



Assessment of Perception of Palliative Care among the Patients of Palliative Therapy

Saba Khan^{1*} and Nikhil Dhande²

¹*Master of Public Health, School of Epidemiology and Public Health, Department of Community Medicine, Jawaharlal Nehru Medical College, Datta Meghe Institute of Medical Sciences, Wardha, India.*

²*Department of Community Medicine, Jawaharlal Nehru Medical College, Datta Meghe Institute of Medical Sciences, Wardha, India.*

Authors' contributions

This work was carried out in collaboration between both authors. Both authors read and approved the final manuscript.

Article Information

DOI: 10.9734/JPRI/2021/v33i36B31966

Editor(s):

(1) Dr. Paola Angelini, University of Perugia, Italy.

Reviewers:

(1) Vetriselvan Subramaniyan, MAHSA University, Malaysia.

(2) Hasta Handayani Idrus, Universitas Muslim Indonesia, Indonesia.

Complete Peer review History: <https://www.sdiarticle4.com/review-history/71218>

Study Protocol

Received 05 May 2021

Accepted 10 July 2021

Published 13 July 2021

ABSTRACT

Background: The assessment of the good health and well-being of palliative care patients is summarised in this protocol analysis. It will bring about the financial and physical wellbeing of patients. The standard of life of patients and their families has been reviewed.

Methods: It is a cross-sectional analysis involving selected villages in the Wardha district. A sample of 95 participants will be taken from Wardha Palliative Care. Patients will be randomly allocated to the survey by the Jawaharlal Nehru Medical College of Wardha District Department of Community Medicine. A pre-designed multidimensional survey questionnaire will be prepared and pre-tested for quantitative data collection. The pro forma used to gather the data will include their current disease and disease management and will integrate the psychosocial and moral elements of hospital care. The motive of this research is to understand the interpretation of palliative care in the lives of affected patients. The goal of this study is to know the conception of a compromised patient living.

Results: Using descriptive and inferential statistics using the chi-square test, the result will be obtained by attributing the baseline and terminal consequences.

Conclusion: The purpose of this research is to define the predictive, mediating and moderating functions of select variables: self-efficacy, disease, psychosocial, spiritual caregiver. The findings of this study will influence the interpretation of the resilience of patients with palliative care and will enhance functional outcomes for emotional, mental and spiritual health. This change in attitude would be beneficial to them in their lives. And the patient's quality of life will improve.

Keywords: Quality of life; spiritual; emotional; palliative care.

1. INTRODUCTION

Good health is the centre of joy & well-being to human. It makes significant contribution for the economic or financial growth, as healthy people live longer lives and are more productive & also save for the better future. Health is defined as "the state of complete physical, mental & social well-being & not merely an absence of any disease or infirmity" as stated by World Health Organization in the year 1948 [1]. Health is multidimensional and thus there are various dimensions of health which plays a vital role to balance the person's life, especially when the focus is mainly on physical dimension, mental & emotional dimension & psychosocial dimension [1]. Palliative care is a care by which there is significant advancement in the quality of life of the patients & it plays a crucial role in the coping process of the family members with the worsening of the disease or death through early diagnosis, prevention and relief from the extreme sufferings, evaluation of the treatment according to or acceptable to physical, psychosocial & spiritual problems. Overall, the prevalence of palliative care is 14% and an estimated 40 million need hospice care each year and about 78% of them come from developing countries [2].

Palliative ensure access to that enriches the lives of patients and their families confronting life-threatening illness conflicts by eliminating and exacerbating distress through early recognition and the impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems. (By WHO, 2002) [2]. The shortage of information and skills of palliative care among health professionals is also a significant hurdle to enhancing infrastructure. The ultimate purpose of palliative care is to enhance the general well-being of individuals for both the patient and the family, irrespective of diagnosis [3,4]. Although, unlike hospice care, palliative care does not depend on prognosis, the role of palliative care as the end of life intensifies and focuses on active symptom management and psychosocial support approaches. An essential component of end-of-life palliative care

is helping patients and their families understand the effectiveness of the treatment and the prognosis [5].

