



## **THE ANGST OF WHERE AND HOW ONE DIES A PLEA FOR CARE AND COMPASSION WITH PALLIATIVE CARE**

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### **ABSTRACT**

*The death and the dying process was a topic that was not discussed openly in public. However, with the debates about the act of allowing a patient to die legally, has widened the scope of many disciplines like legal, medical, psychological and philosophical bracing the ethical values to a wider population of society. Patients that suffer with a terminal disease are left to deal with their emotional, psychological and clinical struggles on their own. As a terminally ill patient faces death every moment the fear of not knowing the time and place of their death is so profound that some of them would request to be assisted to die rather than going through the dying process each day.*

**Keywords:** mortality, physician, euthanasia, perspective, existence, experience

### **INTRODUCTION**

With the evolution of the concept of euthanasia over time, as the original meaning was “the painless killing of a patient suffering from an incurable and painful disease or in an irreversible coma” due to the judicial and ethical dilemmas there are more questions now than ever.

The consequences and the ethical value of life attached to the disease is quite a challenge to solve (Heywood & Mullock, 2016). Finding answers to the dynamics of making euthanasia permissible is complex and sometimes controversial. This paper attempts to bring out the perspectives of the fear of dying due to a terminal disease. There is a gap between the understanding of different perspectives of right to life and the right of an individual to choose to die.

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### **The existential dilemma**

As human beings, discussions on death are the darkest space, which we would not want to visit voluntarily. We know we have a limited amount of time for our existence, we treat ourselves to a healthy lifestyle, most often it is an illusion that we are trying to push our date with death further away (Akhtar & Aronson, 2010). There are times that one may fathom death is for everyone else and they can escape its clutches thinking they will be the last to die. When sickness invades the body, fear becomes the fundamental feeling as it brings a reality that we will die alone. The fear of death is not about dying, but about going into an unknown space and time, one that has never been experienced or seen before.

Though there is a slight change now in the death scenario as patients, physicians and family discuss death, more openly than before. Kurt Gary a famous psychologist-scientist holds that as we near death the thought is most sad and terrifying, but then we realise that death is a lot happier than we can imagine (Association for Psychological Sciences, 2017). This is now made imaginable as there is now an alteration of not hiding behind the curtains of death talks. As there is a growing ethical demand of encouraging the patient to be happier and respected in their last days of living. The health system has their own guiding principles towards the treatment of a patient.

Another fear that cannot be negated is the anxiety of whether death is painful at the time that life exits from the body. It is impossible to understand what the actual process of dying is. This fear has been from primeval to the human race and no amount of study has been able to overcome the angst of dying.

Everyone knows death is the only procedure that no one gets to escape. Human beings are well aware of this fact, yet it is something that is dreaded by all. There are some who commit suicide and we can say that their mental or physical state might be so difficult to live with, that they felt that death was a better choice.

However, even in the case of suicide, it is the torturous fear that leads one to choose death. Here we are considering the fear of a patient who is suffering from a terminal disease. A person is left at the mercy of the spread of the disease, and the way their body reacts to the treatment provided to them. There is a prognosis of the treatment, but there is that amount of unknown knowledge of how a certain human body might react to the medication.

It is this doubt that can play havoc with the mind of a patient. The belief of not being a part of this world after death brings in a melancholic feeling as well. The above reasons make death so anxiety-driven and lead us sometimes into panic situations.

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### **The Troubled Question of Those in Pain**

The only answers that a dying patient is looking for is how long do they have to live? Will they hurt too much? Will they die alone with none of their loved ones with them? One of the questions that a patient remarked a few days before his death, he feared that will he even be aware of his last days or hours of his life? Will Durant (1885-1981) was an American writer, historian and philosopher rightly claims that “death plays with us as a cat plays with a helpless mouse.” (Durant, 2006). So, the troubling pain and angst with death are very natural. The word death has the power to enslave oneself to become melancholic. But another writer Daniel Callahan claims, “even more powerful sometimes is the fear of not dying, and being forced to endure destructive pain or to live out a life of unrelieved pointless suffering.” (Callahan, 1994).

