

# Identifying People in Need of Palliative Care Services in Rural Tamil Nadu: A Survey

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## Abstract

**Background:** As a part of initiating community-based palliative care program in the field practice areas of Urban Health Training Centre (UHTC), Villupuram, it was necessary for us to identify people who need palliative care to plan our services. **Aim:** This study aims to assess the need for palliative care and its determinants in the villages under the UHTC, Villupuram, and to know their sociodemographic characteristics and morbidity profile. **Materials and Methods:** A community-based cross-sectional survey was conducted in the four villages under UHTC between April and September 2016. A house-to-house survey was conducted by a trained team using a structured questionnaire. The available member of the households was interviewed about the need for palliative care and the morbidity profile among all the members of their household. Written informed consent was obtained before the interview. Data were entered and analyzed using EpiInfo (version 7.2.2.6) software. Prevalence ratio, age- and gender-wise prevalence of people in need of palliative care was calculated. **Results:** The overall prevalence of people in need of palliative care was found to be 4.5/1000 population (95% confidence interval: 3.2–6.3). Among them, 73.5% were elderly people. The most common condition requiring palliative care was old age-related weakness (41.2%). **Conclusion:** The need for palliative care services among elderly people was found to be high. This data can be used for planning and implementing community-based palliative care services for the people in our field practice areas.

**Keywords:** Criteria, health services need, home care services, palliative care, selection

## INTRODUCTION

Palliative care is defined as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illnesses, through the prevention and relief of suffering by means of early identification, impeccable assessment, and treatment of pain and other problems, physical, psychosocial, and spiritual.”<sup>[1]</sup> In India, there is a growing need for palliative care among people due to reasons such as increasing number of old people<sup>[2]</sup> and increased burden of Non Communicable Diseases.<sup>[3]</sup> According to the Global Atlas of Palliative care, 22% adults and 24% children need palliative care at the end of life in the South East Asian region.<sup>[4]</sup> It is estimated that <2% of patients in need of palliative care in the country receive it and 90% of all palliative care services in the country are available in the state of Kerala.<sup>[5]</sup> In Tamil Nadu and Puducherry, there are limited palliative care services available in the public sector for the people suffering from chronic incurable illness. An expert team from Institute of Palliative Medicine (IPM), Kerala was

involved in a movement of establishing palliative care services in the state of Puducherry and Tamil Nadu. In response to the movement, we joined the team to establish palliative care service in our field practice areas in rural Tamil Nadu.

The Department of Community Medicine at Sri Manakula Vinayagar Medical College and Hospital, Puducherry, has been running Pain and Palliative care Clinic in collaboration with the Department of Anaesthesia for the last two years by four faculty trained at IPM. We planned to expand our services to the community by initiating community-based palliative care program in the four villages under Urban Health Training Centre (UHTC), Villupuram to reach the needy people. However, the information regarding the proportion of people

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who need palliative care services was limited in the states of Tamil Nadu and Puducherry. The present survey was done to assess the need for palliative care and its determinants in the villages under the UHTC, Villupuram and to know their sociodemographic characteristics and morbidity profile.

## MATERIALS AND METHODS

### Study setting and design

This was a community-based cross-sectional study conducted in the four villages which form the field practice areas of UHTC at Villupuram district in Tamil Nadu. It functions as a peripheral health center under the Department of Community Medicine, Sri Manakula Vinayagar Medical College and Hospital, Puducherry. The total population served is 16,312 with 4070 households. The services provided at UHTC include outpatient care, mobile health clinics, basic laboratory services, and school health education programs apart from training medical interns and postgraduates.

### Study participants

The study participants were the household members available during the time of our visit to the villages and they were mostly the homemakers. We included the participants who consented to take part in the survey.

### Sample size and study duration

Out of the total 4070 households, we were able to cover 1518 households which included details about 7493 individuals. The period of data collection was from April to September 2016.

### Data collection

A pilot-tested structured questionnaire was used to collect data from the respondents in the household. Information on sociodemographic details, need for palliative care among the household members using three criteria and their morbidity profile were collected. The three criteria used to identify the need for palliative care were, in the last 6 months, whether the individual is bedridden or whether the individual is dependent on others for his/her activities of daily living (ADL)<sup>[6]</sup> or whether the individual is not able to go for work due to chronic illness. The morbidities included were any chronic incurable illness as well as debilitating old age for more than last 6 months' duration. We followed the steps given by the World Health Organization for setting up of a new community-based palliative care service.<sup>[7]</sup> As a first step, we had an awareness meeting and discussion with people who are likely to be interested in helping in the four villages. After getting their support, we used a structured pre-tested questionnaire for collecting details about number of people who are incurably ill by house-to-house visits. The questionnaire was administered by a trained team of medical social workers, medical interns, nursing students, postgraduates, and faculty from the department. The study respondents were the available member in the households mainly the homemaker and who were willing to participate in the survey. The details about morbidity were confirmed with the medical records if available. The past 6 months from the date of interview was used as a reference

period to calculate the period prevalence. A minimum of three visits were made to houses which were locked during the survey before excluding them from the study.

