

Original Article

# Estimating the Need for Palliative Care in an Urban Resettlement Colony of New Delhi, North India

Ankit Chandra<sup>1</sup>, Sushma Bhatnagar<sup>2</sup>, Rakesh Kumar<sup>1</sup>, Sanjay Kumar Rai<sup>1</sup>, Baridalyne Nongkynrih<sup>1</sup>

<sup>1</sup>Centre for Community Medicine, All India Institute of Medical Sciences, <sup>2</sup>Department of Onco-Anaesthesia and Palliative Medicine, All India Institute of Medical Sciences, New Delhi, India.

## ABSTRACT

**Objectives:** This study was aimed to estimate the need for palliative care in an urban resettlement colony of Dakshinpuri Extension, New Delhi.

**Material and Methods:** This was a community-based cross-sectional study conducted in New Delhi. We trained four multipurpose workers to screen the households during their routine household-to-household visits. The screening for the need for palliative care was done using three questions – that is, (1) presence of a bedridden patient or (2) person in need for help in activities of daily living or (3) not able to go for work due to any physical chronic illness. If the answer to any of the three screening questions was yes for any member in a household, then these households were visited by a community physician trained in palliative care and a medical social service officer to confirm the need for palliative care. Patients were administered a semi-structured questionnaire containing the sociodemographic details and an assessment of disease status and review of health records was done. The patient and his/her caregiver were also assessed for awareness regarding palliative care.

**Results:** A total of 2028 households were screened and the need for palliative care was found to be 1.5/1000 population (95% CI: 0.9–2.1). The mean age (SD) of patients who need palliative care was 60 years (SD–12.9). The common diseases which required palliative care were stroke with a focal neurological deficit (45.8%), osteoarthritis with marked dependence (20.8%) and cancer (12.5%). None of the patients was receiving palliative care as patients and their caregivers were not aware of the term palliative care/end of life care/home care for bedridden people/community-based care.

**Conclusion:** The need for palliative care in an urban resettlement colony of North India was found to be 1.1/1000 population. Further studies are required to estimate the need for palliative care in North India.

**Keywords:** Palliative care, Need, North India, Caregiver strain, Symptom severity

## INTRODUCTION

Palliative care is defined by the World Health Organisation (WHO) 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.’<sup>[1]</sup> Palliative improves the quality of life and reduces the burden on family for the patients with chronic or life-threatening diseases. Palliative care can be integrated with the curative model for chronic and non-curable diseases such as terminal cancers, Acquired Immunodeficiency Syndrome, chronic respiratory diseases, stroke, heart failure, chronic kidney disease, multiple

sclerosis, cystic fibrosis and filariasis. It can start from the diagnosis of disease until the death bereavement.<sup>[2]</sup> Globally, it is estimated that palliative care is needed in 40–60% of all deaths. Those dying from non-communicable diseases (NCDs) represent around 90% of the burden of end-of-life palliative care. In 2014, it was estimated that only 14% of people needing palliative care at the end of life, actually receive it.<sup>[2]</sup> A study using the mortality trend of 2014 in England reported that the need for palliative care will rise by 25.4% (depending on the rise in mortality).<sup>[3]</sup> Mortality and morbidity increase the need for palliative care.

In the Indian context, there are limited studies evaluating the morbidity and need for palliative care. Various studies have estimated the need for palliative care in India, but these

\*Corresponding author: Baridalyne Nongkynrih, Centre for Community Medicine, All India Institute of Medical Sciences, New Delhi, India.  
baridalyne@gmail.com

Received: 17 March 2022 Accepted: 05 July 2022 Epub Ahead of Print: 10 August 2022 Published: 23 November 2022 DOI: 10.25259/IJPC\_60\_2022

This is an open-access article distributed under the terms of the Creative Commons Attribution-Non Commercial-Share Alike 4.0 License, which allows others to remix, transform, and build upon the work non-commercially, as long as the author is credited and the new creations are licensed under the identical terms.

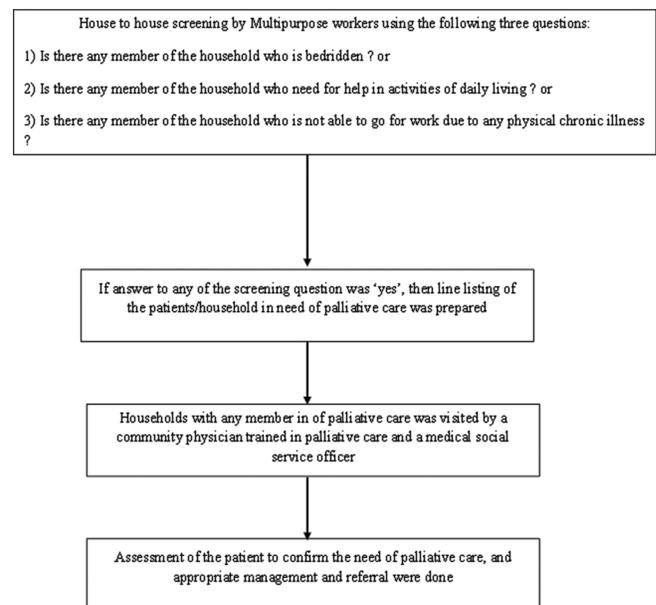
©2022 Published by Scientific Scholar on behalf of Indian Journal of Palliative Care

studies are limited to the southern part of India.<sup>[4-6]</sup> Studies in South India have reported that the need for palliative care in an urban and rural community is reported to be 6/1000 population and 4/1000 population, respectively.<sup>[4,5]</sup> There is a dearth of evidence regarding the need for palliative care in North India, especially from the urban community. Estimation of the need for palliative care can help in planning and designing palliative care services. It can inform the policymaker regarding the burden of chronic/life-threatening illness and the need for palliative care. We conducted this study to estimate the need for palliative care in an urban resettlement colony of Dakshinpuri, New Delhi.