Paul Kalanithi<sup>1</sup> wrote in his book, *When Breath Becomes Air*, “If the weight of mortality does not grow lighter, does it at least get more familiar?” (Kalanithi, 2016), Kalanithi further wrote, “I had to face my mortality and try to understand what made my life worth living”. For some the desire to live can be so intense when a person learns that they have a disease, that it gives them time to understand their existential purpose. Every person might behave differently when they come to know that they are suffering from an illness that will lead them to die sooner than they thought. An oncologist remarked there are three kinds of patients that he has encountered:

*The first type of patients are those who live in denial that they cannot have a life-threatening disease. The truth takes a while to acknowledge, due to which they don't start with the treatment as soon as they know of their disease; they opt for second and third medical opinions.*

*The second type of patients are those who look for other means of treatments besides allopathy like Ayurveda, homoeopathy and other different kinds, these are treatments that can be complementary. An article in the Cancer Research UK, states “You could harm your health if you stop your cancer treatment for an unproven treatment. Some websites might promote Ayurvedic medicine as a cure for cancer. But no reputable scientific cancer organisation supports any of these claims.” (Ayurveda Medicine, 2018).*

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<sup>1</sup> Paul Sudhir Arul Kalanithi (April 1, 1977 – March 9, 2015) was an Indian American neurosurgeon and writer. He was diagnosed with stage IV lung cancer. Kalanithi was a doctor treating patients and the next moment he was a patient that was fighting and struggling to live. Kalanithi died while writing this book, but the way he has penned the words with such intensity and care it makes the reader feel they are there with him in his sickness.



*The third type of patient* is those that face their disease right from the moment they have been informed about their diagnosis and are ready, to begin with, their treatment. A patient of the third category may even ask the physician, “*doctor, how long do I have more to live?*” A doctor hurts the most with such patients, as it shows them their zest for life. In the case of such patients, the burden on the physician increases as they themselves become frustrated if they are not able to cure the disease.

### **Advance healthcare directive**

Some countries have legalised and some are on the verge of legalising euthanasia, physician assisted suicide, withholding and withdrawal of treatment and making advance directives legal. Their major concern will be in keeping highly vigilant tabs on every end of life action taken. Every country that has legalised euthanasia and physician assisted suicide are also aware of the hostile position that they might be putting their sick and vulnerable population into.

*Living Will* – The Indian Supreme court issued a landmark ruling that ‘allows passive euthanasia’ on March 9, 2018, Article 21 of the IPC mentions the final word to determine the law on the subject, of right to life and liberty is given to legislature (Bachal, 1964). The Judicial Bench that gave out the historical ruling comprising of the five judges were, Chief Justice of India - Dipak Misra, Justice A.K. Sikri, Justice A.M. Khanwilkar, Justice D.Y. Chandrachud and Justice Ashok Bhushan. Justice Bhushan said during the ruling, “Every life is a gift of God and sacred...the right to self-determination and bodily integrity has been recognized by this Court. The right to execute an advance medical directive is nothing but a step towards protection of that right by an individual.”

With this ruling being passed there is some relief for those that are on life support system. Medical treatment can be withdrawn or withheld, by refusing life-saving or life-preserving aid by others. Bringing on death earlier than what would have been, had the patient been kept on a ventilator or on life support system knowing that the procedure will be futile.

Perhaps a lot of times the angst of how one’s life will end, makes a living-will all the more important to some of us (Nagraj, 1996). A living will, is also known as an advance directive it is a legal document that specifies the type of medical treatment that an individual will or may not want in the event they are unable to communicate their desire. It helps the family to decide on the treatments that the patient would have wanted if they are not able to give their consent if they go into a state of coma or if they are in a persistent vegetative state. (Dr Fred Plum an American neurologist, developed the term persistent vegetative state). Making life and death decisions in advance are to an extent knowing the way you wanted to be treated in case one becomes incapacitated. On speaking to a 92-year-old cancer patient, few days before

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his death on the 4<sup>th</sup> of January 2020 in the U.S. he said, “I have made my family feel guilt-free for writing out the do not resuscitate in my living will” I tried to understand what he meant by that and thus asked him, he answered, “it is less for my family and more for me as I don’t want them to make an attempt to revive me.” He did not want to take the chance of revival. Can we call that some form of euthanasia? An intentional decision to make no attempt for him to live, the fear of enduring any or some of the pain was enough for him to leave any or no chance for life again.

Also, in some cases, patients would not want to continue treatment once they are aware that life-sustaining treatment is perhaps more painful and futile. They would rather forego any kind of therapy (Brock, 2009). For some the thought of not being in control of life, the fact that if a person becomes incompetent makes them so terrified, that they might just want to end their life on their own terms and time, rather than have someone decide for them how and when their life should end (Humphrey, 1998).

Does it make one feel more secured to have the power of the deciding factor in advance? Yes, to some people this control over future acts of medical assistance/treatment, makes them feel protected towards their body. In the situation of a patient being brain-dead (Pallis, 2020), they wouldn’t have any control over their body’s functioning (Shroff & Navin, 2018). In such a case if there were no advance directives made by the patient, it becomes the responsibility of the family or immediate caretaker to decide for the patient as in some patients of brain death; brain death initiated as an ad hoc, this was so, as it was a way of solving the organ transplantation to procure usable organs for a patient (Henderson, 2011).