### Data analysis and interpretation

The data were entered and analyzed using EpiInfo (version 7.2.2.6) software (Developed by Centers for Disease Control and Prevention, U.S. Department of Health and Human Services). Frequencies and percentages were calculated for sociodemographic variables and morbidity profile. Prevalence ratio (PR) for palliative care need and 95% confidence interval (CI) were calculated. Age- and gender-wise prevalence was represented as proportions and 95% CI.

### Ethical issues

Clearance from the Research Committee and Institutional Human Ethics Committee was obtained (Code No: 08/2015). Informed written consent was obtained from the respondents before the interview.

## RESULTS

Majority of the households (65.6%) belonged to nuclear type followed by joint family (30.8%). Around 85.5% of the households were below the poverty line. Around 97.4% of the households were Hindus, 1.7% Christians, and 0.9% Muslims. The age distribution of the total population showed that 71.9% of the individuals were in the age group of 15–59 years followed by 17.1% <15 years and 11% were elderly. The gender distribution of individuals showed that 51% were male and 49% were female.

The results after administering the three criteria to identify people in need of palliative care showed that 22 (64.7%) were bedridden, 11 (32.4%) need help from others to perform their ADL, and 1 (2.9%) was unable to go for work due to chronic incurable illness. A total of 34 people satisfied the criteria to be included in the need of palliative care services [Table 1].

Among the 34 individuals identified to be in the need of palliative care, 73.5% were elderly (60 years or more), 17.7% were in 15–59 years age group and 8.8% were <15 years of age. Overall mean ( $\pm$ standard deviation) age of people in need of palliative care was 65.2 ( $\pm$ 22.8) years. The gender representation showed that 52.9% were female and 47.1% were

**Table 1: Proportion of people in need of palliative care among the population surveyed with respect to their physical condition**

Serial number	Criteria used	Frequency (%)
1	Number of people who are bedridden	22 (64.7)
2	Number of people who need help from others for ADL excluding bedridden people	11 (32.4)
3	Number of people who are unable to go for work due to chronic illness but not bedridden and not dependent on others for ADL	1 (2.9)
Total		34 (100)

ADL: Activities of daily living

male. Around 85.3% were illiterate and 97.1% were Hindus. Twenty-seven individuals (79.4%) were living in nuclear type

**Table 2: Sociodemographic characteristics of people in need of palliative care (n=34)**

Variable	Frequency (%)
Age (year)	
<15	3 (8.8)
15-59	6 (17.7)
≥60	25 (73.5)
Gender	
Male	16 (47.1)
Female	18 (52.9)
Education	
Illiterate	29 (85.3)
Literate	5 (14.7)
Religion	
Hindu	33 (97.1)
Muslim	1 (2.9)
Type of family	
Nuclear	27 (79.4)
Joint family	6 (17.7)
Living alone	1 (2.9)
Marital status	
Married	22 (64.7)
Unmarried	3 (8.8)
Widowed	9 (26.5)

**Table 3: Morbidity profile of people in need of palliative care according to gender (n=34)**

Serial number	Disease/condition	Male, n (%)	Female, n (%)	Frequency, n (%)
1	Old age	7 (43.8)	7 (38.9)	14 (41.2)
2	Stroke	4 (25)	3 (16.7)	7 (20.6)
3	Old fracture	2 (12.5)	3 (16.7)	5 (14.8)
4	Mental retardation	1 (6.3)	3 (16.7)	4 (11.8)
5	Heart disease	1 (6.3)	0	1 (2.9)
6	Chronic kidney disease	1 (6.3)	0	1 (2.9)
7	Congenital blindness	0	1 (5.6)	1 (2.9)
8	Diabetic foot	0	1 (5.6)	1 (2.9)
Total		16 (100)	18 (100)	34 (100)

Figures in parentheses are percentages

of family, 6 (17.7%) in joint family and 1 (2.9%) was living alone. Out of the total number of people in need of palliative care, 22 (64.7%) were married, 9 (26.5%) were widowed, and 3 (8.8%) were never married [Table 2].

