

Palliative Care and Universal Health Coverage: Don't Leave those Suffering Behind

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Editorial

Palliation is a term that has emerged in modern medicine over the last century. Derived from the Latin word "palliat", palliation notably masks a person's pain. The standard definition of palliative care given by WHO (World Health Organization) is "Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening diseases, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" [1].

Palliative care acts by giving comfort, providing pain relief, symptomatic treatment, and getting rid of stress for the patient and family, and it shouldn't be postponed or its importance shouldn't be overlooked when it is indicated. Evidence from various studies shows that such interventions and communications during end-of-life time decreases length of hospital stay, particularly in the intensive care unit setup and that use of counseling regarding palliative care (especially in the outpatient setting) is effective for improving the outlook and perception of patients and care providers. The use of palliative approach along with disease treatment can help improve the patient compliance and his/her longevity.

Other examples where medicines are given merely to treat symptoms without aiming to cure underlying disease or cause, such as treating nausea related to chemotherapy or giving analgesics like morphine or ibuprofen to relieve the pain of broken leg, etc. can be considered as palliative. In spite of being present since a long time, this concept of palliative care hasn't been used by doctors till recent times, as till now, the focus was mainly on "curing the disease"

With the changing times in the medical field, the field of palliative care, too is expanding and includes not just incurable malignant disease and HIV/AIDS but also many others such as end-stage organ failure (heart failure, kidney failure, respiratory failure and hepatic failure) and degenerative neuromuscular diseases [2].

In majority of the cases, they have questions like "what's wrong?" "Will I suffer? If yes, then, will it be unbearable?" "How much time do I have" "Can I be looked after at home?" these questions should be answered honestly by the doctor in the best way possible, using comforting words, empathizing with them. Some common symptoms faced by the patients during their fatal illness include boredom (commonest symptom), loneliness/isolation, fear/anxiety, pain-physical, emotional, spiritual and social-anorexia, nausea and vomiting, constipation, etc.

Moreover, it is extremely important to try to understand what the patients and the families are going through emotionally and mentally. "The Grief Reaction" model described by Kubler-Ross, provides a useful guideline in understanding the stages the patient and his/her family are experiencing. These five stages are denial and isolation, anger, bargain, depression and lastly, acceptance [3]. A recently evolved specialty is "Hospice care". Hospice care is a part of palliative care, and has been taken from the Latin word "hospes".

Hospice aims to provide "care" and does not focus on "curing" the patient and this can be done even at home, besides is specific hospice centers, hospitals, nursing homes and other long-term care facilities. Such services can be given to anyone without any religion bias. The members of the hospice staff make regular visits to check on the health and progress of the patient and if need be, give the required treatment or services. Hospice staff is on-call 24 hours a day, seven days a week. The hospice team develops a plan for each patient's individual needs for pain management and symptom control. The hospice team usually consists of the care providers which include the family and the hospice nurse, the physician, specialists if needed, speech therapists and so on, if needed.

As we all know, India ranks second in the world in terms of population after China, and today, large number of our population comprises of the geriatric age group, which is in maximum need of hospice and palliative care. In 1986, the first hospice in the city of Mumbai, Maharashtra was started by Professor D'Souza [4-5]. Then it was established in Kerala and Karnataka. Today along with all these pioneer institutions, Pallium India, established in 2003, and many other organizations are working in different parts of the country to serve the community.

Nowadays, home-based palliative care services are becoming more and more common and acceptable. This is because, it is at home that the patient is most secure and comfortable during his/her last days, surrounded and cared by loved ones. Moreover, the approach is better suited to the Indian culture of close knit and joint families, where a family member is present throughout the day to care for the patient at home.

Over the years, there have been thousands of people who have benefited from palliative therapy and have reported satisfaction in getting cared for at home, amongst their loved ones, with one of the greatest examples being the survival story of the humour columnist Art Buchwald, who, following failure of both of his kidneys following loss of half of a leg, decided to go to a hospice care in Washington DC, and there, instead of dying within a few weeks by renal failure, he managed to survive for 5 months, which he believed was due to improvement in his kidney functions by the excellent palliative care at

the hospice, as well as the comfort and solace of his loved ones around him [6].

Hospice care does not aim to either postpone or hasten death. It merely helps the patient to live care free in a secure environment, giving optimum care and letting nature have its way. To commemorate the importance of the field of palliative care, every year, 14th October is celebrated as the world palliative care. Despite being acknowledged all over the world, palliative care is a field that still needs lots of support-financial as well as social-and acceptance by the population particularly in India.

One of the major drawbacks for palliative and hospice care is many insurance policies do not cover the expenses of the hospices/palliative care providers. This is still on a developing basis in countries like India, which would make this more patient friendly once proper measures are to reduce the financial burden on the patients and their families. Moreover doctors hesitate to refer patients to hospices even if they need them, for the very reason that patients might sue them if they manage to survive for more than 6 months under the hospice care, even if the patient and their relatives are ready to discontinue treatments in case offend stage terminal diseases. Besides this, lack of appropriate and timely availability of analgesics (mainly opioid analgesics) for pain relief in terminally ill patients, lack of proper trained and educated personnel (doctors, nurses and volunteers), lack of formulation of proper policies by the government in this field, lack of patient goals and knowledge in patients as to what care they want, tend to cause hurdles in treatment of patients.

Despite these drawbacks, palliative medicine is slowly emerging as one of the greatest pillars of modern medicine. The numerous NGOs

described above, are tirelessly working day and night to bring forth a change in the setup of our country, a change which has influenced thousands of lives already, and is still reaching out to millions. Various training programmes are also guiding more and more youths from the fields of social work as well as medical and para medical staff to indulge in providing hospice care. And, as Ann Richards correctly says, "We cannot change the outcome, but we can affect the journey".

Let us all strive to make a difference, and for those associated in field of health care, let us ensure to make a better world for our patients, keeping in mind the saying "Cure sometimes, relieve often, comfort always". Palliative care is a field that requires passion and commitment. So together, this can be achieved by persistent efforts of one and all.

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