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## Population based need assessment of palliative care in rural Nepal

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### ABSTRACT

**Introductions:** Developing palliative care in rural Nepal is essential to integrate the service into the national health system. This study was done with the aim of assessing the need of patients requiring palliative care in rural Nepal.

**Methods:** This was a cross-sectional population based study in Thaha Municipality using a 30-cluster sampling method and employing the Supportive and Palliative Care Indicators Tool (SPICT) to identify patients with palliative care need. Assessment of symptom burden was done for patients identified to have palliative care need.

**Results:** Out of 330 households with a population of 2168, we found 139 (6.4%) suffering from chronic non-communicable diseases and 66 (3.04%) met the SPICT criteria for palliative care need and 60% were elderly above the age of 60. The disease of respiratory system followed by frailty and dementia were common condition requiring palliative care.

**Conclusions:** This study showed a high level of need for palliative care in a rural population in Nepal. This needs to be considered in further planning of health services in the country.

**Keywords:** need assessment, palliative care, rural, SPICT

## INTRODUCTIONS

Palliative care is “an approach to improve the quality of life of patients and that of families suffering from life limiting illness.”<sup>1</sup> Nepal, as a member state, is amongst the signatories at the World Health Assembly in 2014 of a declaration that committed member states to integrate palliative care into their national health systems.<sup>2</sup> Although there has been some progress in development of palliative care in Nepal, this is limited to urban areas.<sup>3</sup> Of its 27 million population, 80% still live in rural and often inaccessible areas.<sup>4</sup> Developing services to manage non-malignant chronic conditions in rural areas is essential to successfully integrating palliative care into the National Health System.

There is lack of data on assessment of the need of palliative care in rural areas of Nepal. This study was conducted with the aim of assessing the number of patients requiring palliative care, the types of disease and burden of symptoms in a rural population.

## METHODS

This was a cross sectional population based study to identify patients with malignant and non-malignant conditions, living in a rural area, who have palliative care needs. The study was conducted in six Village District Committees (VDCs) of Makwanpur District, which was recently declared as Thaha Municipality by the Government of Nepal. Each VDC is subdivided into wards which consist of several villages. The total population of the municipality is 42,122.<sup>5</sup> Agriculture in this area is the main means of subsistence. This site was selected because it represents a typical rural area in a hilly terrain but in close proximity to Kathmandu, capital of Nepal.

We used a 30-cluster sampling method. This sampling technique has its roots in survey of immunization coverage.<sup>6</sup> The Thaha Municipality was divided into 30 clusters based on population and the wards to be surveyed were identified. The centre of the cluster was located in consultation with the local residents.

A bottle spinning method was used to identify the first house of the cluster. Subsequent houses were sampled based on the closest proximity to the previous house on the right-hand side and 12 households were sampled in each cluster to obtain a total of 360 samples. At each house, the head of the family or a responsible person was interviewed.

The Supportive and Palliative Care Indicators Tool (SPICT)<sup>7</sup> was used to identify patients with palliative care needs and for such patients, symptom burden was assessed. Symptom severity was assessed for pain, shortness of breath and fatigue, common symptoms for people with advanced non-communicable diseases (NCDs). The SPICT includes general indicators of deteriorating health and clinical indicators of one or more specific advanced conditions. It has been used to identify patients with palliative care need for both malignant and non-malignant disease so that physicians can initiate palliative care approach to improve the quality of life.<sup>8</sup> Minor modifications were used to suit the context of rural Nepal. The tool was translated into Nepali and back translated again to English to ensure meaning was not lost. Minor changes were made and field tested by two mid-level health professionals (one, a senior Auxiliary Health Worker and the other, a nurse) who were trained about the details of the SPICT. Both the health workers had been working in this region as community based palliative care professionals following training at Hospice Nepal.

For patients identified to have palliative care needs by SPICT, symptoms were assessed. Scoring of three symptoms - pain, shortness of breath and fatigue was done using the Palliative Care Assessment (PACA)<sup>9</sup> tool, (Table 1). Further demographic details of the responders as well as patients with chronic disease were recorded.

