A Literature Review on How Palliative Care Addresses Physical and Existential Suffering in Symptomatic and Terminally Ill Patients

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Introduction

For as long as humans have existed, disease has caused suffering and death. From the Spanish Flu in 1918 to COVID-19 one century later, scientists have found hundreds of treatments for a variety of diseases. Scientists have also developed treatments for many diseases without curative therapies to keep the condition from progressing. However, sometimes, these treatments are unavailable or are too painful, costly, or insufficient to stop the progression of the disease. In these cases, where the patient has no treatment options or decides they no longer wish to undergo treatment, hospice care may be offered. Similarly, palliative care may be provided to patients undergoing treatment who need assistance with symptom management or who have quality-of-life concerns.

Palliative care first gained attention in the 1950s, when much of the focus of medicine in the oncological field was on discovering a cure for cancer. Those with advanced-stage diseases or deemed incurable were mainly forgotten about and left to die alone. During the 1960s in the United Kingdom, questions were raised about how to handle near-impossible cases. Cicely Saunders is one of the prominent names in the rise of hospice care for cancer patients in the UK. In the late 1950s, she was working on her first major medical publication. Her chapter on “The Management of Patients in the Terminal Stage” was the only work to discuss end-of-life care in a six-volume series on Cancer. During this time, there were very few hospice facilities in the UK. Of the few in existence, nearly all were run by religious organizations. In 1999, the British government appointed Mike Richards to reform and improve cancer services. His efforts led to what is known as palliative care today.[1]

Fortunately, palliative and hospice care look very different in the modern era than they did one hundred years ago. Today, palliative care focuses on alleviating suffering, including physical, spiritual, and existential. Physical suffering consists not only of pain but also symptoms such as nausea, vomiting, neuropathy, and diarrhea. Through therapies such as medication, surgery, or radiotherapy, great strides have been made in the last few decades to reduce patients' physical discomfort.[2] While physical pain management is a huge part of palliative care, other factors must also be considered when addressing all aspects of suffering. At the end of life, patients often experience profound existential thoughts, which cannot be relieved by the methods mentioned previously. Instead, other methods that address existential issues are more efficacious, such as counseling, religious participation, and psychotherapy.

This review paper aims to compile the numerous studies and methods by which palliative care aims to address the whole person, as well as alleviate suffering at the end of life.

Physical Suffering

The goal of palliative care is to reduce suffering caused by disease. One of the most integral parts of this is reducing physical pain. To see if the treatment is effective, there must first be qualitative and quantitative ways to assess pain or discomfort in palliative care patients. A common method to quantify pain is by asking a patient to state the severity of their pain, with a number usually between 1 and 10, with 1 being minimal to almost no pain, 4-5 being moderate pain, and 10 being unbearable pain. Another model that is used is displaying faces with different expressions, ranging from a smiling face to a strained one to one that is crying uncontrollably. The patient is asked to match their pain level with the one they feel most represents how they feel. These models are useful for describing pain because, although it is relative, it allows the patient to describe what they are feeling accurately. Additionally, this same pain scale can be used while administering the therapy to evaluate the effect on the patient's symptoms. The new value the patient uses will be compared to their old assessment, allowing providers to determine if there is any positive or negative effect on the patient. Using adjectives is also useful in determining what kind of therapy should be used. Different types of sensations suggest different kinds of problems in the body. Another important factor in assessing pain is determining the location of the pain. This makes it easier to decide what measures should be taken to reduce the pain because the location allows the examiner to determine the nature of the pain and how to reduce it.[3] After the type of pain has been identified, physicians can begin administering therapy.

The main form of therapy today is medication. The general guideline for administering pain medication to cancer patients was established by the World Health Organization in 1986 but later revised in 1996. This method is still utilized today. The Analgesic Ladder breaks down pain medication management into two sections: one section for the level of pain and one section for the usage of the medication. The section for the pain level is broken down into mild pain, mild to moderate pain, and moderate to severe pain, with each level requiring different types of medication. The section for medication usage is broken down into medication by mouth, by the clock, by ladder, by an individual basis, and with attention to detail. Generally, the main medication consists of opioids and adjuvants, but for lower levels of pain, acetaminophen is used instead of opioids. This is because the goal of the medication is to make the patient feel better with as little medication as possible. As time progresses, however, stronger and stronger opioids may be required to compensate for patients' increasing opioid tolerance. , and medication such as morphine or oxycodone may be required. This structure gives physicians a general framework for administering medication as this basis is widely accepted.[3] Within two years of its proposal, the Analgesic Ladder was validated in 80-90% of its cases, proving that it was a highly effective way of determining what kind of medication was required for the patient.[4]

Research has also been conducted on the usage of cannabinoids in pain management. Although the results suggested using cannabinoids alongside the use of other treatments did have a positive effect on the patients, the results did not suggest that there was any definitive effect on the patients to consider cannabinoids as a therapeutic measure to be used alone. The study mentions that the results should be regarded "as an individual therapeutic trial" and should not be taken alone but alongside other therapeutic measures.

