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## **Insights into the Practice of Palliative Sedation: A Literature Review**

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Insights into the Practice of Palliative Sedation: A Literature Review

An Honors Senior Thesis

Submitted in Fulfillment of the Graduation Requirements of the Honors College

By

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**Table of Contents**

Abstract...p.3

Chapter 1: Introduction & Significance Exploration... p.4

Chapter 2: Background... p.9

Chapter 3: Methods... p.15

Chapter 4: Results & Findings... p.16

Chapter 5: Discussion & Conclusion ... p.37

References... p.42

### **Abstract**

Terminal illness and the concept of death and dying are sensitive topics, especially when relating them to the people we hold near and dear. Unfortunately, along with the end of life comes an unsurmountable amount of pain and suffering for people facing serious illness. For patients with a terminal illness, palliative and hospice care treatment measures are implemented to manage symptoms, provide peace, and enhance the quality of the final days of life. Palliative sedation is one of these measures. It will be explored in depth in order to gain a greater understanding of the treatment options available during this point in life. A review of the literature was performed to retrieve peer reviewed scientific research articles that focused on the use and effects of palliative sedation in persons nearing the end of life. Twenty articles met the inclusion criteria and were included in the review. Using the ethical principles as a conceptual guide, the benefits and risks associated with the implementation of palliative sedation were evaluated and discussed. Nurses who provide care to terminally ill patients should be educated about the use of palliative sedation as a viable option for management of refractory symptoms and existential suffering in patients at the end of life.

## Introduction

Within the last few decades, there has been a shift in the focus of end of life care for nursing professionals. Instead of solely focusing on curative medical care to eradicate the underlying disease at any cost, there is now greater emphasis on quality of life rather than quantity of life. With that being said, more attention is being placed on managing symptoms to enhance livelihood than it is on fighting and treating the disease process. Palliative care is one of the care practices that enables health care professionals to manage these adverse symptoms in patients who live with serious illnesses. The World Health Organization defines palliative care as relief of suffering from physical, psychological, emotional, social or spiritual factors (Palliative Care, 2019). It is “patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering (Hospice and Palliative Nurses Association, 2017, p. 4).” This is a prominent treatment strategy for patients fighting a life-threatening illness that causes secondary symptoms and distress as a result. This treatment becomes hospice care when primary disease treatment is aborted and a diagnosis of less than 6 months to live is given. This shift to hospice care is one that has created peace in the final phase of life for an abundance of patients. On the opposite end, it has also resulted in debates about what measures can be taken to enhance quality of life, and what extent we should go to in order to achieve complete relief.

However, when discussing end of life care, there are a few terms that need defining in order to fully understand this stage and factors involved. There are many types and multiple dimensions of distress at this point. First, we discuss pain which is “an unpleasant sensory or emotional experience associated with tissue damage” (IASP, 2014). This physical pain comes from the disease and disease experience. Psychological distress becomes a factor when a patient is faced with the unsettling task of coming to terms with death and having no knowledge of the

time frame. Frequent distress monitoring and assessment is mandated in patients nearing the end of life because our goal is to relieve suffering and enhance the quality of their last days on earth. This experience is subjective, and as a nurse we need to medicate based on a patient report and experience of suffering. It is intensified during this time because it is often ongoing and chronic, which is an exhausting experience.

Currently, the presence of pain in palliative patients is remarkably high. An analysis of numerous studies concluded that over half of patients nearing the end of life experienced significant pain, while a study of hospice nursing home residents experienced a pain prevalence of almost 60 percent (Hospice and Palliative Nurses Association, 2017). In addition, dyspnea and delirium are common. These statistics are a great concern, and it is a sad fact that many patients spend their final days struggling. The Hospice and Palliative Nurses Association (2017) maintains that the most indispensable thing we, as nurses, can do to promote quality of life is to alleviate pain. This is adequately done by measuring quality, intensity, location, duration and any aggravating and alleviating factors (Lowey, 2015, p. 86-87). Then, by determining the best course of treatment and monitoring the efficacy of such measures. The concept of refractory symptoms is often referenced when discussing patients nearing death. A refractory symptom is defined as “A symptom that cannot be adequately controlled in a tolerable time frame or at a tolerable level despite aggressive use of usual therapies and seems unlikely to be adequately controlled by further invasive or noninvasive therapies without excessive or intolerable acute or chronic side effects/complications (Hospice and Palliative Nurses Association, 2016, p. 5)”. There are several other symptoms that can be refractory, only heightening distress.

Symptoms to be expected during this period range from constipation, restlessness, fatigue, delirium, depression, and anxiety (Lowey, 2015, p. 83). The longer these symptoms go

unmanaged, the worse they become for the patient to live through. This is what we try to avoid when weighing the best way to treat patients suffering immeasurable pain. Two of the biggest concerns are restlessness and refractory dyspnea (Lowey, 2015, p. 98) Dyspnea is referring to the feeling that you cannot get enough air, leaving a person feeling tired and short of breath. This is not only scary, but uncomfortable and acts to heighten the amount of anxiety felt. This often snowballs into fear and panic. Delirium is referred to, in the clinical setting, as terminal restlessness. This causes various levels of consciousness and awareness throughout the day. Lowey (2015) describes multiple other symptoms ranging from constipation to anxiety and depression. In addition, nausea, seizure activity, difficulty swallowing, fatigue and cachexia can be experienced. Lastly, and often not considered, is the emotional pain and spiritual angst that end of life patients are faced with. For some, this is the most excruciating part. This is referred to as existential suffering and will be discussed in depth in sections to come. In sum, “existential suffering is suffering that arises from a loss or interruption of meaning, purpose, or hope in life (Rodrigues, Crokaert & Gastmans, 2018).” To understand the complete experience of such, we much consider what death and dying mean and derive meaning from such.

When considering death, the concept is often combatted with a sense of hope and thoughts of better days. However, for hospice and palliative care patients, this is often not applicable. We are no longer treating the disease or illness in an effort to heal it. The thought of being completely cured and any hope of complete recovery is taken off the table and our focus shifts to managing and maintaining comfort. With this, comes the inevitability of death and dying. Death is an inevitable experience, but it is also a very subjective experience. Dying refers to the process before death. This process is a time that can either lead to existential suffering and unmanaged symptoms or culminate life. In this specific realm, we act to foster a good death by

reducing suffering to allow for a peaceful conclusion of life. The Hospice and Palliative Nurses Association (2017) asserts that the core goal of treatment surrounding this point in life is pain relief. They also conclude that over one fourth of pain management is unsatisfactory at the time of death according to family members of those who have passed. This is a call for more efficient mechanisms of pain and distress relief.

