

Morbidity and Mortality Profile of Patients Receiving Palliative Care at a Tertiary Care Centre in Central India: A Descriptive StudyDhirendra Nath Majhi¹, Rajeev Ranjan², Pankaj P Rao³, Dharmesh⁴, Maninder Pal Singh Pardal⁵¹ Assistant Professor, Dept. of Medicine, Armed Forces Medical Services,² Associate Professor, Dept. of Medicine & Neurology, Armed Forces Medical Services³ Professor, Dept. of Surgery & GI Surgery, Armed Forces Medical Services⁴ Professor, Dept. of Medicine & Oncology, Armed Forces Medical Services⁵ Professor, Dept. of Community Medicine, Armed Forces Medical Services

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Abstract:

Introduction: Palliative care provides comprehensive support for several dimensions of physical, mental, social, emotional and spiritual care needs experienced by patients who live with terminal illnesses. An interdisciplinary professional team supports the broad needs of patients and their care partners and helps them to cope with living with their life limiting illness (es) while proactively planning for the end of life.

Aims and Objectives: 1. To understand and analyse the morbidity, mortality and symptom profiles of a cohort of patients with life-limiting disease and receiving palliative care 2. To determine the prevalence of death within palliative care of those patients receiving palliative care.

Materials and Methods: Our study is a descriptive exploratory secondary analysis of a patient dataset, wherein we proceeded in accordance with the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) checklist. The study was conducted from 01 Jan 2022 to 31 Aug 2024. Standard management protocol was followed for management of the cases. Data collection was carried out prospectively by means of a pilot research study. The pilot research study followed a community-based participatory research methodology. We carried out a descriptive analysis of the results to estimate the proportion of individuals who passed away during the period of the study while receiving palliative care, or sought palliative care in their last 4 weeks of life. Study participants were grouped by way of symptomatology/organ/system.

Results: Our analysis includes 134 study participants from a palliative care centre of a large tertiary care hospital. The study participants comprised of 71 (52.99%) males and 63 (47.01%) females respectively. Mean age of the study participants was 58.05 years (SD 14.85) and median age was 60 years. Mean duration of hospitalisation was 50.55 days (SD 90.06) with a median of 24.5 days. Mean duration of stay in palliative care was 38.29 days (SD 89.22) with a median of 15.5 days. Overall, there were 5131 patient days of stay in palliative care; and 6774 patient days of hospitalisation. From our study sample of 134 study participants, 2 (1.49%) one male and one female died under palliative care.

Keywords: Palliative care, Cerebrovascular accident, Human immunodeficiency virus, Acquired immune deficiency syndrome, Malignancy.

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Introduction

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”. [1]

Palliative care is the active holistic care of people and their families experiencing suffering because of

serious illness, especially near the end of life. It focuses on the prevention, early identification, assessment, and management of physical issues, including pain and other distressing symptoms, psychological distress, spiritual distress, and social needs. [2] Palliative care provides comprehensive support for several dimensions of physical, mental, social, emotional and spiritual care needs experienced by patients who live with terminal illnesses. An interdisciplinary professional team supports the broad needs of patients and their care

partners and helps them to cope with living with their life limiting illness (es) while proactively planning for the end of life. [3]

The proportion of older people is growing due to rising life expectancy and declining fertility rates, ageing is often accompanied by various health conditions such as cardiovascular disease, osteoporosis, diabetes, dementia, cognitive impairment, comorbidities, decreased mobility, and autonomy. Older adults may also experience social changes due to the loss of roles both in the domestic environment as well as in the society. Social isolation and loneliness, due to reduced environmental stimulation further contributes to mental health issues or a perceived decline in health. Thus a significant economic burden and social challenges, including concerning palliative and end-of-life care are imposed on the health care infrastructure on account of this pronounced population ageing. [4]

In the recent past there has been an increase in research concentrating on palliative care [5]. Early provision of specialist palliative care for patients with advanced disease has a strong correlation with a better quality of life. [6,7,8]

In the year 2020, barely 12% of the 56.8 million people in need of palliative care worldwide received it, while the corresponding figure for Africa was less than 5%. Low- and middle-income countries account for 76% of the global need in palliative care. [9,10] Good quality data has a direct impact on palliative care, as it is a major factor which influences decision making by government and various stake holders. [9]

After extensive search and review of existing literature, we observed that there is paucity of studies focusing on palliative care and morbidity and mortality profile of patients receiving palliative care in the Indian subcontinent.