Somatic pain is generally responsive to opioids but sometimes may require additional therapeutic measures. The prevailing medication currently is nonsteroidal anti-inflammatory drugs (NSAIDs). However, NSAIDs have their own side effects, such as nausea and vomiting.[5] Neuropathic pain is generally not responsive to opioids, and different medications should be used. Generally, tricyclic antidepressants and antiseizure medications are used. Anticonvulsant medication can be utilized if the patient does not benefit from these types of drugs. Traditionally, the treatment for pain has been the use of medication. However, there are many nonpharmacological approaches to reducing pain in patients. "Physical interventions include massage, acupuncture, exercise, stretching, passive range of motion, heat therapy, transcutaneous electrical nerve stimulation, and immobilization. Psychosocial interventions include relaxation techniques, imagery, support groups, family counseling, education, biofeedback, and psychotherapy."[3]

Palliative care also focuses on relieving non-pain-related suffering. For example, many patients who undergo chemotherapy experience long and uncomfortable nausea. To treat this discomfort, there are generally two approaches to drug selection: empirical and mechanistic. The empirical approach allows physicians to choose antiemetic drugs based on previous experience. It is akin to the doctor using a one-size-fits-all approach to prescribing medication without considering the cause of the nausea. However, the mechanistic approach uses current knowledge of an empirical approach and how chemicals in the brain and nervous system interact with substances to choose the best medication for the patient based on how it will interact with the receptors in the brain. The mechanistic approach relies on understanding the disease and what causes it to come up with treatments, while the empirical approach relies on clinical experience to suggest medication even if the underlying mechanisms of the disease or the drug are not fully understood. Similar to physical pain, a second medication should be added if the patient is unresponsive to one type of treatment. Many drugs are available for treating nausea and vomiting, including prokinetic agents and antagonist medications, such as antihistamines. For many end-of-life patients, delayed gastric emptying is a common symptom, often secondary to their medications or underlying medical issues. When delayed gastric emptying goes untreated, it can lead to many symptoms, including nausea and vomiting. Prokinetic drugs aim to increase the contraction of muscles in the gastrointestinal tract to stop delayed gastric emptying. This way, they help to prevent feelings of nausea and vomiting. [6] Antihistaminic agents work by targeting parts of the brain. They work mainly by blocking H1 receptors in a part of the medulla that facilitates vomiting and the chemoreceptor trigger zone, the part of the medulla that receives emetic signals and sends this information to the vomiting center of the brain, thereby inducing emesis.[7,8]

Another very common form of discomfort in palliative care patients is constipation, especially as patients are on significant analgesics. Constipation is relieved through medications, including genocides, bisacodyl, and methylcellulose.[9] The most common medication to treat constipation in palliative care patients is macrogol. It has been shown to be the most effective medication for constipation and works for a wide age range of patients.[10]

Existential Suffering

Unfortunately, many times, patients need healing beyond their physical symptoms, and healthcare workers have reported feeling underprepared to deal with the transition of life.[11] Hospice nurses have developed strategies to help patients deal with existentialism. Something to note is that before their existential needs can be addressed, patients' physical suffering must first be relieved since constant pain and nausea will exhaust them to the point where spiritual and existential concerns cannot be properly addressed.

Experienced nurses from a prominent hospice in Norway were invited for an interview, each with extensive experience and qualifications for end-of-life care. Two key themes were determined over the course of the interviews: sensing the existential suffering the patient was experiencing and consoling the patient.[12] Determining what the patient needs is an extremely difficult process since, many times, the patient's suffering is a mix of both physical and emotional, making it difficult to discern what the patient truly needs. Nurses talked about sensing the emotions in patients' rooms, specifically when other family members were present. They reported various emotions in the rooms' atmospheres, from intense dread to being joyful and lively.[12]

Nurses can provide consolation by talking with the patient but, more importantly, by employing active listening techniques. Many times, silence is a very consoling experience for patients. By simply being present and offering a comforting touch, nurses can show compassion in a calm and peaceful manner. Other times, nurses could support the patient emotionally by allowing them to process their feelings by encouraging patients to talk about their feelings about future passing. The nurses noted that patients who talked about their feelings seemed to pass away more peacefully than those who did not.