Much exploration of various mechanisms and more extreme measures to reduce suffering have come as a result. Due to this unachieved relief, new techniques and practices have been explored. One of the most argued topics in the hospice care realm is the subject of palliative sedation. Palliative sedation is a vice that is used for someone nearing the end of life that is suffering immeasurable pain from which they cannot find relief. It is a means of maintaining an unconscious state with a controlled pharmacologic in order to achieve relief from unendurable refractory symptoms and suffering (Hospice and Palliative Nurses Association, 2016). In contrast, Physician Assisted Suicide is defined as “a physician providing, at the patient’s request, a prescription for a lethal dose of medication that the patient can self-administer by ingestion, with the explicit intention of ending life” (American Academy of Hospice and Palliative Medicine, 2016). The same action becomes euthanasia when a Doctor physically administers the life-ending medication themselves. Palliative sedation is different from both of these in the way that it does not hasten death, nor is it implemented to achieve death. Thus far, palliative sedation has been adopted and implemented to treat patients who live with refractory physical symptoms. More controversial, is its use to treat refractory existential distress. This literature will dive into the aspects involved in palliative sedation and the decision leading up to sedation initiation.

### **Significance in Nursing**



Essentially, this is an important debate for nurses to be aware of and tuned into. As a nurse in this care realm, we should be familiarized with knowledge regarding the benefits and downfalls to various treatment options. Both sides of every treatment option should be explored and respected by palliative care nurses. Both sides of the palliative sedation debate are valid in different circumstances due to the subjectivity of each patient situation. While it may not be up to us nursing professionals to decide for a patient, we need to understand and foster each individual wish and make the situation as pleasant as we can. It is imperative to be well versed on the matter before analyzing options with a patient and their family. In this role, we may act as educators and provide information about the practice. It is also relevant to be aware of potential barriers to nursing care in palliative sedation. Overall, being up to date with practice considerations equates to greater nursing care and better patient experiences.

### **Research Purpose**

The purpose of this thesis was to conduct a review of the literature that examines the use of palliative sedation to manage refractory symptoms in patients at the end of life.

### **Research Questions**

What are the current benefits and risks associated with the use of palliative sedation to manage refractory symptoms at the end of life?

What are the current benefits and risks associated with the use of palliative sedation to manage?

What makes palliative sedation different from physician assisted suicide, in terms of ethical considerations and intent?

What are the reasons behind hesitation in the initiation of palliative sedation?

### **Background**

The existing literature surrounding the topic of palliative sedation focuses on the legality and ethics behind its use. It is defined by objective terms and from the viewpoint of strict legal and ethical concepts. What is left out, however, is the personable side to this practice. The practice is deemed legal through the existing articles, but the individual humane effects of such are discussed in much less detail. This literature will focus on examining specific aspects relating to palliative sedation and the end of a human life. Both the benefits and the downfalls will be analyzed as well as the way the treatment course can affect the patient and their families in providing peace and comfort.

### **End of Life Care**

End of life care is encompassed by measures taken at the end of life to enhance quality and satisfaction. The focus becomes psychological, emotional and physical peace. The goal being by providing competent care that addresses all elements of an individual and their wishes, we can mark the end of life with tranquility and grace. The desire being enhancing quality of life for patients at this period of life. Quality of life is referenced by the World Health Organization as “a state of complete physical, mental, and social well-being and not merely the absence of disease and infirmity (Health-Related Quality of Life & Well-Being, 2020). By focusing on the improvement of these categories, we can create a peaceful end of life environment and promote well-being.

### **Palliative Care**

Palliative care is a type of care offered to any persons experiencing a significant illness. This care provides methods of management with a focus to relieve secondary symptoms a person may be experiencing due to their significant illness. Primary treatment of the disease if received in conjunction with these relief measures to optimize quality of life enhancement. There is no time limit and anyone diagnosed with a serious illness can benefit from these services at any point (Palliative Care or Hospice?, 2019).

### **Hospice Care**

In contrast, hospice care is offered to people who are estimated to have less than 6 months of life left. This is referred to as a terminal prognosis. Hospice care abandons treatment of the specific disease and instead focuses on managing distressing symptoms to improve quality of life. Care is determined from a holistic standpoint based on the needs of the patient and their family with the use of an interdisciplinary team (Palliative Care or Hospice?, 2019). By approaching individual needs from multiple dimensions, we can greatly improve quality of life and increase comfort surrounding the time of death. Among these dimensions are spiritual, psychological, emotional, and physical. They are all considered in an effort to foster a dignified death where peace has been achieved.

### **Symptom Management**

The end of life period can be marked with distressing symptoms and inability to find adequate relief. Some of the most common symptoms experienced during this time are delirium, dyspnea, and unrelieved pain (Twycross, 2019). Distress can come from these physical symptoms, but also from psychological suffering as well. This can produce further distress with manifestations like anxiety and depression. Up to date, delirium and pain at the end of life are

under-diagnosed (Twycross, 2019). Patients experience of pain and other distressing symptoms nearing the time of death is higher than optimal, as high as half of patients reporting pain close to the time of death. This is an important consideration since the most critical thing we can do is provide relief from symptoms for these patients.

Various methods of relief are explored in order to achieve relief of symptoms.

Nonpharmacologic techniques include cognitive behavioral therapy which provides comfort through relaxation, imagery, and distraction techniques. Art and music therapy can also provide peace and relaxation for patients. Acupuncture, aromatherapy, or ice packs and heat pads can be implemented to achieve the same results (Lowey, 2015). With emotional distress, measures such as counseling or therapy may be included. However, these measures are routinely used in conjunction with pharmacological treatments in order to maximize comfort and see the best results (Lowey, 2015).

Pharmacologically, the most used methods of pain management will be explored in order to expand upon later. Lowey (2015) describes these pain medications in terms of a metaphorical ladder. The first, and most mild step would be administering NSAIDs. The next step is administering opioids and managing side effects like nausea. Among these are codeine, fentanyl, levorphanol and methadone (Lowey, 2015). Towards the more advanced stages of disease, a stronger opiate, like morphine, may be administered. With these, a feared side effect is respiratory depression. However, when considering prescription, these patients are more likely to experience respiratory depression as a part of their disease process than as a result of medication. Morphine is implemented close to the time of death in order to relieve pain. At first initiation, the patient becomes lethargic or sedated for a short period but often regain consciousness within a couple days (Lowey, 2015). Following this period, they are awake and present with family

members. When receiving these treatments, a patient may still experience a type of pain referred to as “breakthrough pain”. Lowey (2015) defines this as pain that happens in between the routine timed administrations of pain medication. In this case, an adjunct or PRN pain medication can be used. Medications can also be given in order to manage the emotional distress references earlier. For example, an anti-anxiety medication may be given in conjunction with pain medication to further improve quality of life. An anti-emetic may be given to manage nausea or an anti-depressant to increase mood (Lowey, 2015). Marijuana has also been utilized as a mean for symptom relief as of late.

However, adequate relief is often not achieved with these measures for a terminal patient. Further measures of relief are required. Most recently, palliative sedation has become a topic of discussion. This treatment can be thought of as a step above morphine. However, it is distinguished from euthanasia or physician assisted suicide because it does not hasten death. The Complexity of Palliative Sedation is almost immeasurable since there are so many aspects of consideration when discussing it and determining the best course of treatment. This article will discuss the bulk of these pressing considerations and evaluate benefits and difficulties. As a result, we hope to gain a better understanding of legitimation and experience of palliative sedation for both the patient and the nurse involved during treatment.

