

PALLIATIVE CARE: THE PRACTICE OF END OF LIFE CARE

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Abstract

Providing care to the sick is not an obligation but a duty that is bound with human connectedness to each other. Palliative care picks up the strings along with curative treatment to try and provide a comfortable death. Palliative care is provided after a complete assessment is done on the symptoms and the stage of the disease and the condition of the patient. This discipline works not in isolation but with the patient's family or care giver. The family becomes a part of providing treatment to the patient and they are also given emotional and mental support.

Keywords: *treatment, pain management, process, death, comfort care*



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Introduction

The dying process was considered a phenomenon that was a part of life, however modern times explicates death as a sin. Sometimes making the dying process torturous by caring out procedures that may be futile. Death and dying is considered a failure of medicine, a failure of one's ability to maintain a healthy life or an accident that could have been avoided. Due to all these and many more reasons terminally ill patients are considered as lesser human beings. Palliative care strives to negate that sense of hopelessness and instil the intrinsic value of a patient till the very end of life.

Cicely Saunders was instrumental for the modern movement of hospice care in St Christopher's Hospice in London in 1967 (Rajagopal, et. al. 2017). Cicely Saunders in her own words, at a time when modern medicine and technology was not as common as today they had to struggle

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with whatever bare minimal medical aids like instruments and medicine to treat patients (Cicely Saunders, 1966).

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.” (WHO, 2018).

Palliative care is not about providing false hope to a patient that they will live forever or that they will be cured. Palliative care is about being honest with a patient and their family and providing hope that end of life comfort care will be provided till the patient lives. The art of palliative care is to provide dignity and respect to even the most anguished patient. Going back to human’s innate quality of being humane is the only answer to this demanding request to be allowed to die.

Palliative care becomes a part of treating a patient when, it participates in the active total care of patients with life-limiting disease and their families by a multi professional team, when the disease is no longer responsive to curative or life prolonging treatments (Twycross, 2003).

Palliative care works as a team with highly skilled professionals from other fields, such as doctors, nurses, psychologists, physiotherapists, social workers, dieticians. Caregivers and volunteers need not be highly skilled but they need to have compassion and willingness to work alongside a palliative team for the comfort of the patient. When curative treatment becomes unsuitable and futile palliative care is considered in the hope of bridging a balance between quantity and quality towards the end of life.

1. Palliative care offers

1.1 Managing pain is main aim of palliative care

Managing pain symptoms: Margo McCaffrey’s definition of pain has been identified universally as, “whatever the experiencing person says it is, existing whenever the experiencing person says it does” (Bernhofer, 2011). Pain is one of the most dreadful symptoms that a patient can feel during an illness. Pain that is felt for short intervals are acute pain and pain that is felt for longer periods are known as clinical pain that lasts for more than six months. All the adequate inventions in scientific treatment, the one goal that medicine began with was to treat the pain of an ailing patient, sadly that is not being taken care of completely.

The Single Convention on Narcotic Drugs, 1961, recognised that “the medical use of narcotic drugs continues to be indispensable for the relief of pain and suffering and that adequate provision must be made to ensure the availability of narcotic drugs for such purposes”.

Communication for assessing pain becomes very important for the palliative team so that they can provide effective pain relief to the patient. Once a patient is referred for palliation, the team assesses the current clinical and emotional status of the patient by discussing with the patient what they are feeling and what are they looking for. Based on these symptoms medication is administered to relieve the pain. The most daunting part of treating cancer is the process of diagnosing the pain felt by the patient. According to a report by WHO in 2011, cancer causes more deaths than all coronary heart diseases or strokes (Ferley, et. al., 2015). With more than 14 million cases of cancer diagnosed worldwide in 2012, and by 2025 the number is expected to reach more than 20 million, where India has new cases registered at 11,57,294¹ in the year 2018 (Chwistek, 2017), due to which we will witness an escalating requirement for managing pain. Drugs are administered for pain control, however there is a lot of fear that surrounds the usage of drugs as many feel that patients might become addicted to the drug. The assessment of pain in treating patients needs to be carried out carefully as the dosage of drugs is dependent on the amount of pain a patient has and treating it correctly is vital. According to Cicely Saunders, “tolerance and drug dependence is too often due to faulty management (Saunders, 1967).