Palliative care is :

- Provides relief from pain and other distressing symptoms
- Affirms life and considers death as a natural process
- Intends not to hasten or prolong death
- Integrates patient care's psychological and moral elements
- Provides a system of care to help patients live as actively as possible before death.
- Provides a support system to help the family deal with the treatment plan and their own bereavement.
- Using a team approach to meet patients and their families' needs, including therapy for bereavement, if suggested.
- Improve the quality of life and can also have a positive effect on the course of illness [5-6].

In our society, a modern idea is palliative care. This study seeks to find out and compare the knowledge and attitude towards palliative care and its contributing factors of individuals living in the rural area of the Wardha district.

1.1 History of Palliative Healthcare in India

India is relatively aware of the concept of palliative care, which was enforced only in the mid-1980s. Since then, hospice and ambulatory care have flourished through the efforts of dedicated professionals, including Indian health care workers and volunteers, in conjunction with international agencies and individuals from other nations [7]. The Indian government Launched the National Cancer Prevention Program in 1975 [8]. This policy was amended in 1984 to make the assessment of pain one of the necessary infrastructure to be administered at the primary level of health care. In Mumbai, Maharashtra, Central India, the first hospice, Shanti Avedna

Ashram, was opened in 1986 by Professor D'Souza. Similarly, pain clinics have been developed at the Regional Cancer Centre, Trivandrum, Kerala, and the Kidwai Memorial Institute of Oncology, Bangalore, Karnataka, with the help of the WHO [9].

Since the 1990s, there has been a substantial rise in the momentum of hospice development and palliative care provision. This has been illustrated by the increase in the number of programmes, as well as other significant events and initiatives. In 1997, Can Help, which provided North India's first free palliative care home support service, was founded in Delhi.

The Cipla Cancer Palliative Care Centre was established in Pune, Maharashtra, central India. The IAPC organised its first international conference in Varanasi in January 1994 (with the assistance of the WHO and the Government of India) and adopted a constitution [9-10].

2. RATIONALE

Health care practitioners usually prefer to concentrate mostly on organs and their diseases. Palliative care acknowledges that patients are far more than organs placed together; they are all part of who they are, their mind, spirit and feelings, including the families and cultures of the patient [7]. Therefore, the problem faced by a sick person and his/her family is not only limited to the illness; discomfort and pain can occur and Other signs are associated with emotional, social and spiritual problems. Hence Palliative care also focuses on its additional Spiritual Dimension along with Physical, Social, Psychological and Emotional dimension. Furthermore, various scales have been used to assess palliative outcomes, awareness and practices but none of them directly depicts these dimensions [8]. Considering this a study is planned to assess the quality of life of palliative care patients in Wardha district with the help of Multidimensional Survey Questionnaire.

3. OBJECTIVES

- To determine the perceptions of palliative care among palliative therapy patients in the district of Wardha.
- To study the factors associated in the participants.

4. METHODOLOGY

Study settings: Selected villages in Wardha district

Study Design: Cross-sectional study

Study participants: Registered patients of palliative care in Wardha district

Study Duration : Nine months

Sampling procedure: Simple Random Sampling

Data collection tool: A Predesigned Multidimensional Survey Questionnaire.

Data collection process: The participants will be approached through the visits in hospital and community patients by household visits. The study's goal and its possible advantages in local language and terminology will first be clarified to all participants and they will be encouraged to answer and interview, but they will not ask the leading questions.

Statistical Analysis: Data analysis will be done using the SPSS version 17 and Microsoft Excel for windows. Descriptive statistics, chi-square tests and correlation will be use.

Variables: Emotional, Psychological, Spiritual, Education, Occupation.

