

## Hospice and Palliative Care: A New Movement in India

Vikas Bhatia<sup>1\*</sup>, Swayam P Parida<sup>2</sup>

<sup>1\*</sup>Dean, Professor and Head, <sup>2</sup>Assistant professor, Department of Community Medicine and Family Medicine, All India Institute of Medical Sciences, Bhubaneswar, INDIA.

### Article History

Received: 27 Jan 2016

Revised: 30 Jan 2016

Accepted: 07 Feb 2016

### \*Correspondence to:

Dr. Vikas Bhatia  
Dean  
Professor and Head,  
Dept. of Community  
Medicine and Family  
Medicine  
All India Institute of  
Medical Sciences,  
Bhubaneswar  
bhatiaaaims@gmail.com

### ABSTRACT

“Palliative care” is the speciality which delivers care to persons with debilitating illnesses and it starts from diagnosis till death and continues further into bereavement care of family members. The objective of palliative care is to decrease pain and other distressing factors and not merely disease cure. The focus is also on providing psycho-social and spiritual support to the affected, thus making palliative care services inter disciplinary comprising of experts from different fields. The trend of ever increasing elderly population, rising NCDs and cancer burden in India makes it quite comparable to the trends seen in developed countries. The prevalence of cancer has increased in recent years. Nearly one million new cancer cases are diagnosed and more than 80% of cases present themselves in advanced stage. In India every hour around 60 persons die from cancer and pain. The figure might increase because of increased life span and more of chronic diseases. It is estimated that more than 60 % of people who die annually will suffer from advanced diseases. “Hidden lives, hidden patients” is the theme of World Hospice & Palliative care day being organized on 10<sup>th</sup> Oct, 2015, worldwide to bring forth the issues. World Hospice and Palliative Care Day takes place on the second Saturday of October every year and Voices for Hospices takes place on the same date every two years.

**KEYWORDS:** Hospice and Palliative Care.

### INTRODUCTION

The aim of Palliative care is to improve the quality of life of patients and family members of persons suffering from life threatening and terminal illnesses. The primary objective is to provide relief from pain and other associated problems e.g., physical and psychosocial, etc. World Health Organization (WHO) defines palliative care as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, 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”.<sup>1</sup>

Pain is the commonest symptom in persons suffering from cancer. It is associated with 50 to 90% of patients depending on stages of cancer. In India; more than 60 persons die every hour due to cancer and pain.<sup>2</sup>

### HISTORY OF PALLIATIVE CARE AND HOSPICE

Since time immemorial, care of persons with advanced disease, elderly, mentally retarded, children with

neurological diseases had been the responsibility of family members and community. Gradually special places were created e.g. sanatorium for treatment for persons with chronic diseases.

During the early part of 20<sup>th</sup> century, as cancer with its dreaded consequences was realized, the need for pain relief of the patients posed greatest challenge in front of the medical community. It was clear that the demand of patients was something beyond cure; it was more of attaining psychosocial and spiritual health. In 1960s the pioneering work by Cicely Saunders in UK drew attention of medical community towards palliative care and hospice services. By 21<sup>st</sup> century all of the countries and communities realized that palliative care is a necessity and afterwards the hospital & palliative care emerged as a distinct speciality.<sup>3</sup>

This branch focuses on continuum of care which is needed by the patients facing pain, distress & fear of impending death. Not only patient, the suffering and grief of family members become insurmountable with each passing day. The Palliative care specialty too extends the

care and support to the bereaved family members.<sup>3</sup> Initially the voluntary sector took up the challenge to establish Hospice & Palliative care clinics and Day care facilities in UK, Canada, USA and European countries. In 1990, WHO guidelines were released and it endorsed use of morphine for pain relief in cancer patients. Afterwards, many countries including India changed their policy and incorporated palliative care in the existing health system. In India the concept of palliative care evolved in 1980s and hospice centres were established in cities e.g., Ahmedabad, Bangalore, Madurai and Delhi.<sup>4,5</sup>

### **EXTENT OF THE PROBLEM**

In developing countries like India the burden of patients living with cancer, HIV/ AIDS are increasing. The prevalence of cancer has increased in recent years due to advancement in diagnostic services, changed lifestyle and increased life expectancy. It is estimated that about two third of cancer patients reside in developing countries of Africa & South Asia. In India nearly one million new cancer cases are diagnosed and more than 80% of cases present themselves in advanced stage. Approximately 60 persons die from cancer and pain every hour in India. It is estimated that more than 60 % of people who die annually will suffer from advanced diseases.<sup>4,5</sup>

Beyond cancer & pain relief, Palliative care is also applicable for the elderly, people living with HIV AIDS, psychiatric illnesses, disabilities, congenital diseases, rare diseases, dementia, people affected by war or natural calamities etc., who need continuous support both at physical and psychosocial level. The demand on provision of palliative care will continue to increase in future consequent to a growing proportion of people affected by the above mentioned physical and psychosomatic illnesses. Integrating palliative care in to Primary health care system seems to be the obvious solution towards this problem.<sup>6</sup>

### **PRESENT CHALLENGES**

Medical community, in spite of many advances, has realized that half of the cancer patients may not be cured of disease. However lives of cancer patients can be prolonged with availability of improved treatment facilities.

