient's autonomous preference by implying that the nurse is acting out of beneficence or trying to mitigate potential for harm (p. 217).

Nonmaleficence is one of the bases of ethical rules, according to Beauchamp and Childress. The essence of nonmaleficence is to abstain from causing harm (p. 150).

Nurses may feel moral distress administering morphine in fear of hastening death, thereby believing that it would be a maleficent act. In this case, I believe the principle of patient autonomy would override the nurse's concerns, particularly since the nurse would not be basing her feelings on evidenced based practice but rather on misconceptions about morphine. Additionally, allowing a patient to suffer pain or respiratory distress when you have the medicine available to provide relief certainly is causing patient harm.

Beauchamp and Childress urge us to look beyond the basic principles of bioethics they set forth, noting that no one ethical theory will suffice; rather all ethical theories increase our moral knowledge and converge to provide us with strong ethical practice guidelines (p. 383).

Howard Brody's central argument in *The Healer's Power* is that "medical ethics is about power and its responsible use" (1992, p. 12). He outlines three types of power: aimed, shared, and owned. Aimed power, "requires that physicians carefully specify the realistic goals toward which medical therapy is directed, and the appropriate means to achieve them" (p. 155). Shared power involves shared decision making regarding the course of patient care. Brody notes that patients who are seriously ill or incapacitated have less power, which then requires empowerment of family to act on their behalf. Owned power requires the physician (or nurse) to recognize their power in relationship with the patient, and ways in which that power may "interfere with rational analysis of the medical goals and options" (p. 156). Brody believes that abuse of power is inherent in the undertreatment of the dying patient. He urges discernment to determine goals of care

that are reachable and medical interventions that are proportionate. Caring for the dying requires doctors and nurses to “own the true degree of powerlessness over the disease process” (p. 155).

In observation of my nursing colleagues over many years of practice, I believe that we may try to overcome our sense of powerlessness in the face of death by trying to control the trajectory of the dying process. Choosing to administer or withhold morphine from actively dying patients may make nurses feel that they are able to hasten or delay death. It is important for nurses who work with the dying to remain mindful that our actions are focused on to easing patient suffering as we accompany them through their final hours.

In *The Virtues in Medical Practice*, Edmund Pellegrino and David Thomasma connect moral motivation, moral cognition, and moral action, to virtues and character. In virtue ethics, emphasis is on the skills necessary to be a good person rather than on having the skills necessary to carry out professions (1993, p. 6). The two virtues that I believe most strongly support the administration of morphine to dying patients are compassion and phronesis. Pellegrino writes, “Compassion is the character trait that shapes the cognitive aspect of healing to fit the unique predicament of *this* patient” (p. 79). The word compassion is derived from Latin words that mean to suffer together. Co-suffering requires interaction between two people. True compassion requires being open to truly seeing and feeling what the other person is experiencing (p. 80). At the same time, the cognitive element of compassion adds objectivity, allowing the nurse to step back enough to assess what is causing the suffering and determine what can be done. It

would be incredibly difficult to practice as a compassionate nurse, without the capacity to recognize and treat pain or suffering.

Phronesis, according to Pellegrino and Thomasma, is “Medicine’s Indispensable Virtue” (p. 84). In medicine, phronesis, which is synonymous with prudence, is the capacity to discern the moral action that works in the best interest of the patient. In a particular situation, phronesis, or prudence, is used by nurses to determine what the most appropriate course of action is for the good of the patient (p. 84). The authors assert that the right or correct action in medicine is that which is technically and scientifically appropriate, while also being in the best interest of the patient, and morally good (p. 86). Prudence is necessary to strike the right balance between compassion and objectivity. Balancing compassion and objectivity allows nurses to make prudent clinical judgment; to provide competent care to their patients.

Educating nurses in the basic principles of bioethics and the virtues of good medical practice should be a priority; a starting point to ease nurses’ moral distress related to morphine administration. Pain relief for those who are dying is an ethical obligation and barriers that obstruct administration of morphine must be removed.