Hence, with an aim to identify and fill in the gaps in the knowledge, we proceeded to carry out this novel study and describe key elements of morbidity and mortality profile of patients receiving palliative care in our setup.

Aims and Objectives

Objectives:

1. To understand and analyse the morbidity, mortality and symptom profiles of a cohort of patients with life-limiting disease and receiving palliative care
2. To determine the prevalence of death within palliative care of those patients receiving palliative care.

Methods

General settings and study design: Our study is a descriptive exploratory secondary analysis of a patient dataset, wherein we proceeded in accordance with the Strengthening of Reporting of Observational Studies in Epidemiology (STROBE) checklist. [11]

Definition of various terms used in the study:

Prevalence of Death in Palliative Care: All participants who passed away in a hospital in the palliative care unit, in an assisted living facility or a continuing care unit, or a palliative care unit were coded as having died in palliative care.

Sociodemographic Variables:

“Gender” was a dichotomous variable with “Male” and “Female” as possible responses.

“Age” was derived from the participant’s year of birth. It was recorded into different age classes: “0 - 9 years, 10 - 19 years, 20 - 29 years, 30 - 39 years, 40 - 49 years, 50 - 59 years, 60 - 69 years, 70 - 79 years, 80 - 89 years and 90 - 99 years.

“Marital Status”, initially with four possible responses, was recorded into “Divorced/Legally separated” “Single”, “Married”, and “Widowed”.

Socioeconomic status and educational status of the study participants was classified as per modified Kuppaswamy scale. This methodology of classification of educational status has already been validated by Nimonkar et al in their study in 2024. [12]

These definitions have already been validated by several researchers in the past. [4]

Provision of palliative care: Standard management protocol for provision of palliative care was followed for all cases in our palliative care centre during the study period. [13,14]

Data collection: The study was conducted from 01 Jan 2022 to 31 Aug 2024. Data collection was carried out prospectively by means of a pilot research study. The pilot research study followed a community-based participatory research methodology. [15]

Individual, semi structured interviews on or after enrollment were taken. The focus was on demographic profile, clinical data including primary diagnosis, comorbidities and participants’ symptoms to determine their morbidity profile. The length of the interview varied from 10 to 30 minutes. A few follow up interviews were undertaken in required cases due to patient frailty or personal preferences.

Healthcare professional focus groups were conducted with participants from each area

involved in the study. Duration of these focus groups ranged from 30 to 40 min in length, with an average duration of around 36 min. All interviews and focus groups were digitally recorded and transcribed verbatim. Interviews and focus groups were conducted by one author. In order to facilitate accurate recording of the focus groups, an additional member of our research team carried out the onerous responsibility of note taking. Electronic medical records were also perused; and emergency room visits and location of death were also recorded. Information regarding emergency room visits by each participant in the 12 months preceding before enrollment in our study was also recorded. Termination of the study, or death of a patient were the two endpoints either of which were sufficient to define end of the patient participation in the study. This methodology of data collection has already been validated by several researchers in the past.^{5, 16}

Data Analysis: We carried out a descriptive analysis of the results to estimate the proportion of individuals who passed away during the period of the study while receiving palliative care, or sought palliative care in their last 4 weeks of life. The prevalence was standardized by age and gender of death in palliative care, 95% confidence intervals (95% CI), were also estimated; and all results were standardized using demographics of India. [17,18] Methodology of indirect age standardization as described by K Park was used and the standardized mortality ratio was calculated. [19]

Study participants were grouped by way of symptomatology/organ/system. Cases of cerebrovascular accident (irrespective of the cause and location of ischaemia/haemorrhage), head injury, sub dural haematoma, encephalitis, encephalopathy, hypoxic encephalopathy, Guillan Barre syndrome, meningitis, transverse myelitis, astrocytoma, neuroblastoma were grouped under

the organ/system "CNS". Cases of carcinoma oral cavity, metastatic cholangiocarcinoma, multiple myeloma, hepatocellular carcinoma, carcinoma rectum were grouped under the heading "malignancy". Cases of pneumonia, COPD, aspiration pneumonitis were grouped under the "respiratory system". Cases of septic shock, inflammatory polyarthritis and immune surveillance were grouped under the heading "systemic". Cases of rheumatic heart disease, atrial fibrillation etc were grouped under the heading "cardiac".