The foremost problem lies in accessibility of services as Palliative care services are mostly limited within tertiary level hospital or health care setting. Also these centres are concentrated in major cities making it difficult for patients and family members to avail services at the right time. Till date around 150 organisations spread over 16 States and UTs, are currently providing Hospice and Palliative care services throughout India. The accessibility of services too is an issue in rest of the world. WHO report, reveals only 66% of world's

population had no Palliative care services for patients with cancer & other life limiting diseases. Worldwide 42% countries had no palliative care services and in 32% countries, services are available to a small proportion of people. WHO reports worldwide 80% of people do not have adequate access to medications needed & only 8.5% countries have integrated palliative care in their health care system.<sup>6</sup>

This problem is further compounded by lack of adequate trained health professionals to provide services in Palliative care specialty. The current MBBS and Nursing syllabus lacks palliative care course. So the existing health care providers such as Physicians & Staff Nurses are not skilled to provide basic services in palliative care. The problems related to procurement and disbursement of morphine, a drug essential for Pain relief which is a fundamental right of persons with end stage disease, needs relook and modification of National policy.<sup>4</sup>

### **FUTURE OPPORTUNITIES**

A major proportion of patients with terminal illness are present in countries of Asia, Africa and South America, which are already facing burden of communicable & Non-Communicable diseases. The functioning of health system with limited resources; demography; culture & behavioural pattern of residents in respect to health & disease and societal structure & community support are different in comparison to developed nations. So more of research from developing world is required to create effective models of palliative care which will be feasible, adequate, acceptable and available to the population even at the primary health care level. The Calicut model has showed a path of "high quality, flexible, low cost hospice and palliative care delivery in resource poor settings". It also demonstrated effective public private partnership.

Recently the home-based palliative care services are becoming popular where care is provided at the doorstep of patients. This has an added benefit of giving holistic care to patients in a place where they are comfortable being surrounded by loved ones. The objective is to "promote, restore and maintain a person's maximum level of comfort, function and health including care towards a dignified death". The Chandigarh Palliative Care Service became a role model in India in establishing the continuum of care approach in cancer patients.

The services and research has to have an attitude of collaboration between palliative Radiotherapy, Chemotherapy, Physical rehabilitation etc.<sup>4,5,7</sup> In the lines of Constitution of India, which mandates health as a state affair, Govt. of Kerala has taken up certain essential steps such as easing narcotic licensing procedures, beginning of SOP for availability of morphine and passing of a palliative care policy. These

initiatives are indeed praiseworthy and should be followed by other States also.<sup>2</sup>

Nevertheless the palliative care is a specialty fondly referred as “low tech and high touch”, gets its strength from caring hands and a compassionate heart of healers. So training & education of human resources is the utmost urgency in India. Further creation of a community support by motivating and training of volunteers, ASHA, AWW, family and community members are required to enrich the lives of patients.

## CONCLUSION

The hospice & palliative care movement is itself an exemplary service where health services can go beyond the focused vision of care and cure, to provide a life to be lived with dignity even in face of lurking death.

Even after three decades of its inception, the accessibility of palliative care services is not optimum. Three measures are vital for sustainable development and improved coverage of palliative care services. They are proper governmental policy, Education and drug availability. We need to focus on these aspects as India is committed to provide “Health Care for All”. On the occasion of World Hospice Day celebration on the second Saturday of October every year, all of us should take pledge to recognize these hidden patients with hidden lives and help them in living a dignified life.

## REFERENCES

1. World Health Organization. Palliative care. Available from <http://www.who.int/cancer/palliative/definition/en/> [accessed on 02/11/15]
2. Koshy C. The palliative care movement in India: Another freedom struggle or a silent revolution? *Indian J Palliative Care*. 2009; 15(1):10-13. Available at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC288621> [accessed on 07/10/2015].
3. WHO fact sheet on palliative care. Available from <http://www.who.int/mediacentre/factsheets/fs402/en/> [accessed on 02/11/15 ]
4. Mohanty B. Research focus in palliative care. *Indian J of Palliative Care*.2011;17(Suppl):S8-S11. Available at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3140078> [accessed on 07/10/2015]
5. Khosla D.,Patel FD., Sharma S. Palliative care in India: Current progress and future needs. *Indian J Palliative Care*.2012 18(3):149-154. Available at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3573467> [accessed on 07/10/2015]
6. World Hospice & Palliative care report 2015. <http://www.thewhpc.org/images/resources/advocacy/WorldDayReportfinal.pdf> [accessed on 09/10/2015]
7. Singh T., Harding R. Palliative care in South Asia: a systematic review of the evidence of the evidence for care models, interventions and outcomes. *BMC Research Notes* 2015; 8:172. Available at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3573467> [accessed on 07/10/2015]

**Source of Support:** Nil.

**Conflict of Interest:** None Declared.

**Copyright:** © the author(s) and publisher. IJMRP is an official publication of Ibn Sina Academy of Medieval Medicine & Sciences, registered in 2001 under Indian Trusts Act, 1882.

This is an open access article distributed under the terms of the Creative Commons Attribution Non-commercial License, which permits unrestricted non-commercial use, distribution, and reproduction in any medium, provided the original work is properly cited.

**Cite this article as:** Vikas Bhatia, Swayam P Parida. Hospice and Palliative Care: A New Movement in India. *Int J Med Res Prof*. 2016, 2(2); 1-3.