Personal Nursing Narrative IV—Death on Her Terms

Many would consider living to age 98 quite an accomplishment. I have cared for many elderly people who share their prayers for life to end well before that advanced age, but that was not the case for Ruth, she was clinging to life with a steely grip—a life that had its share of challenge.

Ruth was born in the United States at the beginning of the 20th century. She was a daughter of privilege; well-educated, well-traveled, with a natural curiosity. Life wasn't always easy; her first husband was killed in World War II leaving her with two young sons. Ruth forged ahead balancing single motherhood with a solid career in advertising. It was on an overseas work trip, after her sons were off to college, that Ruth met her second husband. Courtship led to marriage and a move to Switzerland where she thrived.

Forty years later, after the death of her beloved second husband, Ruth, at age 92, was facing advanced old age. She listened to the pleas of her sons to return to the United States to be near them once again. Her youngest son helped her settle into a small apartment in a retirement community where she quickly made friends. Her days were filled with reading, corresponding with friends in Europe, and enjoying communal meals in the dining hall each evening.

Sadly, although Ruth's mind remained incredibly sharp, her body betrayed her. Aging bones riddled with osteoporosis gave way; her spinal column crumbled causing her always erect body to shrink. The pressure from her curving spine compressed her chest into her abdomen, affecting her breathing. Soon the effort to walk to the dining room each evening was too much; just moving about her apartment became a challenge. Another move was necessary, this time to the assisted living unit.

Ruth once again reached out to make friends with the residents there and the nurses who assisted her with care—everyone loved her. Mealtime was an opportunity to share conversation with others, yet as Ruth's spine continued to crumble, her stomach had little room to hold food. Over time, her ability to eat became limited to a few small bites. Ruth began an elaborate, self-designed schedule of eating and drinking in an

attempt to nourish her failing body. The small kitchenette in her room was well stocked with high calorie, high protein supplements that she took in small doses. With little breath and no strength to make the trip to the dining room, even by wheelchair, and loss of the ability to eat a full meal, Ruth's world shrank to fit within the walls of her small room. Still she soldiered on, readily engaging in conversation with anyone who would stop in for a visit.

The march of time could not be stopped. Further spinal decay caused more chest and abdominal compression. Even small meals caused Ruth pain and as the pain increased she required stronger medication to manage the pain, now relying on Percocet every six hours to feel comfortable. As food tried to pass through the tight twists and turns of her intestines she often could only lie in bed, writhing in an attempt to ease the discomfort. Her thin frame became emaciated as her weight dropped below ninety pounds. As she weakened, the muscles in her throat weakened as well and she began having difficulty swallowing.

Those of us caring for Ruth knew that the trouble swallowing, making it difficult for her to get even liquid nourishment down, was the beginning of the end for her, yet her desire to live was very strong. A care plan conference took place to discuss options, with Ruth, her son, the dietician, social worker, speech therapist, and nurse in attendance. Ruth and her son, knowing that she could not go on much longer with so little nourishment, questioned whether a feeding tube might be an option. All present at the meeting strongly discouraged this course, fearing that liquid nourishment placed directly into her stomach would only increase pain and risk development of pneumonia as her body struggled to

digest it. Ruth persisted, asserting her autonomy, and ultimately was transferred that afternoon to the hospital where a gastroenterologist could assess her case.

The next day when I arrived at work I found that Ruth had been sent back from the hospital and admitted to the skilled nursing unit to receive hospice care. The doctor who evaluated her for a feeding tube felt it was too risky, too painful, and ultimately would be futile. Sadly, the physical and emotional energy Ruth expended in the transfer to the hospital, during tests and evaluation there, completely sapped her of strength. She returned to us so weak that she was unable to swallow even drops of water without intense choking. Without any food or fluids she most certainly was transitioning from life to death. Reluctantly she agreed to hospice care.

