

A Study to Assess the Barriers for Delivery of Palliative Care in India: Healthcare Providers Perspective

Kumar Vivek¹, Patel Neelesh², Nethi Kranthi K³

¹Junior Resident, Dept of Hospital Administration, Armed Forces Medical College, Pune, Maharashtra, India

²Senior Resident, Dept of Hospital Administration, Armed Forces Medical College, Pune, Maharashtra, India

³MD Hospital Administration

¹Corresponding Author Email: [vivs1311\[at\]gmail.com](mailto:vivs1311[at]gmail.com)

Abstract: India is faced with a twin burden of communicable as well as non-communicable diseases (NCDs). It is estimated that one million new cases of cancer occur each year in India, with over 80% presenting at stage III and IV require palliative care. There are places where excellent palliative care is offered to a lucky few, <2% of those needing palliative care in our country receive it. This study aims to bring about Healthcare providers perspective to assess the barriers in delivery of Palliative care in India.

Keywords: Palliative Care, Hospice, Pain management

1. Introduction

The World Health Organization (WHO) defines Palliative Care as “an approach that improves the quality of life of patients and their families facing 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”.

Palliative care involves a multidisciplinary team including the patient, family, Palliative Medicine and Primary Care physicians, nurses, social workers, pharmacists, clergy, counselors, speech, physical and occupational therapists, dietitians, and volunteers.

Palliative care in India is a comparatively newer concept, developed over the past 30 years, compared to 50 years in the developed nations (1). India is faced with a twin burden of communicable as well as non-communicable diseases (NCDs). With the ever-expanding horizon, NCDs are the leading cause of mortality in India. The modern medicine has turned previously fatal illness into chronic diseases and hence most people live for many years with the symptom burden of one or more serious illnesses, functional or cognitive impairment, and dependence on care from family or society (2).

India is a challenging country for those involved in developing palliative care. The population is estimated to be over 1.3 billion, which is approximately one-sixth of the world's population. India faces serious, enduring problems of widespread poverty and overpopulation. Vast numbers of people live in rural impoverishment, with poor access to transport and communications, and low indices of nutrition and health. It is difficult to assess the exact requirement for palliative care because of inadequate disease registration,

communication problems, and the cultural stigma attached to cancer and HIV/AIDS (3).

In a country as vast and diverse as India, it should not be surprising that one state can develop a World Health Organization (WHO) designated demonstration project on community-led palliative care services while simultaneously other states/union territories are without any palliative care facilities.

2. Aim

Palliative care provision in India has been developing, but progress has been slow and uneven. This study aimed to assess the Barriers for delivery of Palliative care in India from the Healthcare Providers perspective.

3. Methodology

A qualitative study was conducted through institution of 20-point structured validated questionnaire with Cronbach's alpha value of 0.882. The questionnaire was circulated to all the available 250 doctors of a tertiary care teaching hospital. Out of 250, only 209 responded with a response rate of 84%. The demographic profile of the doctors was based on age, gender, and job experience. Among the 209 doctors, 118 were less than 35 years of age, 74 were between 35-45 yrs of age and remaining 17 were more than 45 yrs (Figure-1). Out of the 209 respondents, 116 (55.50%) were male and 93 (45.50%) were female (Figure-2). About the job experience, 44 were less than 5 years of experience, 84 were in the range of 5-10 yrs experience, 38 had 10-15 yrs of experience and remaining 43 had more than 15 yrs of experience (Figure-3). Responses were analyzed using Descriptive statistics.

