

Hospice care in India: A review

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ABSTRACT

Palliative care is the need of the hour, especially in a country like India where the number of terminally ill patients has always been a concern, and with projections showing this number to only go up and increase exponentially, it is much more important that we now shift our focus to providing quality hospice care to the ones that are in need of it. In this article, the authors start out by defining Palliative care and hospice care, all the while maintaining the distinct features of them both. Once the foundation is set for the same, we dive into the history of palliative care in this country and how it has evolved over the years. We then move on to the present scenario of hospice care in India and try to look at it through a more contemporary lens. Further, we discuss the impact of some diseases that most adversely affect individuals and require end-of-life care in its more advanced stages. These include, but are not limited to, end-stage cancer, multidrug resistant (MDR)-tuberculosis and Human immunodeficiency virus-associated acquired immune deficiency syndrome (HIV-AIDS). We then move on to discuss the importance of academic interventions to strengthen the role of hospice care in the India and how research and education can help improve the condition of end-of-life care in all domains. We finally talk about how we can move forward and what positive changes we can bring about in order to make inroads into better and more sustainable hospice care in the Indian context. We hope that our work will cause healthcare professionals, and other people alike to better understand the role of hospice care in their own lives and livelihoods.

Keywords: End-of-life, cancer, HIV-AIDS, hospice, palliative care, terminal, tuberculosis

Introduction

Palliative care is defined by the WHO as a method to raising the standard of living of patients who are experiencing difficulties related with terminal illnesses by preventing and alleviating suffering via timely detection, evaluation, and management of pain and other troubling psycho-social, and mental issues. In reality, whenever a patient receives a prognosis, they might require the most psychological care. It even goes further than the demise of an individual, which is referred to as Bereavement Care.

The basic goal of palliative care is to make the experience as pleasant as possible rather than to prolong it. As a result, the

objective is to enhance sufferers' and caregivers' standard of living by reacting to discomfort and many other uncomfortable manifestations, as well as providing excellent inpatient care and psychological and mental assistance.

Palliative care is a wellness program with or without a medicinal goal, while hospice care is a wellness program without standard therapy or the intention to cure. Physical pain and sign alleviation are the goals including hospice and palliative care, although the goals are often distinct. The purpose of hospice is to give well-being while avoiding invasive fruitless treatment.

Palliative care is a fairly novel idea in the Indian subcontinent, being established only in the last three decades. Ever since, dedicated stakeholders, including Indian healthcare workers and activists, have worked in conjunction with global organizations and like-minded individuals from other nations to create deathbed and palliative care blueprints.

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Discussion

History of hospice care in India

India – A country with an immensely dense population and an equal amount of people holding dreadful diseases like cancers. The whole idea of treating a patient and giving them a suitable care, post treatment takes a turn when it comes to this country. Providing hospice or end day care to such patients is hence a huge problem in the country mainly due to the population density it holds. This problem was keenly assessed by Dr. M.R. Rajagopal who is widely regarded as the country's "Father of Palliative care." With the relentless efforts from the government to make hospice care reach maximum people and so that maximum people utilize hospice care to the utmost, the country has shown great popularity over time.

The Shanti Avedna Sadan is India's first Hospice, a facility that cares for advanced cancer patients who are nearing the end of their lives. It is neither a hospital nor a house, but rather a combination of the two, providing the skilled care of a hospital with the warmth of a home.^[1] With innovations from such facilities across India we have seen a blooming rise in facilities and hospitals providing hospice care. At the same time, pain clinics were recognized with the assistance of a world health organization (WHO) subsidy at the Regional Cancer Centre in Trivandrum, Kerala, and at the Kidwai Memorial Institute of Oncology in Bangalore, Karnataka.^[2] Over the years Shanti Avedna Sadan has inspired many hospitals and also opened several of its branches in Delhi and Goa. Not just with facilities, the Central Government of India is also putting its maximum strength to make opioid available to maximum people without hampering its role to be used as just a medicine. The act was passed by the government in the late 90s that promised to increase opioid availability and also to reduce drug abuse liability.