### **Palliative Sedation**

Palliative sedation is formally defined as “the use of sedative medications to relieve unendurable suffering from refractory symptoms by a reduction in the level of consciousness” (Sadler, 2012, p. 195). Some confusion lies in using different terms referring to palliative sedation. Deep continuous sedation, total sedation, and temporary sedation are a few other types (Sadler, 2012). In some of these practices, sedation is used temporarily for relief and a goal may

be eventual weaning off sedation. This literature is speaking specifically about continuous deep palliative sedation, which is maintained until the time of death. Essentially, deep continuous sedation is used to relieve intolerable refractory symptoms by keeping the patient in a lethargic, sedative state until the time of death. The implementation occurs only after all other treatment options have failed, as a last resort (Cherny, 2019).

An important component of this definition is that it is done when there is “refractory” suffering (Sadler, 2012). Referenced earlier, refractory symptoms are ones that have not been resolved following aggressive and thorough treatment (Sadler, 2012). These symptoms could range from things like delirium, nausea, extreme pain, and trouble breathing. This determination is made only when various other therapies are unsuccessful in relieving intolerable suffering or when the measures cannot provide relief in a reasonable time frame (Cherny, 2019).

Reports have maintained varied use of palliative sedation from 2-25% in terminal patients experiencing distress (Twycross, 2019). The implementation of the practice has expanded worldwide and is becoming increasingly common. However, guidelines and the frequency of use vary dramatically from region to region. This is attributed to the fact that there are numerous considerations and conversations to be had surrounding the decision to initiate sedation. There is also hesitation when identifying the differences in palliative sedation from euthanasia. A common misconception is that palliative sedation hastens death alike euthanasia. All of which will be discussed in detail in sections to come.

In addition to these considerations, there are benefits and risks that need to be weighed. Palliative sedation is a complex measure that is a last resort treatment option. When implemented, it has proven to relieve suffering in a patient nearing the end of life. In this way, it

improves the quality of life and provides a dignified death. Any type of moral distress is negated and evidence of peace in a patient often relieves families concern (Cherny, 2019).

On the other hand, palliative sedation can produce distress in family members and nurses alike. Essentially, by administering medication, the practice cuts a patient off from the social world prematurely. This is a hard reality for family members and can prove distressful for nurses in the process of maintaining the treatment. Both aspects of treatment will be expanded on in much greater detail in pages to follow.

### **Existential Suffering**

In contrast, refractory existential suffering is an internal result of the person living in the state they are in. These symptoms manifest themselves in more psychological or emotional means and cause mental distress. They are amplified and specific to the patient as they are nearing the end of life. These symptoms can range from feelings of despair, loss of independence to feeling unfilled with their life (Sadler, 2012). As a whole, “Suffering can be defined as a state of severe distress associated with events that threaten the intactness of the person (Sadler, 2012, p. 198). Due to the lack of measurement tools for emotional anguish, palliative sedation is used much less for existential symptoms.

### **Sedation Administration**

Choice in medication for therapy should vary depending on the most distressing and prevalent symptom. The class of medications known as benzodiazepines and barbiturates are the most used in practice. Schildmann, Schildmann, & Kiesewetter (2015) analyzed numerous guidelines for palliative sedation therapy and established that Midazolam, a benzodiazepine, has been distinguished as the drug of choice in the vast majority of sedation guidelines. Midazolam

is described as having the mildest adverse effect: with it being agitation (Cherny, 2019).

However, it's use for symptoms like delirium may only exasperate the problem and result in more agitation. If this is mistaken for distress instead of medication side effect, titration of dose increases and relief may not be achieved (Twycross, 2019). Lorazepam is another benzodiazepine used is more common in the United States (Twycross, 2019).

If failure to reach deep continuous sedation occurs with Midazolam, Levomepromazine can also administered is sometimes reportedly used in cases where extreme delirium is present. Phenobarbital and Propofol are used to achieve sedative effects but are last resort drugs. Propofol is reportedly implemented in cases with a severely agitated patient and when no other means is effective. This drug is known to have the least desirable of the adverse effects, which include respiratory depression and hypotension (Schildmann et al., 2015).

In addition to sedative medication, previously prescribed medications are routinely continued if there are conducive to comfort goals. If deemed ineffective or overpowered, they are discontinued. This is also true if they are incompatible with the sedative medication or if signs of overdose are present (Cherny, 2019).

## **Methods**

The purpose of this thesis was to conduct a review of the literature to examine the use and effects of palliative sedation in persons nearing the end of life. Peer-reviewed research articles that were written and published within the last fifteen years were obtained and synthesized. The databases searched and included in this work were CINAHL Complete, MEDLINE and PubMed Central. Keywords searched were *palliative sedation, deep continuous sedation, continuous sedation, prevalence, trends, palliative care, morphine, medications,*



*pharmacology, existential suffering, refractory symptoms, physician assisted suicide, & euthanasia.* The total number of articles that were initially retrieved were 31. Various articles were excluded from this literature analysis due to irrelevance, location of statistics achieved & date of publication. A total of 20 articles met inclusion and exclusion criteria and were included in the review.

## Results

### Description of Sample

The body of articles included in this literature largely encompassed literature review articles with a few focus group, observational and narrative studies used. Over 50% of the articles used were published in the United States. In addition, about 45% were works of peer literature review. Of the primary research studies, primarily participants reported the data, with use of questionnaire and interviews. A table is provided below.

Title	Purpose	Design	Sample	Findings
Day-to-day care in palliative sedation: Survey of nurses' experiences with decision-making and performance. (Arevalo, Rietjens, Swart, Perez, & van der Heide, 2013).	Gain an understanding of nurse's experiences with administering and maintaining deep continuous palliative sedation.	Cross-Sectional Study with use of questionnaires.	Nurses employed in 10 different palliative care and hospice units, 6 home care groups and 7 different hospitals who have all cared for patients receiving palliative sedation.	Nurses are the center of palliative sedation administration, being by the patient always. Therefore, they should assume a more active role and have a say in the decision-making process.
Developing policy, standard orders, and quality-assurance	Develop policy and order for monitoring	Literature Review	Articles based on standard orders were evaluated to	An improvement process is necessary in defining policy for sedation

