

Palliative Care Awareness Among Clinicians in Bhopal: A Survey Based Report

Deepti Agarwal¹, K. K. Thakur², Sudip Bhargava³, Manish Badkur⁴, Sumit Bhargava⁵, Nupur Chakrawarty⁶

^{1,2,4}Assistant Professor Department of Anaesthesiology, L.N. Medical College and J.K. Hospital Bhopal

³Assistant Professor Department of Anaesthesiology, Chirayu Medical College & Research Center

⁵Professor Department of Anaesthesiology, L.N. Medical College and J.K. Hospital Bhopal

⁶Professor & Head, Department of Anaesthesiology, L.N. Medical College and J.K. Hospital Bhopal

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Corresponding author: Dr Manish Badkur

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Abstract

Background: To assess the existing knowledge about palliative care among physicians and to assess the existing awareness about palliative care practices among physicians.

Methods: Cross-sectional, anonymous, self-administered questionnaire survey was done with a group of 100 conveniently sampled physicians. This study used psychometric methods, including item response theory, intraclass correlation coefficients, and known-group validity. included 20 items across the following 4 domains: (1) palliative care, (2) Hospice (3) Terminal illness (4) Pain control . There was a significant difference in the scores between palliative care specialists and other physicians.

Results: Most of the physicians have heard about palliative care in their residency/ post graduation days and are aware that it is mainly for all terminally ill patients. None have received any formal education or training in palliative care. Almost 30% didn't know that the main aim of palliative care is to improve quality of life. Most physicians came to know about palliative care and hospice through their friends and internet. All physicians believe that patients should be taken care of at home or in hospice and there should be judicious use of opioids with spiritual counselling. Most of them were not aware about the Narcotic Drugs and Psychotropic Substances Amendment Act 2014 or WHO ladder of pain .Most only knew about VAS scoring system of pain and didn't know about other pain scores.

Conclusion: Palliative care processes including identification of patient preferences and decision making surrogates, communication between clinicians and patients/families, social and spiritual support, and pain assessment and management, as documented in medical records. Application is triggered by specified lengths of ICU stay. Amongst doctors of various departments, there is a lack of training and awareness in palliative care. Almost all are interested and they are willing to have more training in pain control, breaking bad news, communication skills and terminal care.

Keywords: Palliative care, Hospice, Terminal illness, Pain control

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Introduction

Palliative care is the care of any patient with advanced or incurable disease. The word "palliative" in Latin means "caring." Palliative care is thus the proactive care which seeks to maximize quality of life for people and families facing life-threatening illnesses.² Palliative care takes a holistic approach which acknowledges that suffering is more than physical distress and recognizes that patients require a combination of physical, psychological, social, and spiritual care [1].

The World Health Organization (WHO) defines palliative care as "an approach that improves the quality of life of patients and their families facing the problem 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."³ It falls under the quaternary level of prevention, i.e., preventing unnecessary suffering among patients and their families in situations of terminal diseases [2,3].

Looking at the present scenario, palliative care in India is still in very premature stage, and there are many challenges and barriers in providing palliative care to patients. The major challenge is lack of knowledge among physicians as well as patients and lack of sensitization among policymakers. The knowledge of palliative care is very limited and few professionals are trained to cater the need of patients in India. WHO has recommended palliative care to be made compulsory in basic medical professional courses [4,5].

However, in India, palliative care is taught neither at undergraduate and nor at postgraduate level. Hence, this is high time to

Observation Chart

incorporate principles of palliative care in continuum of medical care in all chronic debilitating diseases. Health-care professionals should have adequate knowledge of palliative care so that this knowledge could be applied practically. Improving knowledge of palliative care will improve the quality of palliative care in the country.

Materials and Methods

Design: Single site study was done using self-report questionnaires. This study was confined to physicians working in L.N. Medical College and J.K. Hospital Bhopal between November 2021 to March 2022. The physicians serving in outpatient departments and wards were recruited to participate in the study. Survey questionnaire were distributed among physicians and residents of our institution.

Survey had following sections-

Section one: This section included basic information of participant of the surveys.

Section two: This section was about assessment of current knowledge of Palliative care and Hospice Care among Physicians

Validity and reliability of the study The questionnaire was validated after approval from 5 experts in the field of Pain and Palliative care.

Inclusion criteria: All physicians, clinical faculty members and residents who give consent for the survey

Exclusion criteria Refusal of Consent

Study Design: Observational, Survey Based Questionnaire.

QUESTIONNAIRE**Part A Participant Details**

Name:

Age/Sex:

Department:

Designation:

Contact:

Email Id:

Part B

You Can Choose More than One Options.