Physicians should give their patients the pain killers before they demand for it, rather than wait for the patient to complain and then request for it. The National Institute for Health and Clinical Excellence (Rodgers, 2002), recommends strong opioids for pain control for the care of people with advanced and progressive disease. Patients that suffer from pain are not only cancer patients but also patients that have heart failures and neurological diseases as well (Bennett, et. al., 2012).

Providing drugs for pain relief is a major concern for patients suffering from severe pain as -

- a. Speaking to some doctors, they discussed that they don't prescribe narcotic drugs to relieve the pain as they might lose their license due to the complicated rules and regulations. There is an amendment in the of the 2014 Narcotic Drugs and Psychotropic Substances Amendment Bill, that allows the medical

¹ “International Agency for Research” on “Cancer is a Global Initiative of Cancer Registry Development.” By WHO.

profession to access essential drugs for their patients that were very stringent in the 1985 bill (Bajwa, 2015).

- b. There are difficulties in getting access to the drug as there is a lack of knowledge and attitude among professionals and also the public in general.
- c. Medical facilities have to go through mandatory and rigorous steps in maintaining accurate documentation of stored drugs and its usage for patients.

The one sentence that is heard by many who have family members being treated for a terminal disease is, “there is nothing more we can do, please take your patient home”

When patients choose palliative or hospice care the one aspect that they look forward is, for pain relief. Here, both places work towards reducing pain and giving comfort. Drugs administered here can range from opioids to non-opioids.

Nonopioid analgesics - non-opioids- (Berry, et.al., 2001)- These drugs relieve a variety of pain that can be from acute pain to chronic pain. They are used for trauma, postoperative, cancer, arthritis pain. Somatic pain is used to distinguish pain that does not arise from the viscera, i.e. internal organs, of the body (Murphy, 2007). Often this is used in somatic pain as well for joint pain or bone pain as well.

Opioid analgesics (opioids)– Opioids are administered on patients when they do not get relief from nonopioids. They are used as a combination of nonopioids so that the dosage of opioid used is not too high. Morphine is the most frequently used drug for pain management for those patients suffering from cancer (Bharti, 2009).

As watching a cancer patient being treated very closely, the aim of the palliation doctor was to administer the pain-relieving drug before the patient started feeling the pain; this was usually in about 5 hours of clock time. After an interview with the patient’s haematologist-oncologist in a palliative setting, he said, “that as physicians that treat cancer patients, usually we don’t wait for the pain to start or increase” they have an approximation of what time they need to administer the next pain-relieving drug. Statistics in 2018 in India: Show an estimated number of people living with the disease: around 2.25 million. Total: 7,84,821, Men: 4,13,519, Women: 3,71,302.

Recent legislative changes have made it easier for doctors to prescribe morphine in India under strict guidelines (Sengupta & Chaterjee, 2013).

1.2 Psycho-Social assistance

Patients that suffer from a terminal disease are confronted with psychosocial² problems as well. The main reason for this feeling is that they are left out of social activities by family members and society, leaving them in an isolated space not only physically but mentally as well. Sometimes patients are kept away from family as they might be suffering with a contagious disease. This feeling of being kept aloof from mundane activities and others can be very distressing and emotional. Palliative care workers spend time with the patients allow them to speak their mind out without being judgemental and listen to what they have to share. Social and psychological specialists try to analyse where the problem lies. Listening is the key element when treating a patient that has psychosocial problem.