monitoring for palliative sedation therapy (Ghafoor & Silus, 2011)	palliative sedation.		determine the current guidelines surrounding the current practice of palliative sedation.	monitoring, to standardize orders and define goals of treatment.
Palliative sedation challenging the professional competency of health care providers and staff: a qualitative focus group and personal written narrative study. (Leboul, Aubry, Peter, Royer, Richard, & Guirimand, 2017).	Gain an understanding of sedation practices as they stand from healthcare professionals on the front line.	Qualitative design using focus group interaction and written narratives.	35 providers from 3 different palliative care units were interviewed.	Providers experience a degree of distress and suffering due to uncertainty in sedation administration and practices.
Palliative sedation for existential suffering: a systemic review of argument-based ethics literature. (Rodrigues, Crokaert, & Gastmans, 2018).	To describe and understanding the ethical arguments surrounding the practice of palliative sedation.	Literature Review	18 articles in peer-reviewed journals before December 31, 2016.	Ethical principles such as the principle of double effect, proportionality and biomedical ethics were defined and used in the debate. A grey area exists within the terminology definition and the debate overall.
Medication and Monitoring in Palliative Sedation Therapy: A systemic review and quality assessment of published guidelines. (Schildmann, Schildmann, & Kiesewetter, 2015).	Assess guidelines for palliative sedation drug administration and monitoring.	Literature Review	9 articles in CINAHL, the Cochrane Library, Embase, PsycINFO and PubMed before July 2014.	Midazolam is the drug of choice however there is a need for more concrete guidelines of medication administration, monitoring and titrating.
Experience of family members of dying patients receiving palliative sedation. (Tursunov, Cherny, & Ganz, 2016).	Define family members experiences of loved ones receiving palliative sedation at the time of initiation and after death.	Descriptive Comparative Study	A convenience sample of 34 family members of patients receiving palliative sedation in one medical center in Israel.	Relatives experiences were positive and perceived a relief of suffering in their loved ones. However, most felt more discussion was needed before sedation initiation due to a perceived lack of preparation and awareness on the part of the family members.

Level of discomfort decreases after the administration of continuous palliative sedation: A prospective multicenter study in hospices and palliative care units (Van Deijck, Hasselaar, Verhagen, Vissers, & Koopmans, 2016)	Identify the pain course in patients receiving palliative sedation.	Prospective multicenter observational study.	106 patients in 9 different hospice and palliative care units were evaluated for discomfort and followed over 4 different time periods.	Patients discomfort scores decreased significantly from the time before sedation to the final phase of sedation maintenance.
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### Considerations

There are many elements that must be considered when weighing palliative sedation and determining best route of care. To begin, we must consider the belief system of the patient.

Thorough examinations and conversations are necessary for nurse to gain an understanding of what will provide the most patient ease near the end of life. One thing that is crucial to integrate into the patient care process is their background. What does the patient believe in? Are they religious? What kinds of things are spiritually acceptable to them and what will leave them with the most peace? Becoming aware of cultural considerations is also necessary to provide culturally congruent care. Discussing these needs can help to identify if the decision to use palliative sedation will provide the most relief to the patient spiritually (Bruce, 2006). The care at end of life is much more than physical. The goal is to provide a dignified death, and in doing so, the patient must be morally in tune with their decision at this stage of life.

Depending on the situation, there can be a variety of stickiness to it. A variety of things influence coping with the initiation of this method. One of these is the realm of care. For instance, when considering geriatrics versus pediatrics. For an elderly person, it may be less unsettling to resort to sedation after they have lived a full life and are content with their

accomplishments. In the case of a young child, it may feel you are taking away a life that has not even been lived yet. There might be more of a natural push to see disease process through in younger patient before resorting to sedation. Other things can also make pediatric sedation tricky. You must consider if the parent should have control over when to initiate these measures. If so, until what age? Palliative pediatric sedation is not well- researched or discussed. However, expanding the hospice and palliative care fields in exploration of such can only promote better care.

Continuing, there is a varying level of resistance based on the reason for initiating the therapy. Sadler (2012) cites the fact that people have a more difficult time understanding sedation that is used to relieve psychological discomforts (i.e. depression) than when it is used for extreme physical symptoms. This consideration leads us to question the subjectivity in the decision to commence. To combat this subjectivity, guidelines are used in practice to determine the appropriate time to initiate this therapy. First, a terminal diagnosis must be given. This assumes that there are less than 6 months of life left. Death should be considered forthcoming and imminent. However, some subjectivity exists between what can be considered imminent. Next, unbearable symptoms must be present. The Hospice and Palliative Nurses Association (2016) establishes the amount and type of refractory suffering experienced by the patient must be evaluated and monitored consistently. From these symptoms, no relief can be found using various alternative therapies and management strategies (Bruce, 2006). The decision of necessity should be concluded within a multidisciplinary care team and decision to begin therapy is based solely with the intent to relieve symptoms (Cherny, 2019). This evaluation provides solidity and rationalization to foster a unanimous discussion prior to implementation. What to expect should be discussed in detail, through various meetings, with the patient and family to assure

understanding. After these variables have been verified, the patient has the ultimate choice in initiation and gives their informed consent. Precise documentation of all of the above along with sedation initiation must occur (Hospice and Palliative Nurses Association, 2016).

On a different note, it is integral to examine the principles behind palliative sedation. Francine Rainone references multiple areas that are important to examine in relation to the topic and where it currently stands in the field (Rainone, 2015). The first discussion topic is the legality of the matter. It is important to keep in mind that the main goal of palliative care is the patient's comfort. Above all else, their wishes and peace should be put first. We are trying to prevent suffering, but there can be guilt associated with sedating a person until their death. For a health professional, any dilemma faced in terms of ethics can be explored in relation to the law.

### **The Law**

Before discussing the law, it is important to decipher continuous deep sedation from euthanasia or physician assisted suicide. In different ways, all of these actions are cutting the individual off from the world prematurely in some way. Sadler (2012) describes the distinction of methods in terms of goals and intent. Euthanasia is conscious and purposeful termination of life (Cherny, 2019). The intent of euthanasia is to cause a brisk death. Physician assisted suicide is the act of providing a lethal medication dose with the intent to cause death (American Academy of Hospice and Palliative Medicine, 2016). The intent with palliative sedation is to relieve the ongoing suffering experienced. It does not hasten death, nor is it implemented to achieve death. The only goal of the practice is to provide complete symptom relief in order to achieve an enhanced comfort status.

In 1997, the United States Supreme Court approved the use of palliative sedation (Sadler 2012). This means that it can be lawfully implemented and used anywhere in the United States. The law has also established the fact that there is a clear distinction between the practices of palliative sedation versus physician assisted suicide and euthanasia. In contrast to palliative sedation, euthanasia is not legal anywhere in the United States. Physician assisted suicide has been deemed legal in nine states thus far which include: California, Colorado, Hawaii, Maine, New Jersey, Oregon, Vermont and Washington. Montana has assumed legality via court rule (States with Legal Physician-Assisted Suicide, 2019). Since ruling the practice legal, the debate has been expanded and been debated more in terms of ethical components.

### **The Ethics**

There are certain ethical principles that have been cited consistently to reason continued use or to justify discontinuation of palliative sedation. These principles are used to guide and evaluate clinical practice today and are described below.

#### **Doctrine of Double Effect**

This principle is called upon when we have two options in front of us and neither one is ideal. There are four aspects which come together to determine the ethics behind an action with two outcomes. The two outcomes being one that is good and intended, and one that is not good but is unintended (Rodrigues et al., 2018). An action with two potential effects is considered ethical if the action is, first, neutral in nature. This means that it is not an immoral action. Next, the only intention that we have while implementing the action is good. Third, the action doesn't bring the good as a secondary effect to the unintended bad effect. Lastly, it must be used for a serious and considerable reason and the intended positive effect must far outweigh any risks

associated (Rodrigues et al., 2018). This provides justification for palliative sedation as a state of complete relief outweighs potential costs.

