

**BIOETHICS AT THE END OF LIFE**

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## **Patients experience of pain at the end of life**

In acknowledgement that death is what awaits every human being, it is pertinent to zero into the final process of death, which is an area most people would wish or desire not to entertain.

Terrified by pain, suffering or just the notion of dying alone we are confronted with our own mortality. Since death affects the general human family, we look for ways to educate ourselves on the dying process to enable us alleviate pain and suffering for those left behind. End of life should be a reflective moment, where families gather together to encourage and to witness a quality life ending with dignity and respect. Unfortunately, most people experienced tremendous kind of pain; be it the physical pain, emotional pain, psychological and spiritual pain.

The main focus of this paper is to describe three main kinds of pain that patients experience at the end of life: Emotional pain, spiritual pain and physical pain.

Pain symptoms at the end of life can be pervasive, it has a detrimental effect in life and its quality. According to a retrospective population-level cohort study completed in Ontario, Canada, 1 in 5 of the study populations reported less pain in the last 30 days of life, especially the cognitive impaired clients who cannot be able to report pain. But functionally impaired and cancer patients reported severe/excoriating pain at the end of life and died miserable.<sup>1</sup>

The experience of pain is different from one person to another, no two people will have similar kind of pain. The American Cancer Society (2004) defines pain as a sensation that hurts. It may cause discomfort, distress, or even agony. Pain may be acute in nature, severe and last a

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<sup>1</sup> Hagarty, A.M., Bush, S.H., Talarico, R. *et al.*) 2020.

relatively short time. Chronic pain, however, may range from mild to severe and be present for a long period of time.<sup>2</sup>

Causes of pain at the end of life:

No one should die in pain. Fear of pain, and fear of dying can make normal dying process a devastated one. It is not every dying patient experience pain at the end of life, for example some people with underlying issues like heart disease, and lung disease can experience less pain, but may have respiratory distress. Some people with arthritis, general body-aches, infections and wounds due to long term bedridden may experience minimal pain. Remember, this type of pain can be treated with mild pain-relieving medication.

But, patients with terminal illness like Cancer, may experience pain as the cancer grows to mount pressures on the internal organs. These levels of pain can be managed with morphine through infusion pump. Encouraging hospice care at the end of life is essential for promoting quality care and quality life, making dying process a dignified one.

Kinds of Pain

The concept of pain at the end of life can be managed well when the different kinds of pain are identified.

Physical pain exists on the surface of the body or in the tissues. Physical pain is that aching sensation, caused by injuries, accident, extreme exercise or lack of health. Physical pain happens to be the most easily identifiable kind of pain from the other kinds, making it easy to be

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<sup>2</sup> American Cancer Society (2004). Retrieved November 14, 2004 from <http://hospicenet.org>

managed. And because physical pains are easily identifiable, it overshadows the other kinds of pain

Emotional pains are pains that have no source of origin. It can be the result of how people treated others. It can be a sense of loss, guilt, regret, or symptoms of depression or anxiety related. Most people do not recognize or address this kind of pain, but they are very severe in nature. How individual reacts to this kind of pain differs but can be very severe in nature. “Emotional pain disorganizes one’s ability to focus on the reality, or to effectively completes daily routine. Such pain can affect one’s quality of life and body systems, which may lead to excessive diarrhea, nausea, dizziness, body aches”.<sup>3</sup>

Spiritual pain: Towards the end of life, most people seek to embrace their various faith and belief, and brings peace and comfort to those individuals, but not all recognize or practice this act. During this period of life, many lost their faith due to illness, many go through grief as they belief they disobeyed their God, while others would like to have a total surrender and reconciliation with their God. Those individuals may invite chaplains to walk through their emotions and feelings, thereby relieving their pains, and to end their life journey peacefully. Spirituality is vital to human, that effect how we handle every physical pain we encounter in life. When spiritual pain is not treated, it may lead to anger, despair and guilt etc.<sup>4</sup>

Ethical Implication of pain at the end of life:

Exploration of ethical theory is necessary to help develop a template to get started and see the some of the critical issues of pain management at the end of life. In the words Mark Sullivan, “A

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<sup>3</sup> Elizabeth Hartney, 2020

<sup>4</sup> Mary T., D.Min., & Caterina M. 2011

brief review of prominent theories follows with some annotation concerning their application to ethical problems in pain management”.<sup>5</sup>

The four principles essential for biomedical ethics reviewed: respect for autonomy, non-maleficence, beneficence, and justice.