There may be a financial problem that the patient is worried about. The cost of treating a terminal disease is very high in such a case if the patient comes from a lower or middle segment of society their worry is that they might be eating into the family income. This situation might finally lead them to run out funds for basic requirements such as food, shelter and education. Another problem that does not remain far behind is that family members might have to change their daily routine and might have to become care takers of a family member. Caretakers might have to give up socialising, go out on holidays and other social gatherings. This might lead to mental exhaustion. Caretakers that are emotionally involved with a terminally patient might get emotionally burnt out too. One may not verbally tell the patient that they are becoming an encumbrance but their actions can be louder than their words. These can be some of the reasons that a terminally ill patient might suffer from psychosocial problems.

Some palliative care centres like Pallium India in Kerala have a day out for their patients, “On January 15, about 60 patients, who are ordinarily bed-bound or wheelchair-bound, and their families got together at Shankhumugham beach to celebrate the State Palliative Care Day.” (Pallium India, 2015). Thus, we find that involving patients even in their final months or days of life can be very uplifting for them and can change their entire emotional and mental state towards their end of life care. “Depression and anxiety are the most common psychiatric comorbidities in palliative care” (Wilson, et. al. 2007).

² “Psychosocial” means “pertaining to the influence of social factors on an individual’s mind or behaviour, and to the interrelation of behavioural and social factors” (Oxford English Dictionary, 2012). OED Online. (2012). Oxford University Press. Dictionary on line <http://www.oed.com/>.

While applying scientific methodology for the care of a patient many of them may feel very anxious and upsetting about the impending fear of death. There is also a spiritual upliftment therapy for both, the patient and the family. Patients might want to do something or say something to their loved ones, doing this might bring them considerable peace. Patients may feel they need to perform some religious activities before or after their death, assuring them that they will be done will put a patient into a calmer space. Integrating the spiritual care by psychosocial workers uplifts the patient's melancholic feeling that surrounds the death and dying process.

1.3. The truth in palliative care is dealt with care and compassion

Many patients die or suffer due to uncontrolled symptoms or futile interventional procedures, doctors are taught only to cure and if a patient is not cured it is a failure on the part of medicine and the treating doctor. The ability of a doctor to effectively communicate with a patient is the core part of the treating process, "the way we saw it, and the way our professors saw it, the purpose of medical schooling was to teach how to save lives, not how to tend to their demise" (Gawande, 2014). Palliative care does not give false hope to a terminally ill patient that they will be cured. Patients are in very subtle manner provided with information that their final journey will be made as comfortable as possible. The disease is neither prolonged nor hastened. However, in some countries like France, Palliative sedation is legal, it is the intentional lowering of awareness towards, and including, unconsciousness for patients with severe and refractory symptoms (Twycross, 2019). When a patient's pain is intolerable to the extent that even being aware of themselves causes immense pain and is beyond their control, in such cases palliative sedation is provided. It is the medication given to patients in their final days or hours towards death if needed.

Deep sedation takes a patient into a state of unawareness of the self, similar to that of going into a coma; however deep sedation is given only to control the pain. Providing deep sedation is not something that is discussed openly or put up on a chart as it is intentionally like, putting a patient into a state of a controlled and temporary coma.

1.4. Affirming the value of life even if it is, at it's end

Palliative care affirms life and its value by providing support to the patient till the end even when all meaning and hope is lost. Palliative care assists patients that are dejected, work to reclaim their autonomy by involving patients in their treatment, talking to them, assisting them with honest opinions in a mindful manner when choices are to be made. There was a historical

landmark ruling that was issued on March 9, 2018, the Indian Supreme court gave out a ruling that ‘allows passive euthanasia’, this made the decisions of withdrawing and withholding of treatment an option for patients that were kept on life support that may be futile.

If a patient seeks to discontinue treatment or does not want to undergo a procedure after being given the prognosis of the treatment, their choices are respected.

Palliative care makes a patient know their intrinsic value by caring for them with compassion and allowing them to be as human as possible. Even if patient’s breakdown or weep, and are anxious and depressed they are still treated as persons not as a bag of diseases or an ailing and dying body.