Study size: Considering the prevalence rate of Palliative care patients of 14 % by WHO the Sample Size is calculated as-

$$\text{Sample Size (n)} = \frac{2 \alpha / 22 \times P \times (1 - P)}{d^2}$$

Where,

α is the level of significance at 5% i.e. 95% confidence interval =1.96

P= Prevalence of palliative care patients =14% =0.14

Desired error of margin 7% = 0.07

d = 14x (1-0.14)

Sample Size (n)= 94.39 \cong 95

Data Sources / Measurements: Using pre-structured and pretested methods formulated in English, data will be obtained through face-to-face interviews. In order to ease the collection of community data, the instruments will also be

translated into Marathi, the native language. The language for the ease of gathering group data. A pre-designed multidimensional survey questionnaire will be the key section of the questionnaire

In order to collect the following details, the questionnaires will target.

- 1) The patient's physical treatment.
- 2) The patient's social ties and status.
- 3) The patient's personal treatment and behavior changes.
- 4) Psychological methods

We will address general problems, such as:

- 1) Years of age.
- 2) Sex in the Male/ Female/ Transgender.
- 3) Education levels, such as Literate/ Illiterate,
- 4) Forms of Primary/ Middle/ High school/ Graduate/ Postgraduate education.
- 5) Occupied/ Unemployed.
- 6) Career type- Farmer/ Daily worker/ Self-employed/ Service etc.
- 7) Approximate monthly earnings in Rupees.
- 8) Marital Status-Married/ Unmarried/ Widowed/ Separated.
- 9) Indulgence/ Addiction in the form of frequency and durations
- 10) Basic history of major medical problems such as Diabetes/ TB/ Asthma/ Hypertension/ Cancer etc.
- 11) History of any previous hospitalization for any major illness.

Other questions comprise of multidimensional views: It involves the physical, moral, social, mental, psychological domain, for which we made the queries as Did the pain affect your everyday routine behavior, what is spiritual treatment, who is the special person in your life who cares about your emotions, how do you deal with stress, feel down, lonely, depressed, and like that

Statistical methods: Data analysis will be done using the SPSS version 17 and Microsoft Excel for windows. Descriptive statistics, chi-square tests and correlation will be used.

5. RESULTS

Will find the perception regarding psychological, spiritual, emotional, physical social care. (The understanding of mental, moral, emotional and physical social care would be discovered.)

Participants: Registered patients of palliative care in Wardha district.

Scope of the study: The study focuses on correlation of various aspects of care they are getting and their expectations with the diagnosis of current illness they are suffered from, which influences the succeeding ways of management. It is a diligent way to provide comfort and support in their life-threatening illness. It incorporates the psychological and moral elements of patient care.

6. DISCUSSION AND CONCLUSION

The current study is designed to evaluate the quality of life of life-limiting patients disorders registered in Wardha district under palliative care with regard to their pain and symptoms, along with additional variables and dimensions such as physical, social, psychological and emotional.

In one report, they found that the national health policy should pay due attention to the PC and that it needs to be integrated into the national nursing education curriculum [9-10].

Some studies have also found that palliative care is about caring for and maintaining comfort for people who die in the last days of life.

The participants' service priorities included: holistic support, symptom treatment; clear communication; and realistic support to promote care choice and support. A crucial factor of promoting palliative care has been the growth of awareness and use of the word itself and targeted educational initiatives.

Palliative care programmes are an exclusive method of treatment. Holistic care that ties all sufferers with each other For physicians at hospitals and their families, home-based Treatment (maintaining at the place of stay a quality of care Via family / group for a bedridden patient Empowerment of qualified teams, and/or home visits, normally with a nurse included) As well as the society, regardless of Social status/age/religious disparities. Palliative treatment, preferably, Services from the time of diagnosis should be given Life-threatening disease, adapting to the growing requirements of As the disease progresses, patients with cancer and their families.

Our analysis provides supporting evidence that, despite a shared agreement on the potential

benefit to patients that may result from palliative care, collaborative effort between palliative care providers is sub-optimal. As such, to introduce all learners to palliative care, clinical education must be strengthened. Our results support the role of specialist palliative care practitioners [10].