Organ transfer is rather a medical procedure that is surrounded by ethical questions. No doubt surgeons have worked with great intensity and admirable effort to make it possible to replace a dysfunctional organ with a good one. The ethical question that might arise, has the person who has been declared brain dead lost the concept of personhood? The donor becomes a means to an end here, for the donor; the end will be considered as the cessation of suffering from a certain disease or unaware of oneself. Before the idea of brain death transplants emerged, patients would remain inactive and life would be prolonged and the process of dying took longer (Tierney, et.al. 1994) Evidence of modern medicine with ethical dilemmas is more at a crossroad than ever before. The rational focus of medicine pays a higher privilege to those that can be saved in comparison to those that will be dead in sometime in the near future. Modern times are seeing a sea-change in the decisions made by patients, families and doctors. Every aspect of this discussion falls under the study of bioethics.

### **Patients’ Desires**





Let us discuss a case that have critically ill patients needing urgent treatment. The decisions taken involves keeping in mind the medical facts and diagnosis of the patient. The medical interventions carried out ought to be appropriate. This will determine the goals and therapeutic means of carrying out further medical assistance.

Let us consider there is a patient 'X' and he is incompetent.

There is the person X, that wrote out a living will wherein the request for treatment and life support to be continued in case of an emergency. So, the family try to keep up with the 'living will' or a prior discussion that the family might have had with this X. The family wants the treatment to continue, however, after thorough analysis of the tests done the doctors have a discussion with the family and let them know that they can continue with the treatment but the treatment is futile and there will be extraordinary means of medical assistance required for the patient to continue to breathe. Here, the X's family will be quite distressed as the living will of the patient gives directives to continue treatment, but in this situation the treatment will be ineffective.

This situation puts them into a bind, where the patient would want treatment to be continued and on the other hand, the treatment will not be worthwhile. How does the family deal with this situation? The treatment can only be given so long as the ability to bear the medical expenses can be borne by the family. A question that will surround this whole situation will be, if there is a living will, how long ought one to respect and continue as per the advance directives? The medical procedure may cause more pain than cure!

In such a case the termination of medical treatment may not be counted as unethical because under the circumstances of medical assistance not working in favour of the patient or may cause more harm, the treatment is then terminated. The desire to continue the treatment by the family is shown, however after the benefits and repercussion briefed by the doctors the family takes the tragic call of discontinuing treatment (McCarthy, et. al. 1989). This decision here surely puts the family into a moral dilemma; the only aspect here that can be considered is about the benefit and doing no harm to the patient, though the patient's consent was to continue treatment (Jonsen, et.al. 2010). It is indeed challenging for everyone involved in this situation.

### **Overcoming the angst of dying by providing care and comfort**

The thought of dying is one of the most tormented feelings that human beings have been trying to deal with. The fact that, who we are or what we do, nothing comes close to the "cruel mathematics that controls our conditions", writes Alfred Camus (1930-1960), (Desbruslais, 2000). The only means to combat the angst of existential apathy is by providing

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care and comfort, including a humane touch as an extension of treatment is urgently required in the field of medicine, this is provided by palliative care. Palliative care defined by WHO is “the prevention and relief of suffering of adult and paediatric patients and their families facing the problems associated with a life-threatening illness. These problems include physical, psychological, social and spiritual suffering of patients and psychological, social and spiritual suffering of family members.” (World Health Organisation). Palliative care can be given from the time of a sickness being diagnosed and along with the treatment provided to the patient and till death as well.

People fear when their physical health deteriorates, they feel a sense of being isolated and not being able to participate in worldly activities anymore (Cree, et. al. 2016). In one’s opinion when a patient requests for to end their life it is not a failure of medical treatment for that particular disease but the failure of the patient’s knowledge of their importance and intrinsic value of life.

The reason for providing care and showing compassion needs to be discussed as this may be the means for many patients to overcome their desire for wanting to deliberately end their life.

## **CONCLUSION**

The ethics of treating terminally ill patients is a science by itself, this ethics is called care. Palliative care as a discipline is about affirming the importance of the life of a person. Palliative care pays much of its attention to the wellbeing towards the spiritual, mental and emotional terms of a patient. Whether science, medicine or religion, all aim at the highest good of humanity. In recent times, we have witnessed that even religion and science have come to accept each other’s existence as a necessity for human existence. Palliative care becomes essential as it is based on the theory of mental, emotional and physical comfort. This discipline does not negate the dying process or the disease neither does it provide false hopes to a patient but assists the patients to embrace and face death. Thus, we learn that providing care compassionately to a dying patient gives them an easier journey on the dying process and allows them to overcome their fear of death if not for all patient’s but for most.

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