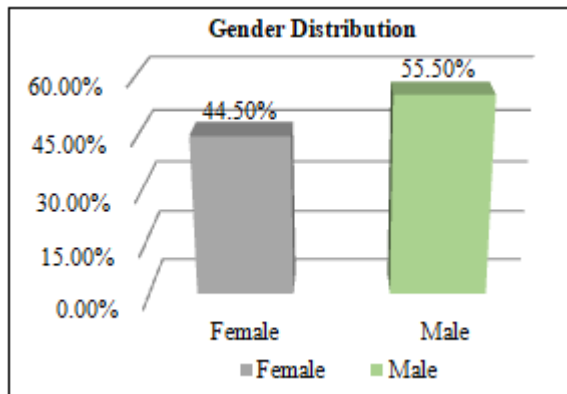


Figure 1

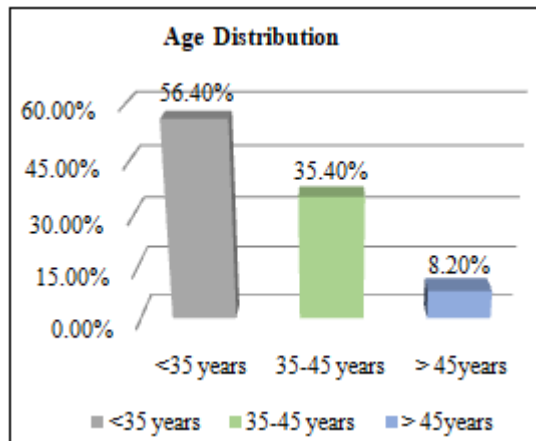


Figure 2

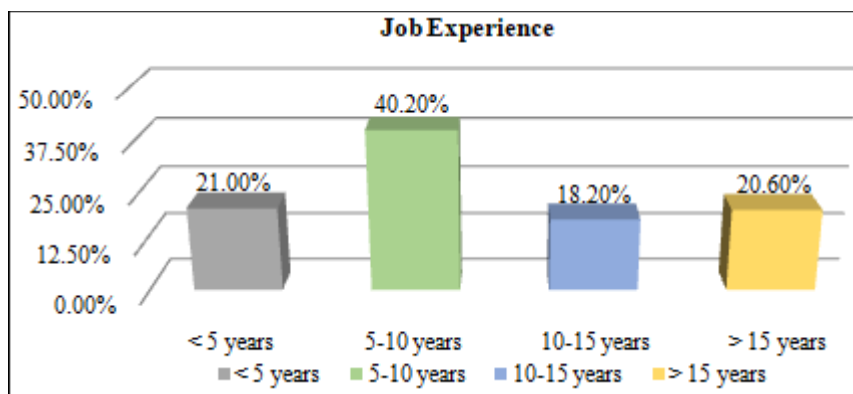


Figure 3

The questions were marked on a five-point Likert scale by all the 209 respondents. The results were grouped with reference to the demographic profile as discussed above. The final results were analyzed using Descriptive statistics,

using the Chi square test and the results with p-value less than 0.05 were taken as significant. The questionnaire used for the study is attached as an appendix to the paper.

Age	
Question	P-Value
Q4 (There is lack of Awareness among the Healthcare providers about Palliative care in India)	0.012
Q20 (A National Policy or legal mandate is essential to improve the delivery of Palliative care)	0.012
Gender	
Question	P-Value
Q8 (Non availability of Infrastructure to provide Palliative care is a serious problem)	0.013
Q10 (Poor availability of Opioids to deliver Palliative care is a problem in India)	0.012
Q14 (There is a lack of trained manpower to deliver Palliative care in Indian Healthcare system)	0.022
Q18 (Inclusion of Palliative care in Health Insurance system will improve the delivery of Palliative care in India)	0.028
Job experience	
Question	P-Value
Q4 (There is lack of Awareness among the Healthcare providers about Palliative care in India)	0.01
Q20 (A National Policy or legal mandate is essential to improve the delivery of Palliative care)	0.01

Figure 4

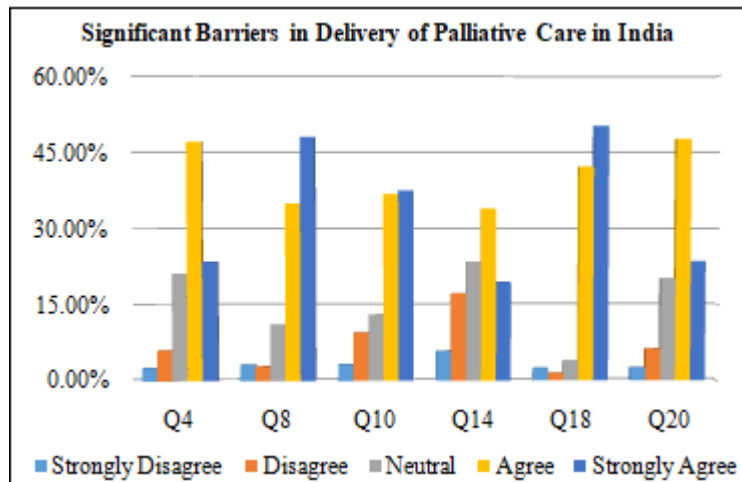


Figure 5

4. Results

The following evidence can be brought about from the above-mentioned questionnaire and data compiled in Fig-5.

- 1) 23.5% of the respondents strongly agree and 47% agree to the fact that focus on Palliative care should begin early in the course of illness.
- 2) 48% of the respondents strongly agree and 35% agree to the statement that it is difficult to assess the exact requirement for Palliative care in a healthcare setup.
- 3) The Health Insurance system in India should provide cover for the Palliative care services. 37.5% respondents strongly agree and 36.8% respondents agree to it.
- 4) Inclusion of Palliative care in Health Insurance system will improve the delivery of Palliative care in India. 34% respondents agree to the statement, whereas 23.5% respondents are neutral towards the same.
- 5) 50.2% of the respondents strongly agree and 42.2% agree to the fact that Palliative care is already a part of comprehensive health care in India.
- 6) 47.7% respondents agree that Palliative care should be a part of integrated care in Hospital.

5. Recommendations

The concept of palliative care is relatively new to India, having been introduced only in the mid-1980s (4). Since then, hospice and palliative care services have developed through the efforts of committed individuals, including Indian health professionals as well as volunteers, in collaboration with international organizations and individuals from other countries. The study results have brought out the barriers in the delivery of Palliative care from the healthcare providers' point of view.