This perspective may lead to the heterogeneity of comprehension of palliative care, affecting the perceptions and use of those patients and families that require it. This suggests that it is not possible to raise public consciousness in isolation, but it allows the notion of palliative care to be taken forward in the delivery of health care systems [11]. Related studies to palliative care in different contexts were reviewed [12-14]. Also studies on primary level care were reported [15-17].

Our aim is to increase awareness and understanding of health care providers and the general population through the introduction of palliative care in the educational curriculum in both the medical and dental fields [18-21]

Key results: In proposed cross sectional study having patients of palliative care various sociodemographic variables such as education, occupation, age, socioeconomic status, marital status, various addictions etc will be analysed after the final statistical analysis we will determine- Opinion, belief and severity of various variables of the participants.

7. LIMITATIONS

- The other confounding factors may not be considered which may affect the patients perceptions.
- The study may not be applicable to people with severe mental disorder.

CONSENT

After explaining the purpose of study, written information consent has obtained. Data obtained will be kept confidential.

ETHICAL APPROVAL

As per international standard or university standard written ethical approval has been collected and preserved by the author(s).

COMPETING INTERESTS

Authors have declared that no competing interests exist.

REFERENCES

1. Paci E, Miccinesi G, Toscani F, Tamburini M, Brunelli C, Constantini M, et al. Quality of life assessment and outcome of palliative care. *Journal of Pain and Symptom Management* [Internet]; 2001;21(3):179–88. [Cited 2021 Feb 9] Available:<https://linkinghub.elsevier.com/retrieve/pii/S0885392401002639>
2. Geneva: World Health Organization; [Last accessed on 2012 Mar 02]. “WHO Definition of Palliative Care”.
3. Subramaniyan V, Chun NK, Shahrudin PNH bt, Singh DSAD, Sivanadam GA, Qi LP, Ahamed MMM, Priya RRR, Zahir RM, Santhi VK, Seng WY, Kumarasamy V, Fuloria NK, Fuloria S. A cross-sectional study on awareness of dyslexia disorder among university students. *Open Access Maced J Med Sci* [Internet]. 2020;8(E):251-5. [Cited 2021 Jul. 5]
4. Lim Jing Hang, Vetrivelvan Subramaniyan, Kok Xiaojun, Mohamad Hazeeq bin Abu Bakar, Teoh Zheng Wei, Meftah Jebriel, Meftah Alshaiwi, Low Wei Ling, Kanesh Ambihabathy, Meram Azzani. Influence of medication error among medical and non-medical students in a Malaysian University. *J Young Pharm.* 2019;11(4):399-403
5. Ventafridda V, De Conno F, Ripamonti C, Gamba A, Tamburini M. Original article: Quality-of-life assessment during a palliative care programme. *Annals of Oncology* [Internet]. 1990;1(6):415–20. [Cited 2021 Feb 9] Available:<https://linkinghub.elsevier.com/retrieve/pii/S0923753420316999>
6. Daniel V, Daniel K. Exercises training program: It's effect on muscle strength and activity of daily living among elderly people. *Nursing and Midwifery.* 2020;1(01):19-23. Available:<https://doi.org/10.52845/NM/2020v1i1a5>
7. McCaffrey N, Bradley S, Ratcliffe J, Currow DC. What aspects of quality of life are important from palliative care patients' perspectives? A Systematic Review of Qualitative Research. *Journal of Pain and*