Current status of palliative care in India

Currently, India is pacing toward betterment in the field of palliative care but it is nowhere close to even ranking under top 50 in the world. A lot of awareness and education needs to be done in the country which will require time. But as of now, in 2015, India was placed 67th out of 80 nations in the world in terms of access to end-of-life care.^[3]

And facing the harsh truth about the country, palliative care is available to less than 1% of India's 1.2 billion people. Since then we have also seen implementation of a national program for palliative care (Originally made in 2012).^[4] The situation in India is so rough that there are roughly 1000 palliative care units in India at the moment, with over 90% of them concentrated in Kerala.^[5]

The rising awareness in the south region of India is the cause that led to such impressive growth there. The non-government organizations provide funding as well. Its help from both the government and NGOs that has made hospice in Kerala and South India a success. Also, a higher literacy rate in South India as compared to the north favors the development of a more

profound healthcare system. When the problem is delivery of hospice care due to lack of space in the area, Kerala has shown to overcome this by delivering hospice at home. Development of a committee like Clinical Consultative Committee) having professionals in the field of hospice putting diligent efforts toward betterment for the diseased, has overcome several problems in a city like Mumbai.^[6] There are more than 150 centers dedicated to providing palliative care currently, and we still believe that this number lacks way behind the hope of people to receive quality palliative care. As revealed and assessed by a lot of organizations, not just the number of palliative care centers matter, but, the quality of care they deliver does too. Quality control and vigilance is hence a vibrant part of such organizations. Fighting an inevitable thing like death needs patience and quality assured drugs.

The bulk of lower classes depend on state institutions that are overburdened and serve as a last resort. It is understandable that they would focus their capacity on those that can be helped. The doctors and clinics tend to be small in remote regions. These individuals are unable to receive healthcare due to the far off location and insufficient transport infrastructure.

The main problem we must overcome to reach greener grass is acclimatization of the state government to whatever policy the central government commands aiming toward helping the condition of hospice.

Disease holding maximum palliative requirement in India

Holding maximum patients in India requiring palliative care, cancer tops the chart in requirement of opioid analgesics as well. The metastasis and the prognosis that cancer seeks is dreadful. Not only the disease in itself tops charts of severity but this disease has also shown to be densely present in India. Statistics from 2018 have proven that over 7,50,000 deaths are seen in patients suffering from cancer and that over a million new cases are diagnosed as well.^[7]

Cancer patients show agonizing pain as the illness progresses. Hence, the requirement of opioid analgesics is high in patients with this illness. Stage 3 and stage 4 cancer usually require hospice care and pain management. However this is not the only disease that requires maximum palliative care in India, MDR-TB (Multidrug resistant-Tuberculosis) is yet another disease that holds seats for the same. With dying hope and no drug that responds, the patient lives with immense pain. This is where the potential of hospice care comes into place. The patients with MDR-TB have a plethora of problems that make life really uneasy. As a result, palliative care is advocated as an essential component of the worldwide tuberculosis strategy. The country with the highest burden of tuberculosis-related illness is India. Nearly half (47%) of the 558,000 MDR-TB cases worldwide were found in India, China, and the Russian Federation. In light of this, the WHO has pushed for palliative care as part of the worldwide MDR-TB response.^[8]

The area revolving around hospice of MDR–TB is mainly focused in relieving symptoms and pain. When a drug fails, it all falls to hope, and that is what is implemented in hospice care. Talking about incurable diseases and not mentioning HIV/AIDS in India is next to impossible. AIDS has conquered nothing in the field of hospice in India. It has failed to gain popularity in the field of hospice. With a disease that progresses to literally breaking down the immunity of the person to dying of even a common cold, it requires utmost care in terms of mending patients hope and also providing them analgesics to control the searing pain. 80% of patients with AIDS or cancer have moderate to severe pain at the end of their life.^[9]

Other diseases that are common in India like Parkinsonism and multiple sclerosis do require palliative care in India. The level of pain experienced by MS patients as a result of their “load of symptoms” is equivalent to that experienced by cancer patients seeking palliative care.^[10]

Parkinsonism has the worst prognosis as well because it progresses to deteriorate and harms the quality of life of patients. With allied symptoms like trembling and slowing of movements, it burdens the patient and the family as well. The non-personal, community-based issue that is a burden for hospice care is overpopulation. Due to overpopulation, the infectious diseases spread and competition for hospice care also seems to rise due to this.

Education and academic scope of palliative care

It is known for any and all disciplines that education and training can lead to much better understanding and intensified research into the discipline. It is thus important for all individuals involved in the discipline to strive to make better inroads into the research and development side of things. This brings us to a very important crossroad.