Ethics Approval and Consent of Respondents:

The research protocol, questionnaire, consent statement, and procedures of obtaining informed consent were approved by the Institutional Research Ethics Committee. Respondents were informed in the local language about their rights to voluntary participate; and to withdraw from the interview at any point of time. The consent form documented the aims, nature, and procedure of the study. Participation of all study subjects was totally voluntary with full written, and verbal, informed consent. Respondents were assured of the anonymity and confidentiality of the data they provided.

Anonymity and confidentiality were strictly maintained. The study follows the ethical guidelines of the 1975 Declaration of Helsinki. [20]

Results

Sociodemographic profile of study participants:

Our analysis includes 134 study participants from a palliative care centre of a large tertiary care hospital. The sociodemographic profile of the study participants is presented in table 1. The study participants comprised of 71 (52.99%) males and 63 (47.01%) females respectively. Mean age of the study participants was 58.05 years (SD 14.85) and median age was 60 years.

Table 1: Demographic profile of the study participants

Gender	Number (%)
Male	071 (52.99)
Female	063 (47.01)
Total (%)	134 (100)
Age group (yrs)	
0 - 9	001 (000.75)
10 - 19	001 (000.75)
20 - 29	005 (003.73)
30 - 39	008 (005.97)
40 - 49	016 (011.94)
50 - 59	035 (026.11)
60 - 69	042 (031.34)
70 - 79	022 (016.42)
80 - 89	003 (002.24)
90 - 99	001 (000.75)
Total (%)	134 (100)
Marital status	

Single	009 (006.72)
Married	119 (088.81)
Divorced/Legally separated	001 (000.75)
Widow/Widower	005 (003.72)
Total (%)	134 (100)
Socioeconomic status	
Upper (I)	004 (002.99)
Upper middle (II)	006 (004.48)
Lower middle (III)	026 (019.40)
Upper lower (IV)	095 (070.90)
Lower (V)	003 (02.23)
Total (%)	134 (100)
Social background	
Urban	016 (011.94)
Rural	118 (088.06)
Total (%)	134 (100)
Educational status	
Professional degree	000 (000.00)
Graduate	005 (003.73)
Intermediate/diploma	044 (032.84)
High school	057 (042.54)
Middle school	000 (000.00)
Primary school	024 (017.91)
Illiterate	004 (002.99)
Total (%)	134 (100)

Clinical profile of study participants: Mean duration of hospitalisation was 50.55 days (SD 90.06) with a median of 24.5 days. Mean duration of stay in palliative care was 38.29 days (SD 89.22) with a median of 15.5 days. Overall, there were 5131 patient days of stay in palliative care; and 6774 patient days of hospitalisation. Out of 134 study participants, 01 (0.75%) was transferred to ICU for management of some complication, 124 (92.54%) were discharged, and 7 (5.22%) were still in hospital as on the date the data collection was

concluded. One female patient had rheumatic heart disease with severe mitral regurgitation; and carcinoma oral cavity. This patient had one spell of hospitalisation for both the illnesses; and another spell of hospitalisation for rheumatic heart disease with severe mitral regurgitation. Both the illnesses and both spells of hospitalisation were taken into account for data collection and data analysis in respect of this patient. Sex and symptomatology/organ/system distribution of the study participants is presented in table 2.

