

# Need of Palliative Care Services in Rural Area of Northern India

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## Abstract

**Background:** Palliative care is comprehensive care that provides symptomatic relief and enhances the quality of life for people experiencing serious health-related suffering. There is an increasing need for palliative care services in India. Estimates for population requiring these services are essential in order to meet the increasing need for palliative care services. **Objectives:** The objective was to assess the proportion of population requiring and receiving palliative care services. **Materials and Methods:** A descriptive cross-sectional research design was adopted for the study. The study was carried out in the village, Dhanas, Chandigarh. All the residents residing in the selected rural area were included in the study. Tools used for data collection were a screening questionnaire consisting of three questions, a sociodemographic sheet, a clinical profile, the Barthel Index of activities of daily living (ADL), and a pain rating scale. Analysis of the data was done using SPSS version 19 (IBM SPSS Statistics for Windows, Version 19.0.: IBM Corp). **Results:** A total of 10,021 people from 884 households were screened in the study. The results revealed that the prevalence of need for palliative care services was 2/1000 population. None of the 19 participants with unmet palliative care needs were receiving any home- or institutional-based palliative care services at the time of assessment. Nearly, one-fourth of the participants had total dependency on caregivers for ADL. **Conclusion:** The study concluded that there is a need of palliative care services in the studied rural community of Chandigarh. These data can be used for planning and implementing community-based palliative care services in the studied area.

**Keywords:** Activities of daily living, palliative care needs assessment, palliative care services

## INTRODUCTION

Palliative care is provided to people who suffer from the serious health-related suffering (SHS).<sup>[1]</sup> The World Health Organization (WHO) defines “palliative care as the prevention and relief of suffering of adult and pediatric patients and their families facing the problems associated with life-threatening illness.”<sup>[2]</sup> These problems include the physical, psychological, social, and spiritual suffering of patients and their families. The main focus of the palliative care is symptomatic management and improving quality of life by promoting physical, psychosocial, and spiritual well-being.<sup>[3]</sup> The need of palliative care services is increasing globally.<sup>[4]</sup> The increase in the number of elderly in the population and the prevalence of noncommunicable diseases (NCDs) are the major contributing factors. NCDs are a major cause of mortality worldwide.<sup>[5]</sup> In 2012, globally, there were 68% deaths due to NCDs, principally cardiovascular diseases (46.2%), cancer (21.7%) and chronic respiratory diseases (10.7%), and diabetes (4%).<sup>[6]</sup> In 2010, cancers and circulatory diseases together accounted for 19% of global disability-adjusted life years.<sup>[2]</sup>

In India, NCDs contributed 63% of the total mortality in 2016.<sup>[7]</sup> In the census report, the proportion of the elderly has also increased from 7% in 2001 to 7.5% in 2011.<sup>[8]</sup> Cancer has become a common terminal illness. In India, one million new cases are estimated to occur every year, and about 80% are Stage 3 and Stage 4. Therefore, there is an increasing need for palliative care services for providing end-of-life care to the individuals suffering from life-threatening diseases.<sup>[9]</sup> The provision and integration of these services is essential to achieve the sustainable development goal on universal health coverage.

Although few studies related to the assessment of need for palliative care services have been done in India,<sup>[10,11]</sup> we could

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not find any study from North India. Hence, the need was felt to estimate the number of people in need of palliative care services in the studied community. Thus, the study was conducted to identify the need of palliative care services for the purposes of planning and development for this emerging and urgent need.

## MATERIALS AND METHODS

A descriptive cross-sectional research design was used for the study. The study was carried out in Dhanas village, Chandigarh (UT). A total of 10,021 people from 884 households residing in that area were assessed for a need of palliative care services. A survey was conducted on the entire population of the village Dhanas. The selection of the village was done by purposive sampling as it is the field practice area of the investigators. House-to-house survey was conducted to collect data. Data collection was done in the month of March 2019. The study respondents were the household members available during the time of data collection. These respondents were interviewed related to the need for palliative care among their family members. The assessment of need of palliative care was done using three criteria: (1) person having terminal illness with no curative treatment available, (2) not able to do activities of daily living (ADL), and (3) probable death within next 12 months. Participants fulfilling any of the above criteria were considered to be in need of palliative care and further assessed for ADL using the Barthel Index of daily living tool<sup>[12]</sup> and for pain using the Wong–Baker pain rating scale.<sup>[13]</sup>

Ethical clearance was sought from the Ethics Committee of National Institute of Nursing Education, PGIMER, Chandigarh. Written informed consent was obtained from participants, and they were assured of confidentiality.