- Symptom Management [Internet]. 2016;52(2):318-328.e5.
[Cited 2021 Feb 9]
Available:<https://linkinghub.elsevier.com/retrieve/pii/S0885392416300781>
8. Payne S, Hughes S, Wilkinson J, Hasselaar J, Preston N. Recommendations on priorities for integrated palliative care: transparent expert consultation with international leaders for the InSuP-C project. *BMC Palliat Care* [Internet]. 2019;18(1):32.
[Cited 2021 Feb 9]
Available:<https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-019-0418-5>
 9. Jr, BFP, Federico R Tewes. What attorneys should understand about medicare set-aside allocations: How medicare set-aside allocation is going to be used to accelerate settlement claims in catastrophic personal injury cases. *Clinical Medicine and Medical Research*. 2021;2(1):61-64.
Available:<https://doi.org/10.52845/CMMR/2021v1i1a1>
 10. Dosani N, Bhargava R, Arya A, Pang C, Tut P, Sharma A, et al. Perceptions of palliative care in a South Asian community: Findings from an observational study. *BMC Palliat Care* [Internet]. 2020;19(1):141.
[Cited 2021 Feb 9]
Available:<https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-020-00646-6>
 11. Gómez-Batiste X, Murray SA, Thomas K, Blay C, Boyd K, Moine S, et al. Comprehensive and integrated palliative care for people with advanced chronic conditions: An update from several european initiatives and recommendations for policy. *Journal of Pain and Symptom Management* [Internet]. 2017;53(3):509–17.
[Cited 2021 Feb 9]
Available:<https://linkinghub.elsevier.com/retrieve/pii/S0885392416312039>
 12. Daniel V, Daniel K. Diabetic neuropathy: New perspectives on early diagnosis and treatments. *Journal of Current Diabetes Reports*. 2020;1(1):12–14.
Available:<https://doi.org/10.52845/JCDR/2020v1i1a3>
 13. Khosla D, Patel FD, Sharma SC. Palliative care in India: Current progress and future needs. *Indian J Palliative Care*. 2012;18(3):149–154.
Available:<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3573467/>
 14. *BMC Palliative Care* | Articles [Internet]; 2020.
Available:<https://bmcpalliatcare.biomedcentral.com/articles>
 15. Joseph MB, Pohekar S, Raut A, Patil M. The palliative care and COVID-19 pandemic. *International Journal of Research in Pharmaceutical Sciences*. 2020;11(Special Issue 1): 618–22.
Available:<https://doi.org/10.26452/ijrps.v11i1SPL1.2861>
 16. Taksande AM, Injeti G, Joshi M, Meshram R. Chylothorax in a young child after a palliative cardiac surgery. *International Journal of Academic Medicine*. 2020;6(4):320–23.
Available:https://doi.org/10.4103/IJAM.IJAM_90_20
 17. Daniel V, Daniel K. Perception of nurses' work in psychiatric clinic. *Clinical Medicine Insights*. 2020;1(1):27-33.
Available:<https://doi.org/10.52845/CMI/2020v1i1a5>
 18. Dhande N, Kumar S, Bolane A. Assessment of psychosocial distress among the palliative care patients in Wardha district of Maharashtra. *Indian Journal of Palliative Care*. 2020;26(3):302–5.
Available:https://doi.org/10.4103/IJPC.IJPC_114_19
 19. Tendolkar VD, Behere P, Quazi Z, Gaidhane A. Heterogeneous group discussion to improve reliability and validity of data tool: A global mental health assessment tool – primary care version study. *Journal of Datta Meghe Institute of Medical Sciences University*. 2017;12(1):45–50.
Available:https://doi.org/10.4103/jdmimsu.jdmimsu_22_17
 20. Quazi Z, Gaidhane A, Das A, Hagopian A, House P. Emergency obstetrics care preparedness in rural hospitals. *Journal of*

- Datta Meghe Institute of Medical Sciences University. 2013;8(2):85–90.
21. Gaidhane S, Khatib N, Zahiruddin QS, Gaidhane A, Kukade S, Zodpey S. Perceptions of primary care doctors towards type 2 diabetes mellitus and challenges for care at primary care level in India. *International Journal of Diabetes in Developing Countries*. 2015;35(1): 14–18.
Available:<https://doi.org/10.1007/s13410-014-0199-6>

© 2021 Khan and Dhande; This is an Open Access article distributed under the terms of the Creative Commons Attribution License (<http://creativecommons.org/licenses/by/4.0>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

Peer-review history:
The peer review history for this paper can be accessed here:
<https://www.sdiarticle4.com/review-history/71218>