Palliative care has an agreement, that withstanding intolerable pain is a heroic challenge by itself but it is not necessary for the sufferer to be the hero every time. However, fighting this intractable suffering for some will be a form of spirituality to not undermine the power of human strength. People find their worth in life by searching for its meaning as Viktor Frankl’s book “Mans Search for Meaning”, (Frankl, 2008) it is precisely what human worth is based on if they find their meaning in the desire to continue to fight their disease or accept their terminal disease life becomes worthy.

2. Challenges of Palliative care

While palliative care is still struggling to be known and recognised as a service that strives for a patient as a whole. The healthcare industry is booming. Before we proceed to understand the challenges faced by the Palliative care fraternity there is one aspect that we may observe about hospitals, they were previously called the “healthcare service sector” today it is known as “healthcare industry” It is so because this sector will cater to a \$250 billion industry by 2020. (Netherlands Enterprise Agency, 2020)

1. Government assistance is necessary for Palliative care growth

The Indian Ministry of Health & Family Welfare does not allocate separate funding for palliative care, which is a grave concern for organisations that provide palliative care. Palliative care comes under the ‘Mission Flexipool’ under National Health Mission (Bhatt & Sandhu, 2016). In 2018-19, the government spending on healthcare in India was only slightly greater than 1% of the GDP. There is a need for palliative care for over six million people each year in India, but only two per cent of them have access to palliative care.

2. The communication gap barrier

Disclosing their sickness to a patient is the first important step to treating the disease. Doctors try to be as casual as possible when letting a patient know of a terminal disease. However, the patient is met with an indifferent attitude. The doctor might be as depressed as the patient but sadly physicians are not taught how to deliver bad news.

An area that is concerning and that needed to be addressed was the doctor-patient communication. For students in India that are pursuing a degree in medicine, there is a communication course as a workshop added to the syllabus (Choudhary & Gupta, 2015). “The patient will never care how much you know until they know how much you care,” said Terry Canale.³ Communication is the underlying cornerstone of medical treatment provided by the health industry today. The reason it is more difficult for a physician to communicate is due to the humongous amount of information that is available through media.

3. Right to Palliation treatment

Every patient has the right to receive palliative treatment. Since many physicians are not knowledgeable about pain relief medication or analgesics they don't provide it to the patient. There is a certain fear of the double effect, as many would also consider it as bringing death nearer or it can be considered as physician-assisted suicide (Mudigonda & Mudigonda, 2010). Providing drugs is a concern due to its difficulty in accessing it. The one important aspect in a country that is developing is the taboo that surrounds the usage of any kind of drug.

4. Treating doctors rarely send patients to palliative care

There are a marginal number of patients that actually receive palliative care, in fact, most of the patients are not provided with the option of care. One of the major concerns is that it might undermine the credibility of the treating physician. The hospital industry is not very welcoming in sending patients across for palliative care as it undermines the capabilities of surgeons and specialists. Physicians feel that by telling patients to get palliative assistance it is a way of letting the patients know that they have not been able to cure their disease. The fear of losing trust in the patient becomes the main hinderance of bridging patients across to palliative care. However, we are now witnessing a gradual feeling of co-existence of each other. This can be pragmatically witnessed, if one is to visit hospitals in the city, there are a few of them that

³ Dr Canale is an orthopaedic and he was talking at 2000 American Academy of Orthopaedic Surgeons Vice Presidential Lecture in 2000.

accommodates a palliative department. These are small beginnings but very welcoming to patients that face death and are in the dying process.

Conclusion

This study shows us that palliative care is pragmatic in nature and care provided to patients in a holistic manner. Palliative care is the inclusion of many fields to form one comprehensive discipline to make the last journey as comfortable as possible. We can use the instrumental value of palliative care to attain the means of preserving life. Exemplifying palliative care as the instrumental worth to sustain life is worthy.

As Dame Cicely Saunders once said,

“You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully but also to live until you die.”

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