However, there is some indecisiveness that comes as a result of judging acts based on intent. Rodrigues et al. (2018) makes the argument that “bad” and “good” are both subjective terms. Who can objectively determine if an action is good or bad and who can identify true intentions? This is the other side of the argument of the principle of double effect.

### **Principle of Proportionality**

This next principal uses the disease of the patient, the necessity of relief, and given consent to justify the practice (Bruce, 2006). Ultimately, the practice must be implemented with all good intentions, and death cannot be one of these intentions. Cherny (2019) asserts that there is no difference in length of survival in patients who received palliative sedation compared to those who did not. In addition, necessity of relief is provided with the presence of refractory symptoms and informed consent is received. This principle provides justification of the procedure (Rodrigues et al., 2018).

In a similar way to the principle of double effect, there are not tools to identify the proportions of positive and negative effects. Having concrete tools would make this argument more objective, and more persuasive. Continuing, this theory can be applied for physical suffering but may be called into question when the practice is implemented for refractory existential suffering. This idea led to a revision being explored, which has come to be referred to as the Principle of Therapeutic Responsiveness.

### **Principle of Therapeutic Responsiveness**

Here, the nature of suffering is explored. It maintains that the response to correct suffering in the final days is justified if the measure is proportionate to suffering, intensity wise. Also, the measure must be efficient for the type of suffering experienced, and the patient or the surrogate must have full knowledge of treatment and assume the risks of such (Rodrigues et al., 2018). With this principle, there is a necessity to evaluate the kind of suffering and to identify adequate means to treat as a result. Following this principle, existential suffering may adequately be treated with palliative sedation because psychological well-being is regained as a result (Rodrigues et al., 2018).

### **Biomedical Ethics**

Additionally, there are four biomedical ethics principles discussed in relation to the conversation. These are commonly evaluated in debates within the healthcare field.

#### **Principle of Autonomy**

This principle maintains the fact that the patient is making an informed choice based on free will with clear capacity and consciousness (Sadler, 2012). “Hallmarks of end-of-life care include respect for patient self-determination, nonjudgmental support for patients’ end-of-life preferences and values, and prevention and alleviation of suffering (American Nurses Association, 2019, p. 1)” In addition to suffering prevention, a main point in end of life care is respecting the patient’s right to decide what happens to them. Based on their competency, if this is what they choose, it is assumed as morally right that we carry out their wishes. This is an important piece in any area of holistic nursing, but especially in the final moments. We are, first and foremost, an advocate for our patients so it becomes our responsibility to grant them this



autonomy. Where the grey area comes in is in relation to autonomy by proxy. This concept is explored later in this work.

### **Beneficence**

When referring to this nursing principle, we weigh the good against the bad with end aim being the benefits exceed all else. The goal of palliative sedation is complete relief from suffering, which demonstrates the essence of beneficence in and of itself. The relief of pain and state of peace can be judged to succeed the costs associated with the treatment course. In addition, the practice is backed by the American Nurses Association's Code of Ethics for Nurses which provides that a nurse may implement measures to relieve pain in a dying patient so long as the intent is not to precipitate death or take away life (American Nurses Association, 2019). In this case, the effort to provide good care and relief overcomes the risks.

### **Nonmaleficence**

Nonmaleficence most simply means that we are not inciting or causing harm in any way. It is established that palliative sedation by no means accelerates death. It does not make it occur sooner, nor does it expand the time of life remaining. Instead, due to terminality of illness, death is foreseen but is not caused by sedation (Bruce, 2006). Therefore, it is not a harmful act.

On the other hand, Cherny (2019) evaluates potential harmful uses of palliative sedation and establishes the fact that clinicians need to be aware of the instance of when the practice would generate harm. With knowledge of potential harmful instances, we can be alert and very vigilant to cases where the patient may potentially be exposed to harm. The first instance discussed is cases where sedation is used in the absence of refractory symptoms. In this case, we would question the use and whether we are hastening death. In addition, when we haven't

explored alternative means of relieving symptoms, the practice should not be implemented due to ease. Further strategies and all other means to achieve relief should have been attempted prior to initiation. Similarly, to the scenarios above, initiation should not occur with family request in the absence of patient request themselves. Steps to minimize family assertion and maximize patient advocacy and independence would be necessary. The last possibility for harm is when palliative sedation therapy is indicated but withheld. This could be the result of several factors and barriers in the care team, some of which will be discussed in depth in the succeeding sections. Not initiating therapy when appropriate will result in insufficient relief and management of symptoms (Cherny, 2019).

### **Justice**

When thinking about the principle of justice, what is fair and what is right are explored in each circumstance. In relation to palliative sedation, we can make an argument of justice because we observe complete relief in a patient. Many factors are conquered with this one intervention. For example, spiritual, emotional, and physical pain can all be relieved with one measure. In a complex situation, a huge burden is lifted and many secondary effects of disease can be treated.

On the opposite side, palliative sedation has been critiqued as being the easy way out. For some institutions, it is questioned whether this means is initiated due to the inexpensive nature and ease of maintaining a patient in this state.

### **Benefits**

The American Nurses Association established a clear position on the practice stating that “when restoration of health is no longer possible, the focus of nursing care is assuring a comfortable, dignified death and the highest possible quality of remaining life (Bruce, 2006, p.

324).” In addition, the practice is supported by The Hospice and Palliative Nurses Association as an efficient means of managing unendurable symptoms. They maintain the position that every end-of-life patient must be advocated for in order to achieve complete relief and eliminate suffering at this point (Hospice and Palliative Nurses Association, 2017).

The most obvious sign of this relief is the marked diminishment of distress seen upon sedation initiation. There is no longer a struggle for breath, or gasps in a struggle to maintain oxygenation. There is no longer facial grimaces of pain or anxiety relating to impending doom. Sadler (2012) references palliative sedation as a holistic approach to a multifaceted pain experience for the patient. Palliative sedation provides a sense of calmness and relaxation. Also, all aspects of an individual’s suffering are dealt with head on through this one intervention. As a result, and by honoring the patients or surrogate’s decision, we are enhancing quality of life. Van Deijck, Hasselaar, Verhagen, Vissers & Koopmans (2019) conducted a study that indicated a significant decrease in discomfort levels for an individual following the initiation of palliative sedation. This increase in comfort was achieved and maintained within 1 to 2 days of treatment which is an adequate time frame. Palliative sedation assures patient comfort and provides that they are leaving this world in peace and in the absence of struggling. However, on the other end of this, it makes the patient that much more vulnerable (Rainone, 2015). In this instance, it becomes an even bigger responsibility to protect and advocate for a patient and their wishes. It also becomes more crucial to protect patient interests and evaluate the treatment course based on their wishes or advanced directives (Cherny, 2019).