Ruth's tenacity served her well in life, but it made acceptance of dying a challenge. When I entered her room she greeted me with eyes wide open and searching. She could only speak one or two word responses to my questions, but I knew that she fully understood what was going on. Her son was at bedside. He shared details of the hospital excursion, including Ruth's struggle but ultimate acceptance that she needed hospice care. Still, she wasn't going to let go easily.

I could tell from the pinched expression in her face and her restless movement in the bed that she was clearly having physical pain. Her inability to swallow meant that she could not take pills any longer so the overnight nurse had given her the usual initial hospice dose of 7.5 milligrams of morphine in drops under her tongue. It was ordered to be given every two hours as needed, and was obviously needed at that frequency. I asked Ruth if she would like to have anti-anxiety medication to help her relax and sleep but she refused.

It was not surprising to us that she remained alive beyond the usual three days expected once a person is no longer able to eat or drink anything. As each day passed Ruth grew weaker and slept more. She would awaken when we spoke to her or gently touched her, and though she was no longer able to speak her eyes communicated many things—anger, sadness, fear, pain, hunger to remain alive and regain strength, and, occasionally, defeat, though also gratitude and love. Her restlessness often indicated physical pain but it was her eyes that shared emotional pain.

Ruth's sons sat at bedside off and on over the course of her final week of life. It isn't easy being present with someone who is in pain, especially when it is someone you so dearly love. Ruth was more restless when her family was there with her, perhaps their presence made it even more difficult for her to let go.

As one day bled into another, we all began to wish that she would just let go. Though she slept most of the time, when she awake she still looked at us with beseeching eyes. With no food, and not being able to tolerate even a few drops of water without choking made her lips crack and her mouth dry. We continued to give her morphine every two hours to keep her comfortable, and as long as she was able to nod yes or no I always asked if she wanted me to give her a larger dose. She continued to refuse. It was frustrating to sense that she was in suffering both physically and psychologically yet I knew that as long as she was able to make decisions I needed to let her determine how much medicine she wanted to take. I spent as much time with her as I could, massaging her hands and feet, reading to her from *The New York Times*, and gently singing lullabies as she slept.

When I checked on her at the start of my shift, a full seven days after she stopped eating, drinking, and began dying, I saw a change in her breathing; heard the telltale rattling of secretions in the back of her throat, and knew that the end was near. It was time for one more dose of morphine, then time to call her family to come be with her. All of us had whispered words of encouragement over the past week for her to let go, to let her spirit fly. Once again I shared those words with her, as I cracked the window in her room to let fresh air in and Ruth's spirit out, if it was searching for a way to go.

When her sons arrived she was unresponsive but her body seemed relaxed, the struggle nearing an end. In fact, as she took her last breaths it seemed that she might be at peace at last with letting go—an image I would like to remember.

I have often wondered if I should have pushed Ruth to take more morphine to make her final days less painful. I wonder still if we found the right balance between respect for her autonomy and compassionate, beneficent care.

Conclusion

The topic for this thesis grew from a seed planted in conversation with a friend just before I began my study of Medical Humanities. We talked about my interest in end of life care, and bioethics which was motivating my pursuit of this degree. I told her that my biggest worry, before even taking a single class, was figuring out what to write my thesis about. She immediately jumped in, telling me that I should research why patients who are dying are allowed to suffer, why nurses won't give dying patients enough morphine to make dying easier. She recalled with great emotion the agony of her sister's death from cancer the year before. Even though her sister was an inpatient in a hospital

based hospice unit, they had to “beg” the nurses to increase her morphine, and in the end, as the family all sat vigil, they were left feeling that she died in pain.

Recently I gave a presentation about end of life care decisions to a group of seniors. During that presentation we discussed what hospice care would entail, including details about the symptom relief medication we use. One of the participants shared with the group the story of his mother, who was dying on hospice care and had resisted taking morphine until finally her pain was no longer tolerable. Shortly after receiving her first dose, she felt such relief, both physical and psychological that she emphatically said, “Now I can see why people become drug addicts, keep that medicine coming for me and don’t stop it!” They did continue the morphine and her son felt that it allowed her to have a good death.