Beauchamp and Childress define personal autonomy as “personal rule of the self, free from both controlling interferences by others and from personal limitations that prevent meaningful choice.”<sup>6</sup>

Two essential conditions are required for autonomy to be authentic: liberty and agency. In illness patients depend on the expertise of their physician and they trust that decision made by their physician is the best for their health condition. It is only by getting the valid consent of their patients will the physician actually effect and respect the autonomy of the patient. Situation when patients are not able to grant their consent or unable like an infant or demented patient creates a huge challenge for physician to address the needs of the patients. Eric Cassel explains: “For the suffering person, autonomy is removed when purposes are directed by the immediate needs of the sick baby or by the compulsion to address what is perceived to be the source or suffering”.<sup>7</sup>

In this principle of Non-maleficence is one of the regularly cited maxims of biomedical ethics. At the end of life, non-maleficence poses a Huge challenge for the physician, especially when the patients are terminally ill. “Providing a surgical procedure for a patient in severe pain known to provide only short-term relief and severe problems over long term would also be considered a violation of non-maleficence”.<sup>8</sup>

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<sup>5</sup> Mark Sullivan, MD, PhD. 2001

<sup>6</sup> Beauchamp TL, Childress JF. Principles of Biomedical Ethics

<sup>7</sup> Eric Cassell EJ. Pain and Suffering

<sup>8</sup> Mark Sullivan, MD, PhD. 2001

The principle of beneficence at the end of Life obliges physician to have a positive attitude to see to the well-being of others not just to refrain from harm. “Since moderate to excruciating pain can be physically and psychologically harmful, preventing or alleviating such pain is not merely a matter of doing good (beneficence) but also of preventing harm (nonmaleficence).”<sup>9</sup>

There is a thin line in the application of this principle since it is not clear for physician to relieve all pain of their patients, as to hasten the death of a patient.

When patients at the end of life are going through excruciating pain cannot give consent the physician at this point has to make sure that the patient gets justice.

#### Pain management at the end of life

Pain sensation is unique to individuals. Association for the study of pain defined pain as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of that damage.”<sup>10</sup>

Pain can come in as acute, chronic or combination of both, either way, it is very unpleasant, can be devastating, and reduces the quality of life. The management of pain at the end of life is beneficial through the use of pain management and palliative care. The pain management aspect of pain control is through non palliative opioids medication. Collaboration of care between the physician and palliative is required to improve the quality of life at the end of life. Palliative management of pain involved a continuous pain management from the hospital to home. The physician uses opioids to manage the moderate to severe pain, and these opioids can be titrated as ordered and in accordance with WHO. Non opioid medications can be used to treat

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<sup>9</sup> Ibid.

<sup>10</sup> Platt 2010

neuropathic and somatic pain such as anti-epileptic, antidepressants, and other combinations of medications according to the physician prescription. But opioids are the main pain approach which has proven up to 90 percent effectiveness in the treatment of pain at the end of life.<sup>11</sup>

There are other remedies that the palliative medicine and physician can use to alleviate pain at the end of life, which has proven to be effective.

Among the noninvasive pain management at the end of life, acupuncture is the most effective and often used in patients at the end of life. Acupuncture is one of the effective pain relievers use at the end of life. Its mode of action remains a mystery, it helps in the relieve of backache, headache and muscle pain. Due to its great effect at the end of life, palliative patients often get relieve from pain under one section of treatment, others may benefit in multiple sections depending on the level of pain. Most patients find acupuncture relaxing and effective in pain management and at the end of life (Platt, 2020)

#### Education about pain at the end of life

For there to be effective pain management, every effort must be made to provide education. This will help to certain degree the recognition of pain in its diverse forms. Since the final goal of medicine is to alleviate pain and suffering there will be structure to attend to this goal. It is of human right to manage all pain, also part of the health care values. Through education, population should be aware of the important of recognizing pain and its symptoms, for early pain assessment helps in early commencement of treatment and care. “Knowledge of pain (as a

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<sup>11</sup> Platt, 2010

symptom, disease, and /or illness and phenomenon, ie, total pain) must be the basis for all constructs in pain medicine.”<sup>12</sup>

## Objection

Understanding that the overarching goal of medicine and nursing is the alleviation of pain and suffering. At the end of life when every attempt to cure or stop the progression of the disease fails, the relief of pain and suffering becomes the overarching goal over the primary goal. In this situation, attention is given to pain management. Furthermore, the availability of Ritual and sacramentals, provides very meaningful stance for both the patients and the family members. Neither can we ignore the impact of calming reach of music, relaxing tones that touches the soul. Ultimately, when all goes well, healing is measured not by the condition of the body; rather the peace that radiates and permeated the person. when pain is recognized and managed well it helps the patient peaceful transition.

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<sup>1</sup> <https://unabridged.merriam-webster.com>

<sup>1</sup> American Cancer Society (2004). Retrieved November 14, 2004 from <http://hospicenet.org>

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<sup>12</sup> Carvalho et al: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5962306>

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