1. When did you first hear about Palliative Care?

- a. UG
- b. b.PG
- c. SR Ship
- d. Hearing it First Time.

2. Which type of patients required Palliative Care?

- a. Terminally ill Cancer Patients
- b. Terminally ill Cardiac Patients
- c. Terminally ill Kidney Patients
- d. All Terminally Ill Patients

3. Have you received any Formal Training in Palliative Care?

- a. No
- b. During UG
- c. During PG
- d. During Resident ship

4. What is aim of Palliative care?

- a. Prolonging Life
- b. Improving Quality of Life
- c. Pain Control
- d. Rehabilitation

5 a. In your opinion, what is the objective of hospice care?

- a. to give supportive care to people in the final phase of a terminal illness
- b. care focussed on comfort and quality of life,
- c. Care based on high-quality effective treatment.
- d. All the above
- e. None of the above

5.b As per your knowledge, what is the final goal of hospice care?

- a. to enable patients to be comfortable and free of pain, so that they live each day as fully as possible
- b. To offer high quality treatment avoiding cost of super speciality hospitals
- c. To speed-up recovery and bring back patient to normal productive life as fast as possible
- d. All the above

6. Do you think Palliative Care should be included in Curriculum of UG?

- a. Yes
- b. No

7. Are you interested in attending a formal training in palliative care?

- a. Yes
- b. No

8. What is your source of knowledge about palliative care?

- a. Books
- b. Internet
- c. Friends
- d. Formal Education

9. Where should we take care of Patients with Terminal Illness?

- a. ICU
- b. Home
- c. Hospice
- d. Anywhere

10. Opioids are mainstay of Treatment of Pain in Palliative Care. Do you agree?

- a. Yes
- b. No

11. Have you ever referred the Patient and their relatives to consider Spiritual Counselling?

- a. Yes to all terminally ill patients
- b. Sometimes
- c. Never

12. Do you think Euthanasia is a better option than Palliative Care for terminally ill patients?

- a. Yes
- b. No
- c. Cant Say

13. What is the most common barrier according to you in palliative care?

- a. Income
- b. Formal Training
- c. Social acceptance
- d. Dont know

14. Have you heard of Narcotic Drugs and Psychotropic Substances Amendment Act 2014?

- a. Yes
- b. No

15. Do you believe that palliative care services will be more required in our country?

- a. Yes
- b. No
- c. Cant Say

16. Have you heard about WHO ladder of Pain Control?

- a. Yes and we do follow that
- b. Yes but we don't follow that
- c. No

16 a. If yes, tell us about the number of steps this ladder has?

- a. One
- b. Two
- c. Three
- d. Four

e. Eleven

17. Are you aware of different pain scales used in chronic pain patients?

- a. Yes almost all of them
- b. Yes but they are not of much use
- c. No

18. How frequently you find a communication gap between health care professionals and family members regarding goals of care for terminally ill patients?

- a. Almost always
- b. Not very frequently
- c. Never

19. Are you aware of any palliative care centre near you where you can refer the patients?

- a. Yes
- b. No
- c. There must be one.

20. Do you think patients with terminal illness are abandoned by health care facilities in their final times?

- a. Yes almost always
- b. Sometimes due to lack of resources
- c. c. Never

Results

Most of the physicians had heard about palliative care in their residency/ post graduation days and are aware that it is mainly for all terminally ill patients. None have received any formal education or training in palliative care. Almost 30% didn't know that the main aim of palliative care is to improve quality of life.

Most physicians came to know about palliative care and hospice through their friends and internet. All physicians believed that patients should be taken care of at home or in hospice and there should be judicious use of opioids with spiritual counselling. Most of them were not aware about the Narcotic Drugs and Psychotropic Substances Amendment Act 2014 or WHO ladder of pain. Most only knew about VAS scoring system of pain and didn't know about other pain scores.

They accepted that there is a huge communication gap between the health care professionals and family members of the terminally ill. Terminally ill patients are

usually abandoned by the family members and the society and are a huge burden on the community. Almost all physicians opposed euthanasia and were determined to get educated about removing various barriers faced in palliative care. They welcomed the idea of including palliative care in the U.G. curriculum and were of the opinion that a formal training is the need of the hour.

Statistical Analysis

The data will be entered into EPI-INFO version 7. Chi-square and logistic regression were computed in order to assess statistical association and to see the level of significance, respectively.

Discussion

The core components of palliative care include the assessment and treatment of physical and psychological symptoms, identification of and support for spiritual distress, expert communication to establish goals of care and assist with complex medical decision making, and coordination of care.

Ideally, many of these components can and should be provided by primary treating clinicians much in the way that uncomplicated hypertension or diabetes is managed by primary care physicians rather than by cardiologists or endocrinologists with specialist-level palliative care teams providing care in the most complex and difficult clinical cases. However, in reality, most physicians and other health care professionals currently in practice have had limited or no formal training in these areas [5-7].