On the other hand, much needs to be done to remove misconceptions about morphine both in the medical community and in the general public. Last week I admitted a patient for hospice care; a woman who had been receiving nursing visits from a homecare nurse in my agency. The patient’s condition was worsening, and all agreed she did not want to go back into the hospital for further aggressive care. Still, there was hesitation in the family about putting her on hospice care. Shortly after I arrived at their home her son commented, “The homecare nurse promised us that you wouldn’t give her morphine unless she absolutely needed it.” Thankfully I was able to confidently assure him that we would not give morphine unless it was indicated, but also that there was no scientific evidence that morphine would hasten his mother’s death.

As the patient’s goals of medical care change from quest for cure to desire for comfort, barriers obstructing use of morphine must be eliminated. Optimal care for dying

patients strives to relieve suffering for the patient, minimize distress for the family, and allow for the best death possible.

The importance of caring well for the dying falls squarely on the shoulders of nurses. In 2010 the American Nurses Association (ANA), recognized the value of nursing expertise required to provide relief of existential, spiritual, emotional, and physical suffering of the dying. The ANA developed a Position Statement to inform and guide nurses in providing end of life care to patients. This document provides valuable information regarding end of life care, and equally important, refers nurses to organizations that offer educational programs on care for the dying such as The End-of-Life Nursing Education Consortium (ELNEC), (ANA, 2010).

Recognizing that few nursing schools offered a course specific to end-of-life care, the ELNEC developed a comprehensive, concise guideline of nursing competencies in end of life care for integration into existing course curricula. The goal was to disseminate necessary information to teach nurses about care of the dying (Barrere, C., Durkin, A, 2014). Additionally, the Institute of Medicine convened a committee to update and expand upon their 1997 report, *Approaching Death*. Given the aging population in the United States, the increase in life-expectancy and ongoing matters of death and dying that raise political, ethical, and societal questions, the time is right for a reexamination of how we approach death.

Advances in care for the dying may include pharmacological research that produces medication to relieve the physical and emotional pain that often accompanies dying. Until that happens, morphine remains the drug of choice, the gold standard to ease suffering for patients who are actively dying. Morphine is inexpensive; easily

administered transmucosally to patients who can no longer swallow; is short-acting and easily titrated; and is highly effective in relieving pain and easing respiratory distress in dying patients.

Additionally, ethical care for the dying requires nurses to set aside any personal bias regarding morphine administration. Nurses must respect patient autonomy, including honoring the wishes of family members who speak on behalf of the patient, and give morphine to relieve pain and suffering as the patient and family desire. The principles of beneficence and nonmaleficence support use of morphine to minimize the patient's pain and suffering as death nears. Virtuous care calls upon nurses to be prudent and compassionate in recognizing the patient's needs and providing care for them.

The best nursing practice relies on evidenced based medicine, yet we are susceptible to influence from our human experience. In sharing stories of care for the dying, we often highlight tales of giving the last dose of morphine to a patient, perhaps perpetuating the myth that morphine has hastened death. We must rely on evidenced based medicine to understand the effects and efficacy of morphine in care for the dying, as well as develop a better understanding of the physiology of dying to accept that it is a myth that morphine administration has an impact on the length of the dying process. Following evidenced based medicine to care for the dying will result in appropriate use of morphine to relieve pain and respiratory distress, thereby allowing for more peaceful death (Perkins, E., 2002).

Hospice nurses speak of caring for our patients during their final days of life as a privilege. Metaphorically, our patients are on the culminating journey of their lives, perhaps similar to climbing Mt. Everest, and we, their nurses, together with the patient's

family, are the Sherpas accompanying them. We are along on the journey to provide guidance; the necessary tools to navigate the terrain; encouragement; and support. Early on in the journey the Sherpa's role is to show the hiker the trail, at times to lead, at other times to follow. Along the way there are pauses to allow the hiker to acclimate; to adjust to the thinner air and the harsh conditions; to rest, and mentally prepare for the harder climb ahead. The Sherpa cannot control many of the variables of the climb--the weather, the hiker's response to changes in altitude—but they bring with them supplies--oxygen, warm gear--to ease the hiker's suffering from these variables.