In addition to patient comfort, relief may be experienced by families in the same way. Families no longer must witness struggle in a loved one. Palliative care is a holistic area of practice that requires care of the family in addition to the patient. It is undeniable that the greatest

success within palliative care comes as a result of both the patient and the family being satisfied and at peace with the treatment course. As a result of all this relief, nurse burden may be alleviated as well. If all protocol is followed and everyone is on the same page, this measure can be a powerful one that provides respite.

Within the healthcare field, we often refer to a concept known as patient advocacy. The way that someone spends their final days should be undoubtedly under their control. If we take away this option and deny the freedom to choose this measure if they wish, we are doing an injustice. There can be few things worse than filling out your final days feeling as if you are not being heard, like you have lost the opportunity to make decisions, or without any sense of independence. If we restrict the amount of options our patients have in their final days, whether we are providing the most competent care possible is called into question. A true act of beneficence and competent care would take all of this into consideration. Having this option available provides more variation and more options in a time where patient circumstances vary dramatically.

### **Risks Associated with Palliative Sedation**

Referring back to the familial experience surrounding the initiation of palliative sedation, comes the other side of the debate. Although the family might have been involved in the initiation, Bruce (2006) acknowledges that there is sometimes guilt associated with palliative sedation. This can be experienced in both the family and the nurse involved in treatment administration. A huge consideration when caring for a patient is their family. This is not easy. Their loved one becomes completely interactive and no further meaningful conversation can be conducted. They can no longer sense how they are feeling, and no longer communicate to ease

uncomfortability of the unknown. Some family members have reported feeling like they have lost their loved ones before they really have. Guilt, anxiety, and suffering can come as a result (Bruce, 2006). They are unable to feel connection and the patient is unable to feel and know their family's presence at the time of death (Rainone, 2015). All of this is only intensified by the fact that they must come to terms with this lethargic state and disconnection until the time of death.

This brings up the concept referred to as a premature end to a person's "biographical life" (Twycross, 2019, p. 1). This idea encompasses the fact that meaningful social interactions are no longer possible following initiation of continuous palliative sedation. As a result, the physical body is the only thing there until they are ready to pass on. Essentially, a patient is cut off from the interactive, social world prematurely. Rainone (2015) reinforces the concept of a "social death" maintaining a denial of any further experiences to be had. This can be considered a loss before actual physical death. Rainone (2015) expands by arguing the inability of the patient to grow anymore, especially in a spiritual sense. If a sense of spiritual peace has not been gained before the time of sedation, we may be ignoring an important end of life consideration. However, we must consider the fact that the decision to introduce palliative sedation may be an indicator that spiritual peace has already been reached.

When considering safety, we must be weary of abusing the practice. Yes, this practice is legal. However, if implemented too often, with less and less rigid protocol each time, the debate moves from a legality issue to a safety issue. Many researchers have argued that this practice will lead to a slippery slope. The question becomes what is stopping us from abusing the practice? If its goal is to relieve suffering, is the next step to use it for someone suffering from a mental illness that does not respond to other treatment? Safeguards against abuse would be beneficial for the future (Rainone, 2015). It is maintained that sedation should not be implemented as a form of

relief in instances where there could be a different reversal agent of distress (Palliative Sedation, 2019). All options must be considered, and a complex case should be present and evident.

The next thing to consider is whether struggle always equals suffering. For every person, there is some degree of struggle in life. Also, the disease process does not always have to be a linear, declining slope. Rainone (2015) brings up the question of whether pain changes during the disease course. By sedating patients, we don't give any further chance to see whether progression leads to less suffering and improvement or further declination in health. If we begin to sedate based on present struggle, how can we be sure that this suffering cannot be overcome (Rainone, 2015). Twycross (2019) furthered this aspect questioning whether more regular initiation of this measure would lead to desensitization relating to the ethical issues associated. In the same respect, if the practice becomes normalized, a mindset may be created where we associate all suffering as unconquerable (Twycross, 2019). This backs the argument that tight regulations should be established and adhered.

Lastly, communication strategies may not be optimal in the present practice. Tursunov, Cherny & Ganz (2016) found that there was a lack of effective communication both to the family and the patient themselves throughout the process. Many families reported wishes that the therapy had been discussed more thoroughly and further in advance. Other grievances alluded to the fact that there was a gap in explanation of what the sedation therapy would entail prior to its commencement. In addition to this, the study reported family members acknowledging the fact that they did not feel very supported or kept in the loop as the treatment was being administered. It was also established that this was the first study done on family members of dying patients that gathered information both during treatment and following the death of their loved one (Tursunov et al., 2016). There is a clear need for more attention to be given into this area, as a

comprehensive picture of nursing care includes family members and is centered on them after the patient has passed.

### **Barriers to Exceptional Nursing Care**

While there are benefits and downfalls surrounding initiation of palliative sedation, many of the cons can be greatly mitigated with a few practice tweaks. As currently reported, the practice may be overlooked and under considered. So, the reasons for such and modifications in response need to be addressed. When discussing Sedation initiation and the current prevalence rates of palliative sedation, it is important to consider barriers to this route of care. In addition, it is instrumental to take a closer lens at the way healthcare professionals can overcome these barriers. This will enhance the palliative sedation practice and create better patient care.

First, looking at the realm of nurses and their duties in relation to palliative sedation. As mentioned previously, palliative sedation can be a factor of distress for nurses. It is important to think about the impact that this executing this treatment day to day can have on a nurse. Earlier research has focused specifically on physicians and their experiences with administering palliative sedation. Unfortunately, there is not a great deal of research that investigates the impact on nurses, nor do we have programs helping nurses deal with distress. Ultimately, this may impact the quality of care given. This is a clear call for expansion of research in this area of the field. Arevalo, Rietjens & Swart et. al (2013) drive this point home saying, “Research focusing on understanding nurses’ experience with end-of-life decisions, in particular about their involvement in the decision-making and performance of continuous palliative sedation might contribute to an evidence-based practice of continuous palliative sedation that improves the wellbeing of the patient (p. 614)” Often, the nurse is the one that is continuously by the patient’s side: beginning, middle and end of treatment. The impact on the nurse is, therefore, much greater

if not of the same magnitude. Arevalo, Rietjens & Swart et. Al (2013) discuss the reality of the matter. At the start of palliative sedation: 80% of the time a nurse is there, compared to the physician being present about 45% of the time. The duty that a nurse has expands into a very active one as they face administering the therapy and continue being a steady presence for the patient and their family. The prior research established that a nurse is often left alone to administer and help the patient through this time. An immense amount of the responsibility and burden is placed on a palliative care nurse's shoulders throughout this process. Monitoring, assessing, administering, comforting puts a huge responsibility on the nurse, and this can result in strain and grief. Ultimately, the physician is not the one called upon to give the continuous doses of drugs. This allows them to remain goal focused, while the nurse feels the immediate effects. This is especially true if they are left to do so in solitary.