The morbidity profile of people identified to be in need of palliative care according to gender showed 41.2% of them require palliative care services due to old age-related weakness with slightly greater proportion being males as compared to females (43.8% vs. 38.9%). The other common morbidities seen were paralysis due to stroke (20.6%) and old fractures (14.8%). Mental retardation was present in 5 (11.8%) people, which was more common among female as compared to male (16.7% vs. 6.3%). An equal proportion of people (2.9% each) had heart disease, chronic kidney disease, congenital blindness, and diabetic foot [Table 3].

The overall prevalence of people in need of palliative care was found to be 4.5/1000 population (95% CI: 3.2–6.3). Age-wise prevalence per 1000 population showed that the need among elderly was 30.3 (95% CI: 18.6–42) followed by <15 years (PR: 2.3, 95% CI: 0.6–6.4) and 15–59 years (PR: 1.1, 95% CI: 0.2–2.0). Gender-wise prevalence per 1000 males and females were 4.2 and 4.9, respectively. The need for palliative care services among elderly people was 28 times more (PR: 28, 95% CI: 11.5–68.6) than the individuals in 15–59 years age group. Individuals <15 years age group need palliative care 2.1 times more (PR: 2.1, 0.5–8.5) than the people in 15–59 years age group. Females have 1.2 times higher need of requiring palliative care than their male counterparts (PR: 1.2, 95% CI: 0.6–2.3) [Table 4].

## DISCUSSION

In the present study, the overall prevalence of people identified to be in need of palliative care was 4.5/1000 population (95% CI: 3.2–6.3). Among them, 73.5% were elderly and mean age of people in need of palliative care was 65.2 years (±22.8). The most common condition requiring palliative care was old age-related weakness (41.2%) with a greater proportion being males (43.8%). Our study results found that elderly people need palliative care 28 times more (PR: 28, 95% CI: 11.5–68.6) than the individuals in 15–59 years age group.

**Table 4: Age- and gender-specific prevalence of people in need of palliative care**

Serial number	Variable	Total population, n (%)	Number of people in need of palliative care (in each category)	Prevalence (per 1000)	95% CI*	Prevalence ratio	95% CI*
1	Overall prevalence	7493	34	4.5	3.2-6.3	-	-
2	Age (years)						
	<15	1278	3	2.3	0.6-6.4	2.1	0.5-8.5
	15-59	5390	6	1.1	0.2-2.0	1	-
	≥60	825	25	30.3	18.6-42.0	28	11.5-68.6
3	Gender						
	Male	3819	16	4.2	2.5-6.6	1	-
	Female	3674	18	4.9	3.0-7.6	1.2	0.6-2.3

\*CI: Confidence Interval

A community-based study by Daya *et al.*<sup>[8]</sup> calculated a period prevalence (22/3554) of 6.1/1000 urban population in Puducherry for people in need of palliative care which is higher than the prevalence found in the present study. The reasons could be the differences in the geographical location, availability of health-care services, health-care seeking behavior, and felt needs of the people. Community-based studies done in other countries show a lower prevalence of people requiring palliative and support care at home in primary care setting and the majority being elderly.<sup>[9]</sup> According to the Global Atlas of Palliative care, 69% of people in need of palliative care are over 60 years old.<sup>[4]</sup> These data support the findings of the present study.

A study done in Puducherry found that the mean age of people requiring palliative care was 62 years which is less compared to the present study.<sup>[8]</sup> This variation might be due to the difference in study setting, changing lifestyle contributing to the early onset of risk factors increasing their need for palliative care. Studies done in other regions of the world showed that the most common disease condition requiring palliative care services was old age-related weakness which is similar to the findings of our study.<sup>[8,9]</sup>

The findings of the current study become important in the light of the National Health Policy 2017 which commits itself to culturally appropriate community-centered solutions to meet the health needs of the aging community.<sup>[10]</sup> The policy also recognizes the growing need for palliative and rehabilitative care for all geriatric illnesses and advocates the continuity of care across all levels. Hence, there is a space in the existing health-care system for providing palliative care services for the elderly people as a part of primary care.

The strength of the present study was it being a community-based survey done intensively in a small geographical area. However, self-reporting of chronic illness by the study respondents is a limitation of the study.

## CONCLUSION

Our study reports the prevalence of people in need of palliative care in rural Tamil Nadu as 4.5/1000 population. This data can be used for planning the community-based palliative care services, especially for the elderly population in our service

areas. This region-specific prevalence would give direction to palliative care service providers in designing, planning, and implementation of community-based palliative care services.

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## Conflicts of interest

There are no conflicts of interest.

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