As the summit nears, the hiker may no longer be able to carry their own pack; all of their effort goes toward reaching the peak, one step at a time. The Sherpa takes on the burden of the hiker's pack, and even if that extra weight makes the journey more challenging, they will push through it, continuing to guide, encourage, and support the hiker. All focus and effort, of both hiker and Sherpa, is on successfully climbing to the top of the mountain, and when the summit is reached there is feeling of completion.

The journey of death is challenging, has many variables; teamwork allows it to be navigated with less distress or suffering. The goal is for the patient to have as smooth a journey as is possible, with peaceful moments along the way. It is not always easy for nurses to overcome the focus on their own emotion during the process, yet it is the patient on whom care must be centered. Thus, it is imperative for nurses to set aside misconceptions about morphine; misguided belief that their actions are controlling the trajectory of dying; and egoism; to allow for compassionate, clinically competent care of the dying.

When I make the final visit to pronounce a patient dead, I always make sure to tell the family, “You did everything right.” Death is hard. Those present during the final days and moments will relive the event to create their own narrative of the journey. It is always my hope that those involved will feel that we gave our best effort to do everything right.

Personal Nursing Narrative V – To Everything There is a Season

After many years working as a nurse in long term care I returned to hospice nursing. One of my first cases reminded me that birth and death are similar in unpredictability and course.

Grace lived in an elegant home set high on a hillside. For over a decade she shared her home with a devoted caregiver, a lovely, young woman named Sylvia. Initially Sylvia worked only as a housekeeper, but as Grace aged she eventually began to rely on Sylvia for personal care. The two of them were very close.

Grace had also developed a close relationship with her primary physician; so close that as she reached her 90s he began making house calls rather than make her travel to his office. It was on one of those house calls that Grace told him of nagging pain in her belly and dizzy spells she was having. When he examined her he discovered a large mass in her abdomen, he knew it could only be bad news. He was gentle in telling this to Grace, but she was realistic and strongly insisted that at her age she did not want to undergo any major surgery or treatment.

Grace's decline was rapid and unpleasant. Within weeks she could barely tolerate food and had unrelenting abdominal pain. Since she was determined to stay at home, her doctor called hospice and arranged for her to be admitted.

On my first visit to her home I found Grace resting in bed, fully clothed in a wool suit, stockings and all. She smiled sweetly but spoke little, and when she did her words were halting. Her skirt strained tightly across her protruding abdomen, the mass was easily palpable when I examined her. Grace's doctor had already delivered a bottle of liquid morphine and instructed Sylvia on how much to give when Grace had pain. They were following the "start low and go slow" mantra that we tell patients, using only 5 mg. of morphine every four to six hours. Still, it was enough to allow her rest more easily.

Over the next two weeks Grace's condition rapidly declined. She became too weak to get out of bed even to go to the bathroom, became very confused, and eventually lost the ability to speak. Sylvia began sleeping on a cot in Grace's room to tend to her overnight, always keeping her clean and dry. I instructed Sylvia how to use all of the medication in our hospice symptom relief kit to manage the symptoms of dying. She was giving Grace morphine every four hours, and also started giving her lorazepam when she was restless, and scopolamine to dry up secretions when Grace began to have some congestion in her lungs.

When I visited on Grace on a Wednesday morning, she was minimally responsive. She wouldn't open her eyes. Her only response was to flinch or moan when Sylvia and I turned and repositioned her. She hadn't eaten for the past day. Her breathing was rapid, her respirations shallow, and her blood oxygen level was below 90%, not compatible with life. It was clear that she was actively dying. I once again reviewed all of

the medication that Sylvia could use to keep Grace comfortable, and we agreed that she should increase the morphine dosing from every four hours to every two hours. I gave her my cell phone number to call so that I would be the nurse to go if Grace died. I felt certain that she would go that night.