Hospice care workers are vital when helping families share and express grief. Many patients do not wish to share difficult information with their families. For instance, dying parents hide their emotions not to scare their children, or spouses may withhold information from one another over the fear of causing them distress. When patients find it difficult to talk to their families, nurses are able to facilitate the conversation.

During times of despair, many patients find comfort in their religion. Hospice workers can help patients by allowing them to connect with their religion. For example, nurses can refer patients to hospice chaplains to help them with religious support, or they can directly support patients by providing them with the things they need to practice their religion. The nurses in the interview stated that for Christian patients they would pray for the patients and their families and read from the Bible if requested. Nurses are also able to help patients with religions that they are not very familiar with. For example, although the nurses interviewed were not very well versed in the Muslim faith, they were still able to provide religious consolation by providing them with things such as halal food and a prayer space.[12]

Patients can also engage in other activities like drawing, painting, listening to music, or playing with animals. Data on art therapy has been collected on numerous populations with different diseases and symptoms, from cancer to dementia, and the results show that art therapy has a tremendously positive impact on end-of-life patients. Most patients who participate in any kind of art-based activity have been shown to have a better quality of life after engaging in them. These patients report not only less emotional symptoms, such as anxiety and depression but also physical symptoms, such as reduced fatigue and pain.[13] The use of music therapy has also shown a positive effect on the lives of patients in hospice care. As an evidence-based therapeutic treatment, it has been shown to decrease depression, stress, and anxiety in patients.[14] Music therapists analyze the needs of patients and then use various methods such as compositional, improvisational, receptive, and re-creative therapy to facilitate a healing environment. In each of these methods, patients can either create or listen to music, allowing the patient to express themselves or be more relaxed.[15]

The use of animal companionship as a form of therapy has proven helpful in other settings, such as pediatric wards and correctional facilities, and they have a similarly positive effect on hospice patients. A study was conducted in a day hospice in England in which two trained cocker spaniels were brought to visit the patients, as well as a resident budgerigar and some tropical fish. While the bird and the fish received positive yet mixed reviews from the patients, the dogs received an overwhelmingly positive response, with more than 86 percent of the patients reporting a “very keen” attitude to the dogs. Many patients had previously had an animal companion, making them much more open to meeting the animals. Still, even patients who had not previously had pets were willing to meet with the animals. Physical contact with the dogs made the patients feel more relaxed and happy, and affectionate dogs brightened the atmosphere significantly. The presence of dogs makes the hospice environment feel less clinical and more friendly, greatly improving the moods of the patients.[16]

Conclusion

Before hospice and palliative care, most patients were left to die if they were considered to be past the point of saving. Thanks to the work of people like Nurse Cicely Saunders, palliative and hospice care have grown from being nonexistent to now being an established field of medicine with an ACGME-accredited fellowship. Palliative care providers help patients in the advanced stages of their disease by addressing physical and existential suffering.

To properly treat physical suffering, it is important to first quantify it in a way that makes it easy to determine what the proper therapy should be. It is also important to determine the location of the discomfort for the best treatment. The creation of the Analgesic Ladder by the World Health Organization was a monumental step in standardizing how patients receive proper treatment based on the level of pain they are experiencing.

To address physical pain, the general approach is to use different types of medication. However, other nonpharmacological approaches can also be used, such as massage or acupuncture. Other non-pain-related symptoms are also very common among palliative and hospice care patients. Other types of somatic symptoms include nausea, vomiting, and constipation. These symptoms are treated with different types of medication.

In addition to addressing physical suffering, palliative and hospice care place a large importance of addressing existential suffering as well. Hospice nurses are trained to sense patients' feelings and console them through various methods, such as active listening and a comforting presence. Nurses are also vital to facilitating conversation between patients and their loved ones, as it may be difficult for the families to discuss their feelings. Patients can also engage in other activities, such as art therapy, music therapy, and animal companionship.

Massive strides have been made and are continuing to be made in the field of palliative and hospice care. As new fields in the vast ocean of medicine, it is important to highlight the importance and impact they have had on numerous patients and their families. By combining medical knowledge with human compassion, these new fields have developed and continue to develop that provide quality and dignified care to all types of patients regardless of who they are, bringing all of us closer together.

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