Table 2: Sex and symptomatology/organ/system distribution of the study participants

Age group (yrs)	CNS (%)	Malignancy (%)	Respiratory (%)	Cardiac (%)	Systemic (%)	Total (%)
Sex						
Male	052 (73.24)	010 (14.08)	003 (04.23)	003 (04.23)	003 (04.23)	071 (100)
Female	046 (73.02)	008 (12.70)	002 (03.17)	003 (04.76)	004 (06.35)	063 (100)
Total	108 (73.13)	018 (13.43)	005 (03.73)	006 (04.48)	007 (05.22)	134 (100)

Note: In the first two rows the percentage has been calculated out of total male and total female study participant's i.e 71 and 63 respectively. In the last row the percentage has been calculated out of total study participant's i.e 134.

Death in palliative care: From our study sample of 134 study participants, 2 (1.49%) one male and one female died under palliative care. Both the deaths in our study occurred in CNS cases, out of which one case was Road traffic accident with head injury, while the other death was in a case of Cerebrovascular accident. Thus palliative care

mortality rate was 0% in malignancy, respiratory, cardiac and systemic causes. The mortality rate observed in women was marginally higher than in men (01.59% vs. 01.41%). Age of the male was 75 years, while age of the female was 49 years. The age specific death rate for males was 5.26% and for females it was 14.29%. After indirect standardization the age specific death rate i.e the standardized mortality ratio was 0.11% and 2.07%. Mean age of death was 62 years. The prevalence of death in palliative care by symptomatology/organ/system and sex of the study participants is tabulated in table 3.

Table 3: Prevalence of death in palliative care by symptomatology/organ/system

Age group (yrs)	CNS (%)	Malignancy (%)	Respiratory (%)	Cardiac (%)	Systemic (%)	Total (%)
Sex						
Male	01 (01.92)	00 (00.00)	00 (00.00)	00 (00.00)	00 (00.00)	01 (01.41)
Female	01 (02.17)	00 (00.00)	00 (00.00)	00 (00.00)	00 (00.00)	01 (01.59)
Total	02 (1.49)	00 (00.00)	00 (00.00)	00 (00.00)	00 (00.00)	02 (1.49)

Note: In the first two rows of each column the percentage has been calculated out of total male and total female study participants of the respective symptomatology/organ/system. In the last row the percentage has been calculated out of total study participant's i.e 134

Discussion

Our study consisted of 134 study participants with a life limiting illness, undergoing palliative care. The mean age of enrolment of the study participants in our study was 58 years; and median age was 60 years. This is similar to the study carried out by Moore H et al and Schneider E et al. [5,21]

The mean age at death of our study participant's i.e 62 is well below the 2017 average life expectancy of India of 69 years. [22] It is also well below the worldwide average life expectancy of 73.3 years. [23] The hospital death rate in this study was only 1.49%, which is much higher than the crude population death rates (0.63%) of India.20 However, the death rate in our study was much lower than the 3.44% hospital mortality rate reported by Godale L et al and the 70% mortality rate reported by Temel et al in their respective studies. [24,25]

The mortality rate of 1.49% observed in our study is also in stark contrast to the 55.8% mortality reported by Quinn et al in their study in the year 2020. [2]

Consultations provided by all palliative care professionals also involved advising social service professionals. Advice rendered by social service professionals covered somatic as well as psychosocial aspects. Palliative care and social service professionals also perceived an added value of the intervention on collaboration, competency, quality and timing of palliative care.

Palliative care has its origins in end-of-life care for patients with terminal illnesses, as reflected in the WHO technical report series of 1990. [24] In the present era, much has changed in favor of patients. Today, palliative care is understood as an integrated service which works in conjunction with various other medical specialities, improves the quality of life; and mitigates symptom burden regardless of prognosis in case of any life-threatening disease. [26] By systematic and early integration of palliative care several beneficial effects have been observed, viz, reduction of

symptom burden and depression, improvement of quality of life, satisfaction of next-of-kin, and better likelihood of survival in patients with terminal illnesses. [24,26]

In our observational study, provision of palliative care appears to have a beneficial effect on symptoms, besides a positive effect on the quality of life of patients admitted in the palliative care centre. Extremely low mortality in our palliative care centre can be attributed to the high standard of management and care provided to all the patients by our qualified, dedicated, and professionally competent staff, as per standard management protocol.