Bhadra K *et al* enquired about the level of awareness regarding various important aspects of palliative medicine among doctors of various departments in four medical colleges in Kolkata through a questionnaire which was developed by few members of Indian Association of Palliative Care. The results suggested that 85% doctors felt that cancer was the commonest reason for the palliative care teams to be involved. Seventy four percent mentioned that pain control was their prime job. Thinking of the future, 92% of the doctors think more and more people will need palliative care in the coming days. They concluded that amongst doctors of various departments, there is a lack of training and awareness in palliative care. Almost all the doctors are interested and they are willing to have more training in pain control, breaking bad news, communication skills and terminal care [8].

Salins N *et al* conducted a study to ascertain the perceptions of Indian palliative care providers regarding the feasibility and acceptability of implementing the international program in the Indian setting. All participants were asked to complete the survey questionnaire that had both open- and close-ended questions. They found that twenty-three participants completed this survey. The majority of items in the international program were considered relevant, representative of end-of-life care and acceptable in Indian setting. While most

participants thought relevance, representation, and applicability of assessing skin integrity as important, a few participants felt this assessment challenging, especially in home setting, and recommended Braden scale to be used instead of Waterlow for assessing skin integrity. Most participants agreed on the importance of assisted hydration and nutrition; however, again a minority highlighted challenges in this area. Authors concluded that the survey of palliative care providers about the feasibility and acceptability of integrated care plan at end of life has shown that the international program is relevant, representative of end-of-life care, and acceptable in Indian setting. As would be expected, a number of items need careful consideration and appropriate modification to ensure relevance, representation, and applicability to Indian socio cultural context. The results also suggest that palliative care providers need additional training for the implementation of some of the items in the development of an India-specific document and supporting quality improvement program [9].

Kiss Lane *et al* surveyed needs and feasibility regarding e-learning in Palliative care. Indian, Australian and North American palliative care experts developed an electronic survey using Qualtrics, emailed to all registrants of the 2017 Indian Association of Palliative Care (IAPC) conference and distributed during the conference. Most (90.9%) received palliative care training in India or overseas with 41% trained in a Trivandrum Institute of Palliative Sciences residential course (4-6 weeks). 17% completed the IAPC essential certificate and 22% had undertaken various distance learning courses. Interest in online training was substantial for most aspects of palliative care. They concluded that there was a high level of interest and reported feasibility in taking a case-based online course. This pilot survey provides support for online case-based education in India, particularly among physicians [10].

Yamamoto R *et al* prepared a palliative care knowledge questionnaire for reliability and validity of an instrument to measure palliative care knowledge among physicians. Effective delivery of such programs relies on adequate evaluations of program efficacy. They conducted a cross-sectional, anonymous, self-administered questionnaire survey with a group of 801 conveniently sampled physicians in October 2010. This study used psychometric methods, including item response theory, intraclass correlation coefficients, and known-group validity. included 33 items across the following 9 domains: (1) philosophy of palliative care, (2) cancer pain, (3) side effects of opioids, (4) dyspnea, (5) nausea and vomiting, (6) psychological distress, (7) delirium, (8) communication regarding palliative care, and (9) community-based palliative care. There was a significant difference in the scores between palliative care specialists and other physicians. They successfully validated a newly developed palliative care knowledge questionnaire to evaluate PEACE effectiveness (PEACE-Q). The PEACE-Q could be useful for evaluating both palliative care knowledge among physicians and education programs in primary palliative care [11].

Nakazawa Y *et al* made the palliative care knowledge test accessing the reliability and validity of an instrument to measure palliative care knowledge among health professionals. The aim of this study was to develop an assessment to measure the efficacy of palliative care educational programmes. The questionnaire survey was validated with a group of 940 nurses at two facilities. This tool was designed to evaluate a wider range of palliative care knowledge than currently available assessments and can be used for general physicians and nurses. The evaluation of educational programmes and the clarification of actual knowledge acquired are possible using this instrument [12].