Also, there is uncertainty that comes with unclear guides about when to titrate medication. Some research establishes titration schedules, others warn against such since an increase in consciousness and lucidity would result in a patient experience of pain and symptoms reoccurrence tenfold. Factors like the subjectivity of distress, ambiguous monitoring scales, along with low confidence levels surrounding assessing distress are barriers and have deferred the treatment path away from sedation commencement. There is a lack in pain education and low availability of information to turn to in challenging pain cases, as most palliative cases are (Hospice and Palliative Nurses Association, 2017).

Leboul, Aubry, Peter, Royer, Richard & Guirimand (2017) discusses the concept of emotional distress in nurses further. He references a huge source of this distress comes from the uncertainty of the treatment given due to the subjectivity of determining distress in an unconscious patient. The lines are blurred in terms of the best way to monitor a patient once a



sedative state has been achieved. With consideration of this knowledge, it has become difficult for a nurse to be confident in care they are able to provide. Rogier et al. (2016) argues the fact that there has been no gold standard of tools established to monitor and decipher the level of discomfort patients are experiencing. So, by providing trainings and developing and implementing standardized scales for distress assessment in a sedated patient, we can improve nurse's confidence and reduce nurse quandaries.

There has also been evidence that concludes nurses face an ethical dilemma as a result of medication administration and fear of doing harm with too much. All of this considered, there is ultimately uneasiness in the decision to use certain sedatives over others, with an unclear picture of which work best in which circumstances. In response, standardizing guides relating to which pharmacologic to use in the presence of which refractory symptoms would enhance practice and confidence levels. In the same boat, we will expand the treatment field, and enhance patient care as a result.

While the nurse is very close to the heart of the issue, a physician's role is also crucial to consider, as they are at the heart of the treatment course. The Hospice and Palliative Nurses Association (2017) refers to this concept of "Prescriber hubris". This, in essence, is a prescriber acting on his/her own and neglecting asking palliative care and pain specialists for input. This is something that needs to be overcome to achieve greatest patient satisfaction and full relief of pain. This can be mitigated using an interdisciplinary team in the decision-making process.

Continuing with this idea is the concern of whether a nurse's values can influence course of treatment. At this point, it is important for a nurse to reflect on their own values. In some cases, we must put these aside to be the best advocate for our patients. In others, we may not be aware of how our beliefs are impacting and guiding treatment. Due to its controversial nature,

palliative sedation can be a morally distressing action for a nurse. Sadler (2012) identifies the fact that strong values that nurses hold can impact care in unconscious ways. “Nurses should reflect on personal values related to medical aid in dying and be aware of how those values inform one’s ability to provide objective information in response to a patient’s request (American Nurses Association, 2019, p.2).” If personal feelings are ignored, this can hinder the level of care provided. So, in complex cases, it becomes necessary to allow time to debrief our feelings and become truly aware of our biases and vulnerabilities. If you are aware of such, you can make a competent decision to provide care based on patient wishes or pass care onto someone who is able.

This information incites further change to occur within the field as new methods of dealing with such distress become a necessity for the healthcare workers. This leads us into the topic of teamwork and support. Leboul et al., (2017) proposes that the only way to effectively face the uncertainty and still provide the best care is to do so as a team. This means engaging in discussions. It involves interpreting the situation as a whole and then determining the best course of treatment as a result. It means communicating before, during and after treatments and making sure the next shift of nurses is on the same page with a clear picture of the situation. It means that all members lend their points of view. This type of collectivity not only relieves staff burden because individuals no longer feel alone in the decision-making process, but it enhances patient experience as they receive continuity of care. The outcome is benevolent and improves the teams functioning along with patient experiences. Much more satisfaction and confidence would be achieved with involvement of a multi-disciplinary team all taking a very active role in patient care and in supporting one another. In sum, “Teamwork helps reduce individual distress by

clarifying the course of action, providing an opportunity for dialogue and organization and offering professional recognition and support (Leboul et al., 2017, p. 9)”.

### **The Subjectivity of the Matter**

Especially towards the end of life, care becomes exceedingly subjective. What is right for one patient may not be the best option for another. Likewise, each patient will have different wishes, each patient will have different circumstances, and each patients' families will differ in terms of coping. Being aware of both sides of the debate is crucial in explaining, guiding and taking care of a patient and their family. This is also the only way we can provide competent care and guide our patients to the best course of treatment for them.

Although there is much argument about the benefits of this practice, there is an undeniable grey area that cannot be ignored. To begin, what is deemed intolerable is an extremely subjective concept. The things that may be considered unbearable very much differ from person to person (Sadler, 2012). What may be considered or reported as unbearable by myself, may not be to another person. Following autonomy principles, what the patient says is what we go by. However, the concept of autonomy becomes more ambiguous when the patient loses the capacity to make the decision for him/herself (Rainone, 2015, p. 157). When someone else makes the decision, the ethics behind the autonomous decision-making process are no longer applicable. Once decision-making capability has been lost, there is no way to know their wishes. How then do we protect these individuals? This is an important consideration.

Next, we turn the to the variation of circumstances permitting initiation of palliative sedation. At the present moment, palliative sedation is more commonly accepted for refractory physical suffering. What is more controversial, however, is the use of the practice for refractory

existential suffering. This, in part, is because there is much more subjectivity in analyzing existential suffering than there is in suffering of the physical nature. Existential suffering was mentioned previously and is thought of as the psychological, mental or emotional distress that occurs as a result of knowledge of impending death. It could be anxiety, depression, or inability to cope with the loss of life or with dissatisfaction of the life that has been lived. This type of anguish is common and can be equally debilitating as physical symptoms, but it is much more difficult to predict the course of these symptoms (Palliative Sedation, 2019). Unfortunately, no measure has been identified to analyze and characterize existential suffering in the field (Rodrigues et al., 2018) which allows room for doubt. At what point do we determine psychologic symptoms to be unbearable enough to rationalize sedation commencement? Also, when considering the normal paths of treatment for such symptoms, we question the use of sedation in place of things like therapy and counseling (Palliative Sedation, 2019). Still, we do need to consider the combination of this experience with the dying experience. There is questioning of whether this type of suffering should be considered different from other types. If a person reports unbearable suffering, by any means, shouldn't the goal be alleviation of such suffering? The current practice essentially overlooks a whole degree of human suffering. No consensus has been reached on the best ways to measure the refractoriness of this type of suffering. By characterizing this existential suffering for palliative sedation use, we can provide a more comprehensive use of the practice for all forms of human suffering.

Continuing, Schildmann et al. (2015) found there was a neglect for guidelines surrounding routine monitoring of distress. There are inconsistent and unclear guidelines as to how we should monitor patients once they are in an unconscious state. Some refer to the use of "physician expertise" (Schildmann et al., 2015). What this means is entirely subjective and can

be taken, used and applied in various ways depending on the interpreter. This is established earlier as a reason why nurses feel uncomfortable with palliative sedation and monitoring patients (Hospice and Palliative Nurses Association, 2017). This shows a clear path for improvement of this specific measure and is a consideration that should be researched further in order to provide even better patient outcomes. There is maintenance and monitoring of the level of sedation. However, the goal of the therapy is to reduce suffering. There seems to be a disconnect between the goal of therapy and the practices in this field thus far. There is no definitive and established means to evaluate the level of discomfort once the patient is unconscious (Rainone, 2015). With deep sedation, once commenced, the patient themselves cannot change their minds. Depending on the dose and medication chosen, palliative sedation is not unfailing. How can we be sure of its efficacy in the absence of communication?