To our knowledge, our study is one of the pioneering study in exploring the overall situation of hospital based palliative care in the Indian subcontinent.

Conclusion, recommendations, limitations and strengths

Our study provides a valuable insight into the palliative care services in a large tertiary care hospital, the morbidity and mortality profile of patients in the palliative care centre. It also provides a deeper look at the demographic profile of patients in the palliative care centre. Our study also explored the status of palliative care, morbidity and mortality profile of patients and challenges involved in a palliative care centre in a large tertiary care hospital.

The findings of our study demonstrate that a model of early and systematic integration of palliative care with clinical management augments the quality of life of patients with terminal illnesses. Through integration of care, clinicians and specialised palliative care personnel should team together to improve the quality of life of patients with terminal illnesses.

Shared decision making needs careful consideration of patient's values and beliefs. Clinicians and palliative care specialists need to be honest, yet compassionate, about likely outcomes, and patients and families need considerable support to be involved in decision making. Closer working between clinicians and palliative care clinicians will go a long way in facilitating better sharing of ideas and knowledge, and help ensure that the palliative care needs of patients are adequately met.

Patients, caregivers, and healthcare systems struggle with the growing burden of medical complexity that is associated with poor quality of life and enormous healthcare expenditure. End-of-life care that involves hospital admission and intensive care unit admission is costly and poses a tremendous burden on the patients and their families. Our study supports the role palliative care has in providing high value end-of-life care to people dying from various terminal illnesses.

For patients approaching the end of life, hospice may be a viable option to provide symptom care and supportive services for patients and their families while promoting patients' ability to die in their preferred environment. Palliative care should not be as an alternative to offering life-sustaining therapies or other evidence based treatment for patients suffering from various terminal illnesses, but as an important supplement that can enhance care delivery for patients, their families, and providers alike.

There is a pressing need to engage patients in need of palliative care as partners in research to co-design services that recognize who they are at every moment. Further research would be helpful to explore patient characteristics and symptom burden in other locations.

Patients with life limiting terminal illnesses in need of palliative care in different stages of disease progression may have different needs regarding the structure and process of care. The specific needs of patients in different stages of disease progression could be further explored by carrying out more research regarding this aspect of palliative care. Further studies in larger populations, with particular attention to selection of the optimal scales to assess symptom control and the quality of end of life care in patients with life limiting terminal illnesses are warranted.

Financial and technical support at the local, regional and national levels for investment in the structural components of care is of prime importance to improve the quality of palliative care and quality of life of the patients.

One limitation of our study worth mentioning is that our study was conducted at a single, tertiary care site with a specialized group of specialists, super specialists and palliative care providers. Thus, the generalization of the results to other settings with other types of patients in need of palliative care is limited. Besides, our study sample lacked diversity with respect to race and ethnic group. Hence, we were unable to assess the effect of these important factors on study outcomes. The setting of our study is limited to institutional care, which mostly involves patients approaching the end of life. Secondly, our study reported only descriptive data were reported; and hence, the

results of our study should be seen as informative rather than definitive.

Our study is also limited by the lack of information on patient and caregiver preferences for care. We believe that these inputs are vital for providing high quality, patient goal directed palliative care. We assumed that patients received palliative care for issues related to their symptomatology.

Another limitation of our study was that the ability to provide consent was a requirement for study inclusion. This may have led to selection of a study group with higher performance status due to the exclusion of those patients who are too unwell to give their consent to participate in the study. Besides, individual palliative care needs or specific palliative therapies were not measured among patients in our study. A final limitation of our study is the self-reporting nature of the questionnaire. This may be a potential cause for reporting bias and human errors.

A strength of our study was that we followed a recruitment approach designed to obtain a representative sample of our study participants. The low rate of loss to follow-up and the high percentage of participants who completed the study was another strength of our study.

Our descriptive exploratory analysis is based on data prospectively collected through a pilot research study involving a population experiencing the need for palliative care on account of life limiting illness. Our study was able to provide novel insight into the symptomatology of patients in need of palliative care. The findings of our study support the call for radical health system changes to address the needs of those in need of palliative care.

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