Kelley AS *et al* worked on palliative care for

the seriously ill. The core components of palliative care include the assessment and treatment of physical and psychological symptoms, identification of and support for spiritual distress, expert communication to establish goals of care and assist with complex medical decision making, and coordination of care. Ideally, many of these components can and should be provided by primary treating clinicians — much in the way that uncomplicated hypertension or diabetes is managed by primary care physicians rather than by cardiologists or endocrinologists — with specialist-level palliative care teams providing care in the most complex and difficult clinical cases. However, in reality, most physicians and other health care professionals currently in practice have had limited or no formal training in these areas [13].

de Haes H *et al* did a review of recent literature and emphasised on communication in palliative care. The quality of communication with patients, family, and team members is an extremely important. Trust was found to be a major factor for relationship building. Information gathered by patient self-report is the method of choice, given improved insight in symptom prevalence, duration, frequency, and interference. Cultural factors in information giving, the optimal process and content, and the difficulty of conveying hope were addressed. Decision making in palliative care requires a complex integration of conceptual knowledge, ethical and legal implications, and communication skills. Aspects of manageability are explored. Although health care providers must communicate about emotions, the existential distress of cancer patients and carers often goes overlooked in the last phases of life. Themes included the education of health care providers, the need to care for carers, and interdisciplinary communication. Little attention was given to the growing population of elderly patients. Observer-based studies are unfortunately

scarce, making the practice of palliative communication unseen. Finally, few studies report the cost-effectiveness of palliative care interventions though such studies may enhance palliative care and convince policy makers of the need to support such care. More empirical work is needed to improve the level of quality needed to ensure a good remaining lifetime for cancer patients whose disease cannot be cured [14].

Identifying and overcoming the barriers to high-quality palliative care in the intensive care unit. Initiatives to improve end-of-life care in intensive care units face several important barriers. These include inflated expectations for critical care therapies, which are shared by many clinicians and many patients and families; preoccupation with an unattainable level of prognostic certainty, delaying attention to palliative needs; and fragmentation of the healthcare team into separate “silos” of disciplines and specialties. The article by Nelson JE *et al* reviews these barriers and relevant empirical evidence. Specific strategies to improve intensive care unit palliative care, including consultation by palliative care specialists, and palliative care quality measurement are discussed [15].

A practical new tool for palliative care performance measurement and feedback was devised by Nelson JE *et al* for improving comfort and communication in the ICU. Objective was to develop a practical set of measures for routine monitoring, performance feedback, and improvement in the quality of palliative care in the intensive care unit (ICU). Use of an interdisciplinary iterative process to create a prototype “bundle” of indicators within previously established domains of ICU palliative care quality; operationalization of indicators as specified measures; and pilot implementation to evaluate feasibility and baseline ICU performance. Pilot testing in 19 ICUs (review of >100 patients’ records) documented feasibility, while revealing opportunities for quality improvement in clinician-

patient/family communication and other key components of ICU palliative care. The new bundle of measures is a prototype for routine measurement of the quality of palliative care in the ICU. Further investigation is needed to confirm associations between measured processes and outcomes of importance to patients and families, as well as other aspects of validity [16].

A literature review of educational interventions in palliative care (PC) for primary care physicians (PCP) was performed by Alvarez MP, to evaluate its impact in changing professional practice. Educative methods were: role model training, small group discussions, and distribution of guidelines. Quality of the studies was low. Opioids prescription improved in two studies. Discrepancies were shown between the perception of PCP in symptom management, determined through questionnaires, and the data concerning opioids prescription. Knowledge improved in all studies. Some benefit of multifaceted approach was stated. Carers were satisfied, in general, with the PCP care, but dissatisfied with patients' pain control. It was concluded that PC education for PCP is poorly studied. Adequate research designs are necessary in future studies with objective outcomes and patient opinion [17].

Medical futility at the end of life is a growing challenge to medicine. The goals of the authors- Jox RJ *et al* were to elucidate how clinicians define futility, when they perceive life-sustaining treatment (LST) to be futile, how they communicate this situation and why LST is sometimes continued despite being recognised as futile. The authors reviewed ethics case consultation protocols and conducted semi-structured interviews with 18 physicians and 11 nurses from adult intensive and palliative care units at a tertiary hospital in Germany. The transcripts were subjected to qualitative content analysis. Managing futility could be improved by communication training, knowledge transfer, organisational improvements and emotional and ethical

support systems. The authors propose an algorithm for end-of-life decision making focusing on goals of treatment [18].

Conclusion

Palliative care providers know about the feasibility and acceptability of the international program about integrated care plan at end of life . It is relevant, representative of end-of-life care, and acceptable in Indian setting. A number of items need careful consideration and appropriate modification to ensure relevance, representation, and applicability to Indian socio cultural context. The results also suggest that palliative care providers need additional training for the implementation of some of the items in the development of an India-specific document and supporting quality improvement program.

Limitations of Study: This is a simple survey based study hence participants involvement is the critical factor for accurate assessment. Validity of survey is done by simple Face Validation technique which is not a very effective method of validation.

What this study add to existing knowledge:

With this study we will be assessing the existing level of knowledge, attitude and practices among physicians regarding palliative care. This study will help in developing policy regarding palliative care in our institution.

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