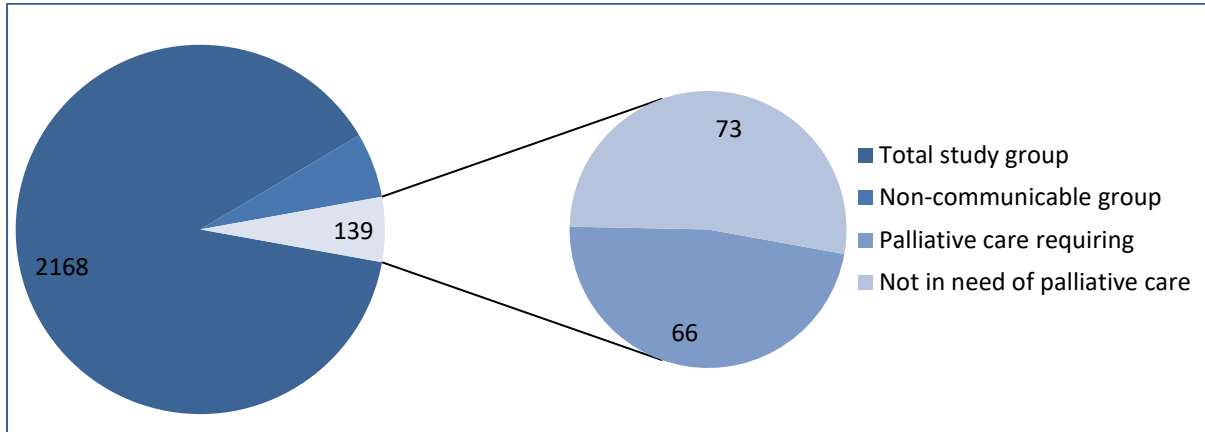
**Table 1. Palliative Care Assessment (PACA)<sup>9</sup> scoring of symptoms**

Score	Meaning
0	No symptom
1	Present but not affecting daily life
2	Moderate effect on daily life
3	Life dominated by symptom

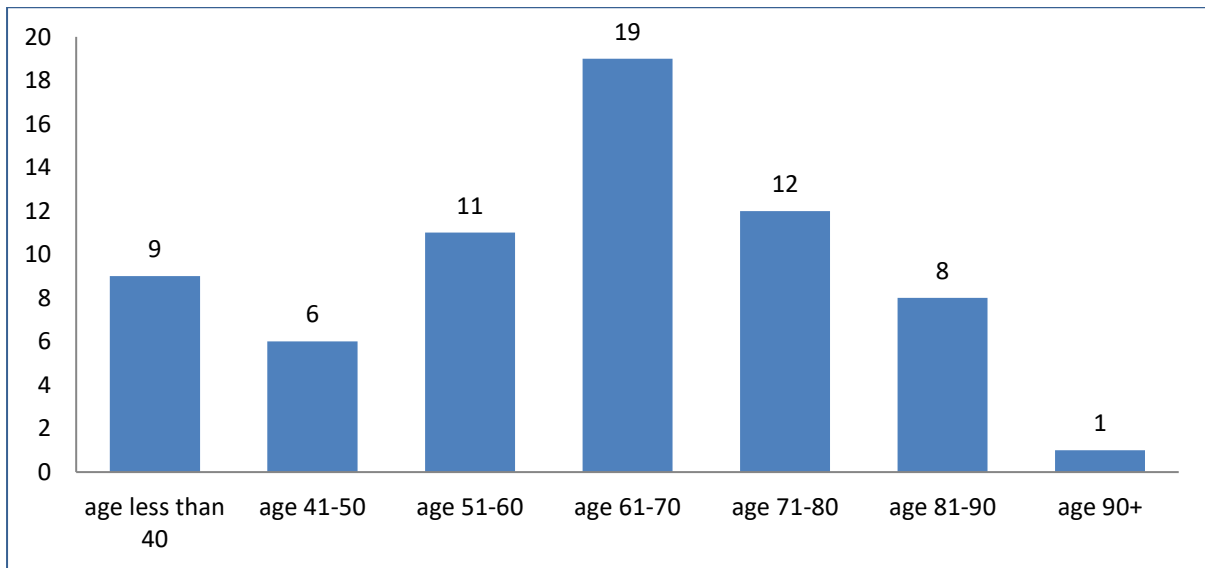
Approval for the study was obtained from Institutional Review Committee of Patan Academy of Health Sciences (IRC-PAHS). Informed written consent was obtained from the head of the household or responsible adult participants.

**RESULTS**

Out of 360 households encompassing 2168 individuals surveyed, 52% were male and 48% female with the average age of 51.33 years.



**Figure 1. NCD prevalence and Palliative Care requirement in rural Nepal**



**Figure 2. Age distribution of individuals requiring Palliative Care in rural Nepal**

There were 153 (42.5%) respondents illiterate and 346 (96.1%) households depended on agriculture as one source of income while 239 (66.3%) households depended on agriculture alone.

We found 139 (6.4%) individuals suffering from chronic NCDs and 66 (3.04%) met the SPICT criteria for palliative care need, (Figure 1)

Of the people requiring palliative care, 44% were males and 60% were above the age of 60, (Figure 2).