Death has its own timeline. I visited Grace the next day, finding little change in her condition. Her physician visited just before I arrived and told Sylvia that death was imminent. Sylvia, exhausted from providing around the clock care, was very emotional as she faced the death of her employer and friend. She was also fearful about being with Grace when she died so I promised that I would do my best to anticipate that and be present with her.

Grace's chest rose and fell rapidly with shallow respirations, her mouth gaped open. Other than that, her body seemed relaxed, but every now and then the muscles of her arms or legs twitched rapidly causing them to jerk awkwardly. She had been using oxygen for several days, which is often considered a comfort measure, but at this point I thought it would be more comfortable for her to have the prongs removed from her nose, and more pleasant to shut off the noise of the air compressor. Grace's hands and feet were dusky purple, a clear indicator that her blood oxygen level was very low. Before I left to see other patients I gave Grace a double dose of morphine in hope that it would slow her breathing to ease it a little. We have physician orders to double the dose up to two times, if needed, to manage pain or respiratory distress. If we want to continue to give the higher dose we must call the physician to discuss it and get new orders.

As I visited my other patients I waited for a phone call from Sylvia to tell me that Grace had gotten worse, or had died, but my phone never rang. Before heading home I

decided to go back to Grace's house to check in. Sylvia greeted me at the door, "no change." Sure enough, Grace was almost exactly as I'd left her six hours earlier, completely unresponsive to voice or touch; lying on her back; mouth open; taking shallow, rapid breaths. She hadn't had anything to eat or drink for over three days, and hadn't made any urine for over twenty four hours. Throughout this time Sylvia had kept vigil alone, Grace's children lived at a distance and would not come before she died.

Shortly after I arrived, a friend of Sylvia's stopped by. I encouraged Sylvia to take a break with her friend and sit on the front porch for awhile. Left alone with Grace, I gave her the next scheduled dose of morphine. As I took my turn sitting vigil at Grace's bedside it felt both a privilege and burden to watch her die so slowl. Aside from the effort of her rapid breathing, and the small, coarse noise she emitted with each breath, she seemed fairly comfortable. In need of something to do, I massaged her hands and feet, now not just blue, but cold and blue from lack of circulation. Next I pulled out my computer to finish up charting on my other patients, softly singing to maintain some connection with Grace. Time slowly ticked by and still she kept up her relentless, rapid breathing.

I looked at her gaping mouth, her pale face devoid of all expression, her blue hands and feet, and contemplated how mortified this dignified, elegant woman would be if she could see herself. I checked my watch; I counted her respirations, 60 a minute and no sign of slowing down or stopping. Finally, it was time to give her another dose of morphine, and I chose to double it as I had done that morning in order to slow her respirations a little. It was time change her position, to turn her on her side. I thought that a change in position might alter her pattern of breathing, help her relax, and make her

more comfortable. I rolled her gently onto her side, placed a pillow behind her back, one between her knees, and rubbed the back of her head where her hair was matted from being pressed against the pillow all day. Sure enough, perhaps that little change or perhaps the few extra milligrams of morphine eased her breathing. As the hour passed her respirations slowed, mellowed, and gradually, gradually, her breathing quietly stopped. The room was totally quiet; Grace was totally still, her heart no longer beating.

Sylvia was overcome with both sadness and relief when I went downstairs to tell her. She also made it very clear that she did not want to see Grace's dead body. When I called Grace's son to tell him his mother had died, he shared with me the story of his brother's death many years ago. His brother, too, had died at home, and before his mother let the funeral home take the body she gathered all of the family around to gently bathe and dress him so that he would leave the house in a dignified manner. Grace's son then asked if I would mind dressing his mother in her favorite lavender linen dress before the funeral director arrived to take her body away.

As I prepared Grace's body as her son wished, I thought about her final hours, reflecting on the beauty of her quiet death at home. While I might have wished for the dying process to be shorter, I was reminded that the timing of death is not in my hands. For that I feel thankful.

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