There is lack of awareness among the Healthcare providers about Palliative care in India. This barrier can be overcome by incorporating the concept of Palliative care in the undergraduate curriculum and in the Paramedical training (5). A specialization in Palliative care medicine has already been started in our country.

Non availability of Infrastructure to provide Palliative care is a serious problem. Each year, it is estimated over 56.8 million people, including 25.7 million in the last year of life need palliative care, of whom 78% live in low-and middle-income countries. However, it is estimated that only about 12% of people needing palliative care actually receive this care (6). The availability and accessibility of healthcare facilities in developing countries like India has always been a problem when it comes for delivering a Quality healthcare.

	Q4		Q8		Q10		Q14		Q18		Q20	
Strongly Disagree	2.50%	5.2	3.20%	6.7	3.20%	6.7	5.80%	12.1	2.40%	5	2.50%	5.2
Disagree	6.00%	12.5	2.80%	5.9	9.50%	19.9	17.20%	35.9	1.40%	2.9	6.20%	13
Neutral	21.00%	43.9	11.00%	23	13.00%	27.2	23.50%	49.1	3.80%	7.9	20.10%	42
Agree	47.00%	98.2	35.00%	73.2	36.80%	76.9	34.00%	71.1	42.20%	88.2	47.70%	99.7
Strongly Agree	23.50%	49.1	48.00%	100.3	37.50%	78.4	19.50%	40.8	50.20%	104.9	23.50%	49.1
	100.00%	209	100.00%	209	100.00%	209	100.00%	209	100.00%	209	100.00%	209

The Palliative care delivery centers also known as Hospice provide palliation of a patient's pain and symptoms and also attend to their emotional and spiritual needs at the end of life (7). There has been some progress in the field of palliative care in India, but the fact remains that despite this, even today palliative care reaches only about 1% of the people in India.

6. Conclusion

This study brings about the following important conclusions.

- 1) It is difficult to assess the exact requirement for Palliative care. Palliative care is required in a broad spectrum of diseases. It ranges from chronic diseases such as cardiovascular diseases, cancer, chronic respiratory diseases, to kidney failure, chronic liver disease,

rheumatoid arthritis, and neurological disease. Worldwide, only about 14% of people who need palliative care currently receive it. This proportion is even less in developing countries such as India (~1%).

- 2) Focus on Palliative care should begin early in the course of illness.
- 3) The Health Insurance system in India should provide cover for the Palliative care services. Early palliative care not only improves quality of life for patients but also reduces unnecessary hospitalizations and out-of-pocket expenditure on health-care services.
- 4) Inclusion of Palliative care in Health Insurance system will improve the delivery of Palliative care in India.
- 5) Palliative care is already a part of comprehensive health care in India. The Indian National Health Policy (NHP) 2017 and other international bodies endorse palliative care as an essential health-care service component. NHP 2017 also recommends development of distance and continuing education options for general practitioners to upgrade their skills to provide timely interventions and avoid unnecessary referrals (8).
- 6) Palliative care should be a part of Integrated care in Hospital. World Health Organisation (WHO) endorses integrated palliative care which has a significant impact on quality of life and satisfaction with care. Effective integration between hospices, palliative care services, hospitals and primary care services are required to support patients with palliative care needs.

References

- [1] Jagannathan A, Juvva S. Palliative Care: An Indian Perspective. *Oxford Textbook Palliat Soc Work*.2013; 1 (4): 561–6.
- [2] Meier DE. Increased access to palliative care and hospice services: Opportunities to improve value in health care. *Milbank Q*.2011; 89 (3): 343–80
- [3] Hawley P. (2017). Barriers to Access to Palliative Care. *Palliative care*, 10, 1178224216688887. <https://doi.org/10.1177/1178224216688887>
- [4] Khosla, D., Patel, F. D., & Sharma, S. C. (2012). Palliative care in India: current progress and future needs. *Indian journal of palliative care*, 18 (3), 149–154. <https://doi.org/10.4103/0973-1075.105683>
- [5] Directorate General of Health Services, Ministry of Health & Family Welfare. Proposal of Strategies for Palliative Care in India.
- [6] Assessing national capacity for the prevention and control of noncommunicable diseases: report of the 2019 global survey. Geneva: World Health Organization; 2020
- [7] Doyle D. Getting Started: Guidelines and Suggestions for those Starting a Hospice/Palliative Care Service [Internet].2009.1–76 p.
- [8] Jeba, J., Atreya, S., Chakraborty, S., et al. (2018). Joint position statement Indian Association of Palliative Care and Academy of Family Physicians of India-The way forward for developing community-based palliative care program throughout India: Policy, education, and service delivery considerations. *Journal of family medicine and primary care*, 7 (2), 291–302. https://doi.org/10.4103/jfmpc.jfmpc_99_18