## RESULTS

The total population assessed was 10,021, out of which 19 participants were in the need of palliative care services. The prevalence of palliative care need in the present study was 2/1000 population.

Sociodemographic profile of 19 participants in need for palliative care services revealed that the mean age of the participants was 50 ( $\pm 25.95$ ) years, the median age was 56 years, and the interquartile range was 37. Majority (73.6%) of the participants were male. Nearly, two-third (68.4%) were Hindus, 42.1% were illiterate, and majority (89.1%) were unemployed [Table 1].

The functional ability assessment was done using the Barthel Index of ADL. The study revealed that 26.3% of the participants had total dependency on caregivers for ADL, 47.3% had severe dependency, and 26.3% had moderate dependency levels [Table 2].

Pain assessment of the participants revealed that 42% had the minimum pain score of 0–2. However, 15.7%, 31.5%, and 10.5% of the participants were in the pain score range of 3–4, 5–6, and 7–8, respectively. None of the 19 participants

**Table 1: Sociodemographic data of the participants that need palliative care (n=19)**

	n (%)
Age	
0-20	3 (15.7)
21-40	4 (21.0)
41-60	5 (26.3)
61-80	4 (21.0)
81-100	3 (15.7)
Sex	
Male	14 (73.6)
Female	05 (26.3)
Religion	
Hindus	13 (68.4)
Sikhs	2 (10.5)
Muslims	4 (21.2)
Education	
Illiterate	8 (42.1)
Just literate	1 (5.3)
Primary education	6 (31.6)
Middle education	1 (5.3)
Matric education	1 (5.3)
Secondary education	1 (5.3)
Postgraduation	1 (5.3)
Occupation	
Homemaker	2 (10.5)
Unemployed	17 (89.5)
Marital status	
Married	9 (47.4)
Single	5 (26.3)
Widow/widower	5 (26.3)
Family type	
Joint	9 (47.4)
Nuclear	10 (52.6)

**Table 2: Dependency level as per the Barthel Index**

Score	Dependency level	n (%)
0-20	Total dependency	5 (26.3)
21-60	Severe dependency	9 (47.3)
61-90	Moderate dependency	5 (26.3)
91-99	Slight dependency	0 (0)
100	Complete independence	0 (0)

had the highest pain score of 9–10 on the numerical pain rating scale. The most common disease conditions among participants needing palliative care were age-related frailty, end-stage renal disease, mental retardation, and senile dementia.

## DISCUSSION

Palliative care is the comprehensive care given to people suffering from the terminal illnesses. In India, there is a growing need of palliative care among people because of the increasing elderly population and high burden of NCDs.

Although the palliative care was started largely for advanced cancer patients, the scope had broadened to include other SHSs. The WHO, in their definition of the palliative care have use the term any life threatening illness rather than specifying any disease condition. In the present study, the need for palliative care was assessed, keeping in mind all the SHSs, and included all the age groups.

The prevalence of need of palliative care services in the present population was found to be 2 per 1000 population. A community-based study conducted by Daya *et al.*<sup>[14]</sup> found the prevalence of 6.1 per 1000 urban population in Puducherry, for people in need of palliative care. Another study conducted by Elayaperumal *et al.*<sup>[11]</sup> reported the prevalence of 4.5 per 1000 population in Tamil Nadu. The prevalence rates of both these studies were higher than those found in our present study. The difference could be because of various factors such as geographical location, availability of health-care services, health care-seeking behavior, and the reliability of the interviewed household member to identify palliative care needs in the home.

According to the Global Atlas of Palliative Care, 69% of people in need of palliative care are over 60-year-old. However, in the present study, only 36.7% of the participants in need of palliative care were elderly (aged > 60 years). The reason could also be attributed to the fact that the various NCDs occur at a lower age in low- and middle-income countries as compared to the rest of the world.<sup>[15]</sup>

The strength of the present study is that it was a community-based survey intensively done in a selected geographical area. However, the study also had certain limitations, i.e., small sample size and during the screening process, one member of the household was interviewed to obtain information about the need of palliative care services among the family members, as it was difficult to interview each and every member.

## CONCLUSION

The study concluded that there is a need for palliative care services in the community setting of Dhanas, Chandigarh. There are no home- or institutional-based palliative care services available for population in the studied area. In conjunction with other community-based surveys, the amount of staffing needed to serve the population needing palliative care services will be better planned. The study also has implications for community health workers and Accredited Social health activist who can do the assessment of palliative care needs using the simple tool used in the study.

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## Conflicts of interest

There are no conflicts of interest.

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