The commonest condition warranting palliative care was chronic respiratory disease (51.5%), followed by dementia and frailty (30.3%), heart disease (22.2%) and diseases of the nervous system (22.2%). Only three patients had cancer, (Figure 3).

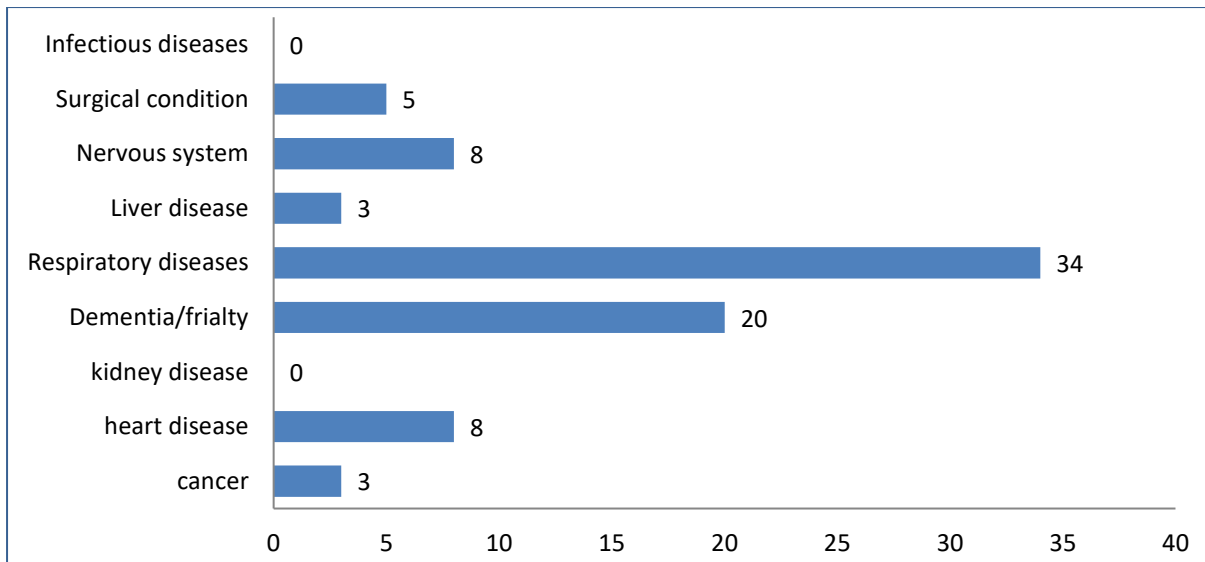


Figure 3. Diseases of system requiring Palliative Care

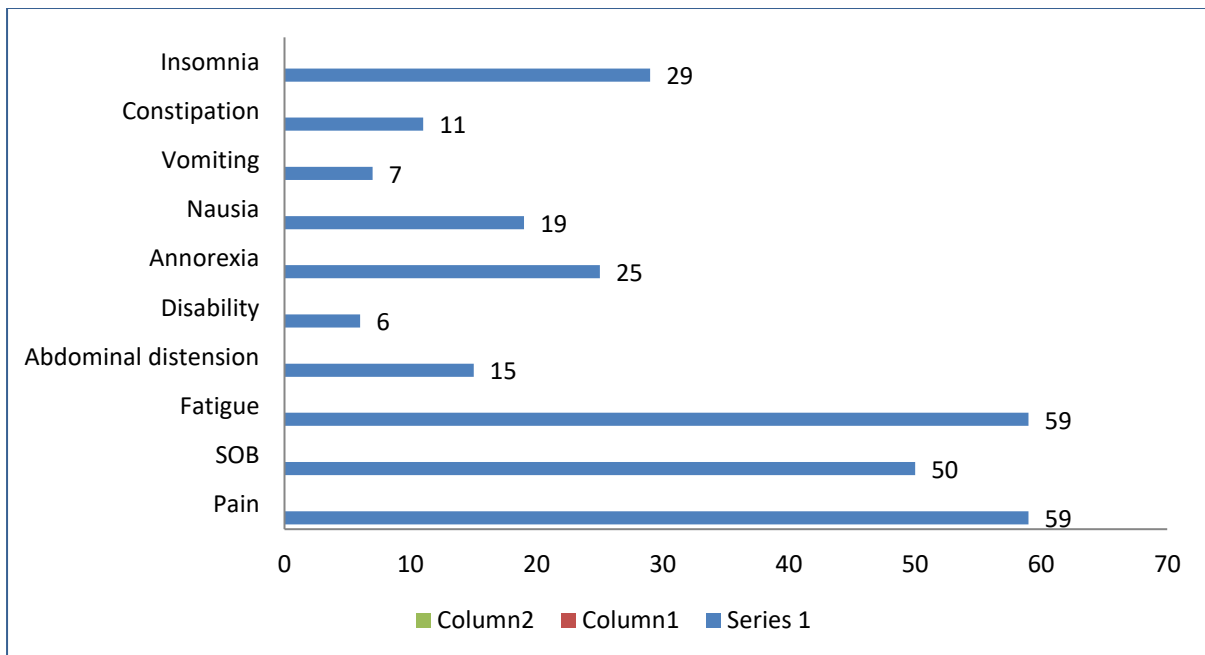


Figure 4. Symptom burden for patients requiring Palliative care

Table 2. Severity of symptoms based of PACA score of patients needing palliative care

Symptom	Score 0	Score 1	Score 2	Score 3	Total Patients
Pain	7	17	25	17	66
SOB	16	10	25	15	66
Fatigue	7	13	36	10	66

Pain (89%), Shortness of breath (75%) and fatigue (89%) were the common symptoms in the patients identified with palliative care need, (Figure 4).

The severity of symptom burden among patients who met the SPICt criteria for palliative care need showed that many patients had symptoms severe enough to dominate their life, with PACA score 3 for pain in 26%

(17/66), SOB in 23% for and fatigue in 15%, (Table 2).

## DISCUSSIONS

Our study showed that 3.04% of the population in a rural area of Nepal require palliative care. For the total population of Thaha Municipality, this translates into around 1280 patients.

Unlike other international studies, in our case, it is difficult to obtain death registration certificates and cause of death is not documented systematically. Hence, it is not possible to use death registration data to calculate the need. Instead, we used household survey as the method which provides us with present day data which do not need to be extrapolated.

Population based need assessment has been done in developed countries using data obtained from death registration. Murtagh et al. used the numbers of deaths from cancer and six selected non-cancer disease groups multiplied by symptom prevalence for key symptoms in each of these groups, to estimate the need for palliative care.<sup>10</sup> Using this method, they estimated that 63% of deaths in the UK require palliative care. Similarly, a cross national study using death registration data in 12 countries (Belgium, Czech Republic, France, Hungary, Italy, Spain (Andalusia, 2010), Sweden, Canada, the United States (2007), Korea, Mexico, and New Zealand) showed that between 38% and 74% of people who died required palliative care.<sup>11</sup>

A population based need assessment done in Catalonia in Spain among patients with chronic illness identified by primary health centres showed 1.5% of the population required palliative care.<sup>12</sup>