These facts exemplify a clear need to explore further methods of evaluating effectiveness. This would not only enhance patient experience but provide reassurance that we are implementing measures that undoubtedly helping. Leboul et al. (2017) furthered this argument by discussing the ambiguity of medication adjustments parameters and distress assessment tools. He explores the ways we can misinterpret values based on these scales. There is a lot of room for subjective opinions in symptom identification. If we were to assess a patient grimacing and report anxiety as a result, is this partly our own anxieties showing up in our decision-making process? (Leboul et al., 2017). Rainone describes this ambiguity as “Subjective decisions without objective confirmations (Rainone, 2015, p. 159).”

As explored earlier, Schildmann et al. (2015) established the most used medications for achieving sedation. However, there is a clear lack of research regarding different indications for using different medications. Guidelines can vary remarkably from institution to institution as

well. This supports a case that Leboul et al. (2017) also establishes regarding the necessity of new research to expand expertise and work to do away with the uncertainty. If more precise sedation policies were to be identified, maybe physicians, nurses, and families would be more comfortable with this measure. Taking away this grey area would be the next step towards competency and affirmation of this practice.

### **Discussion**

Deep Continuous Palliative Sedation is a treatment option for patients. Palliative sedation is initiation of an unconscious state with the sole intent of relieving refractory human suffering near the end of life. In no way does it cause death, nor does it accelerate death. It is implemented as a last resort measured after all other means are exhausted (Cherny, 2019). This is all done to promote well-being and enhance the quality of end of life.

Benefits surrounding initiation include complete relief of distressing refractory symptoms. It also provides family ease and assurance as they visually see a decrease in distress in a loved one (Sadler, 2012). Quality of life for the patient is enhanced with the relief and the practice allows promotion of a peaceful and dignified death.

Risks associated include initiating a social death before a physical one, cutting the patient off from the world prematurely (Twycross, 2019). Family distress can occur because there can be guilt associated. There is also ambiguity in identifying distress in an unconscious patient which causes nurse distress and low confidence levels due to inadequate training (Schildmann, 2015). Furthermore, uncertainty regarding which medication should be used in the presence of certain refractory symptoms causes uneasiness.

Alike many other disease management plans, there are benefits and risks associated with treatment. There are also grey areas in treatment course that render decision making to subjective parties and opinions. As a result, there is hesitation surrounding initiation of sedation. Due to its controversial nature, the amount of time palliative sedation is utilized is not often. Prevalence rates are remarkably low, not very well reported and are very hard to identify.

The practice seems to be implemented and accommodated much more thoroughly into various other parts of the world, where the U.S. lags in comparison. Multiple countries establish a higher and more frequent use of the practice at the current point in time (Rietjens, Heijltjes, van Delden, Onwuteaka-Philipsen, & van der Heide, 2019). With forward thinking and by making some advancements in the field, we can improve the practice and accommodate its use more frequently in the United States as a result. This means providing trainings and developing standardized distress assessment scales, creating standardized policies relating to medication use in the presence of each refractory symptom, providing education and implementing quality-assurance monitoring tools.

### **Limitations**

This body of literature is limited in a few respects. First, about one half of the published literature came from various areas of the world. These ranged from the Netherlands to Germany. Healthcare practices vary from region to region so it may be naïve to group the same findings in one body of literature. The lack of articles relating to the composition of this literature also forced articles to be used from 2006-2020. The age of some of the article may result in outdated statistics and affect accuracy. On the same coin, guidelines for titration and implementation vary so to say that they are all incomprehensive and insufficient in practice takes on a narrowed lens. Practices vary from institution to institution in the same respect. Lastly, the author lacks first-

hand experience with the use and administration of palliative sedation. The presence of such may increase knowledge and competency in describing the practice.

### **Looking Towards the Future**

Based upon the amount of knowledge generated, there is an evident need for more research in the palliative care area moving forward. For one, to establish clear and definitive policy orders of palliative sedation in order to provide affirmation (Ghafoor & Silus, 2011). There are a substantial number of considerations that are specific to palliative care. A holistic viewpoint is necessary in determining the experiences of individuals nearing the end of life and when determining the best strategies to handle such experiences. Yet, there is an evidently inadequate amount of research done on existential suffering in specific relation to end of life care. This presents a need to establish and characterize varying degrees of existential psychologic distress in order to increase the use of palliative sedation for such. This would provide a more comprehensive use of the practice for all forms of suffering. The field can only improve with the understanding of patient's unique reality with a treatment course tailored in response.

The role that nurses have in the topic and the debate can, and should, expand greatly going forward. We, as nurses, are the one spending the most time face-to-face with the patients involved in these practices and these decisions. No, we are not the ones prescribing the treatment. Still, the nurse by the patient's side as they forego other wishes and initiate the treatment. Expanding our knowledge through education, becoming a part of the conversation, and being trained in monitoring distress and sedation levels can only improve the experience for our patients. This can also improve a nurse's experience and efficacy as an informant and participant in treatment discussions.



**What this literature hopes to contribute to the Palliative Sedation debate**

With the fact that distress at the end of life is still a huge concern, and extremely prevalent, a case is made that we should not restrict the option of palliative sedation, but make improvements to better the practice and ensure safety to ease the minds of all involved. Similarly, because there are numerous barriers identified that affect the quality of care provided every day, it is proposed that further training and research be done on possible means to overcome such.

Advancements like providing objective policy about quality assurance monitoring, providing training and education in staff, patients, and families and lastly, standardizing policy regarding which medication should be used in the presence of specific symptoms are indicated as next steps. These guidelines should be as standardized as possible regarding goals, medication use and titration schedules (Ghafoor et al., 2011). There is a huge potential for growth in the palliative care realm. In addition, there is huge potential adjustment and enhancement of palliative sedation. Palliative sedation relieves pain and suffering and can be a valuable option for some in the end of life. If training and field improvements are done, we would minimize the amount of grey area and provide enhanced satisfaction for all involved. The level of care and confidence levels would increase dramatically as a result.

**Conclusion**

Ultimately, the end of life is the most crucial time for creation of an individualized plan of care. This plan is based on patient wishes and implementation of treatment methods that will provide the most peace in accordance. We, as healthcare professionals, have a responsibility to accommodate patient wishes but also to have up to date knowledge and demonstrate competency

within practice. Barriers evaluated above are indication for further training and policy advancement. These are indicated as the next steps. Still, whether it is used in half of hospice cases, or in one percent of cases, palliative sedation's existence expands the field and availability of treatment options. The specificity and subjectivity of care makes the case that palliative sedation should be available as a viable option. End of life is such an individualized time that needs to be constructed subjectively to fit each patient's differing situation. In some cases, palliative sedation is what is going to provide the patient and their family with the most peace, this is the goal of palliative treatment. Therefore, it is a valuable resource.

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