Hospice research is critical to providing strong palliative care. Discovering and applying the most up-to-date data ought to be the motto of our everyday work. Hospice care that has scientific proof is urgently needed. In hospice care, we ought to conduct top-quality studies. Hospice research has led to several breakthroughs, including drugs for cancer cachexia, pain in metastatic tumors, and Opiates for the relief of dyspnea in fatal sickness. In the context of Indian hospice care, there is also a lot of room for building a scientific temper.^[2]

Several current medical developments make it more difficult for cancer patients to get hospice treatment. Problems transferring to a quasi-treatment phase, unwillingness to want the talk about mortality with the relatives and the affected, and unwillingness of the patients and caregivers to surrender trying to find a treatment are all reasons for the delayed shift to hospice care and bereavement. Shortly after the onset of treatment for cancer, a shift in medical services to include hospice care can begin to acquaint the relative with hospice care services, initiate

dialogue about mortality sooner in the path of anticancer therapy, and allow for a discourse of management objectives amongst everyone concerned.^[2]

The scarcity of data in this field adds to the difficulty of implementing hospice care. Evidence-based investigations are required to help people make informed choices about managing pain, diverse medical systems, therapeutic judgement techniques, dialogue on delicate themes like mortality, and assistance for family members. To establish analysis operations in pain management, India’s current ability, hospice institutions, specialists, and specialists in this sector must be combined.

Academic involvement, extensive studies, and education are all attempts to enhance the implementation of hospice care. Nurses, doctors, and other medical care professionals have been the focus of research initiatives in hospice and terminal illness care. Public policy, knowledge, and substance use are the three basic factors proposed by the WHO for establishing hospice care. They are crucial for developing a long-term hospice system and obtaining meaningful scale. Hospice care should be included in the UG program of all physicians and surgeons as a cost-effective method to widen the foundation of hospice provision at the country level.^[2]

The future of hospice in India

Hospice is about fighting death and pain. To overcome this fight there is a need to use hope as the weapon. Hence, a vital component of hospice care is to instill hope and help patients recover mentally from their end stage diseases. Mending their emotional stability and supporting their family members is also an integrated part of a good palliative care. A community-based palliative care strategy may assist to strengthen people’s support networks, reducing pain. Increasing funds for the government based hospitals and facilities have shown to be great for the patients. Rich countries fared best, with Australia and New Zealand coming in second and third, respectively. In addition, the United Kingdom is ranked first.^[11]

The funding needs to be more focused toward these facilities as seen in other countries. Adaptation and habituation of acts made by the government will also help. Introducing studies of hospice care in general science and also in studies for allied medical streams. Self-care strategies and practices among the participants in this study ranged from physical activity, exercises, dance, and daily walks to spending quality time with family and children, while some admitted to crying and withdrawing from work to deal with emotional distress because they could not cry in front of patients and others.^[12] Diagnosing cancers and HIV-like diseases at an early stage will also reduce the requirement of hospice in patients. Other coping mechanisms should be taught to patients suffering from such diseases. Spirituality has been recommended as being necessary for palliative care practitioners to understand various religious beliefs and practices in order to address the individual requirements of their patients and

families.^[12] Vigilance and quality control should be mandate in every government-based hospice care setting. Building hospices will not be a financial burden on the government because palliative care is not a high-cost specialty when compared to others.^[13]

Conclusion

Palliative care in India is a relatively novel establishment due to the fact that its only close to three decades old. However, it is a concept that needs rapid popularization and acceptance from the masses. In a country like India, which is home to some of the highest numbers of terminally ill cases throughout the world, the need for hospice care has been lost on the healthcare industry. The onus, therefore, falls on the healthcare workers and the general public, to make it a norm to provide adequate end-of-life care to the people and families who are in the need for the same.

The task ahead of us is to contact those suffering from long-term terminal illnesses who are poor and appear to lack finances. When they are diagnosed with a persistent fatal condition, it is a devastating strike. Palliative care may be successful in limited resource situations when the proportion of participants needing management is large but the amount of medical professionals capable of supplying their services is limited, by using local healers and activists overseen by professionals educated in hospice care. As a result, public or home-based hospice management is critical, with treatment delivered right to the affected person's home.

Via government regulations or policy decisions, we must ensure that patients and families that suffer from terminal diseases like end-stage cancer, chronic liver diseases and MDR tuberculosis find easy and accessible end-of-life care, that will somewhat ease the burden with which they have to pass their days, although numbered. This is not only desirable, but is also absolutely necessary, due to the simple fact that all humans are created in the image of the almighty and each one of them deserves the same level of care and compassion as all others.

With the advent of diseases like HIV, there has been a bit more stern focus toward patients that become terminally ill. However, this is solely from a healthcare perspective, and still needs attention from regulatory bodies such as the ministry of health and family welfare (MoHFW) and other central research bodies. The data on these matters is in. With a better focus on terminal illness, we can immensely improve the quality of life for both these patients and their families in our country.

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Conflicts of interest

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