Similarly, a population based household survey done in an urban area in Puducherry, South India, reported that 0.6% of the population required palliative care.<sup>13</sup> This estimate is much lower than in our study. This may be explained by the criteria for palliative care being much

more restrictive as it included only people who were bed ridden or could not go to work because of physical incapacity or needed help in activities of daily living. Further, this study was done in an urban population where the people may be healthier and have better access to health care.

Our study showed 60% of the patients requiring palliative care were above the age of 60. This is similar to the study from Puducherry where 59% were above age 60.<sup>13</sup> In the study from Catalonia, Spain, the age of patients requiring palliative care was much higher; i.e. 67.5% were above age 80.<sup>12</sup> This indicates higher life expectancy in the Spanish population (80 in male and 86 for female)<sup>14</sup> compared to that of Nepal (68 for males and 71 for females)<sup>15</sup> and India (67 for males and 70 for females).<sup>16</sup>

The most common conditions needing palliative care in our study was respiratory diseases. This is in keeping with the prevalence of NCDs in a hospital based study from Nepal which showed that respiratory disease is the most common NCD (43%)<sup>17</sup> which likely reflects the prevalence in the community. Frailty and dementia (20%) together was the second most common condition requiring palliative care. In the study from south India and Spain, the most common condition was frailty due to old age. This probably reflects the high percentage of older age in the general population in India and Spain.

The most common symptoms among the patients meeting the SPICT criteria in our study were pain, fatigue and shortness of breath, with a quarter of patients having pain severe enough to dominate their daily life. This level of need indicates the importance of good palliative care service in rural area.

This study was limited to one area in the rural hills of Nepal and therefore may not be representative of all rural areas of Nepal. Similar studies in different parts of the country will enable the true level of need for palliative care in rural Nepal to emerge.

## CONCLUSIONS

The need for palliative care in rural area is high and needs to be taken into account in health planning and program design by the Ministry of Health, Nepal.

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