## MATERIAL AND METHODS

It was a community-based cross-sectional study conducted in the urban field practice area of the Centre for Community Medicine (All India Institute of Medical Sciences, New Delhi). It is an urban resettlement colony located at Dakshinpuri Extension, New Delhi. It caters to a population of 35,618. The health services at the urban field practice area are being catered by four community clinics/dispensaries of the Government of Delhi and an urban health centre of the Centre for Community Medicine. Various health workers (ASHA, Anganwadi workers, multipurpose health workers) work at the ground level to provide the services. The mean age of the population residing in the urban field practice area is 31.6 years (SD-18.1). The proportion of population >60 year is 7.9%. The majority of the population is young. We selected five blocks randomly out of the ten blocks using a lottery method. This study was conducted from 20<sup>th</sup> December 2021 to 20<sup>th</sup> January 2022. Households were screened consecutively by the four multipurpose workers during their routine visits as per the planned schedule. The multipurpose workers were given basic training by a trained physician on palliative care. During the household screening, the informant (age  $\geq 18$  years) within the household was selected, with preference given to the head of the household and/or the most educated person in the household who could provide the data regarding the other household members. The households found locked on two separate visits were excluded from the study. The screening for the need for palliative care was done by multipurpose workers using three questions – that is, (1) presence of a bedridden patient or (2) person in need for help in activities of daily living or, (3) not able to go for work due to any physical chronic illness.<sup>[4,5,7]</sup> If the answer to any of the three screening questions was yes for any member in a household, then a line listing of such households were prepared. To increase the sensitivity of screening, we asked the workers to include the names of patients having chronic/life-threatening diseases such as cancer, stroke, epilepsy, HIV/AIDS, epilepsy, dementia, cerebral palsy, mental retardation and severe cardiac/renal/liver/respiratory/neurological diseases. These

households were visited by a community physician trained in palliative care and a medical social service officer to confirm the need for palliative care [Figure 1]. A person with a need for help in activities of daily living (in conditions, e.g., old age weakness or osteoarthritis) was, further, assessed for marked dependence using Barthel Index (score ranges from 0 to 100). A score of  $\leq 60$  on the Barthel Index was considered as marked dependence and it was considered as a need for palliative care.<sup>[8]</sup> Patients identified with the need for palliative care were administered, a semi-structured interview questionnaire containing the sociodemographic details, Barthel Index for dependency, disease details and review of health records was done. Patients were assessed for the severity of their symptoms using the Edmonton symptom assessment tool.<sup>[9]</sup> Patients identified with palliative care needs were given medical and social advice and appropriate referral was done. The patient's caregivers were assessed for perceived strain using a modified caregiver strain index.<sup>[10]</sup> Patient and their caregiver were also assessed for awareness regarding palliative care by asking 'Have you heard about the term palliative care/end of life care/home care for bedridden people/community-based care?' Data regarding the age, sex and education of the study population were extracted from the health management information system. Data were collected in Epicollect5<sup>[11]</sup> and analysis was done using R software. Descriptive analysis was done for the sociodemographic and quantitative variables. The prevalence of need for palliative care was reported with a 95% confidence interval. Answers for problems faced by the patient and the caregiver were organised into meaningful themes.



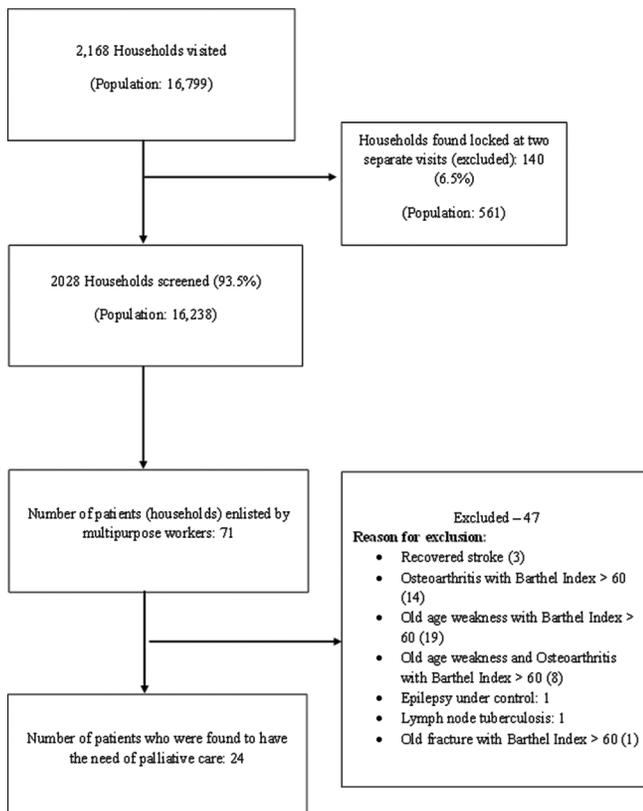
**Figure 1:** Flow chart showing the methodology of the study to assess.

## Ethical statement

Ethical approval was obtained from the Institute Ethics Committee of AIIMS, New Delhi (Reference number: IEC-815/3.12.2021).

## RESULTS

A total of 2168 households were visited and 140 houses were found to be locked at two separate visits [Figure 2]. The mean age of the population included and excluded in the study were 31.4 years (SD – 17.9) and 31.2 years (SD – 16.8), respectively. The years of education of the population included and excluded in the study were 7.1 years (SD – 5.1) and 7.7 years (SD – 4.9), respectively. The representation of females was 50% [Table 1]. Among the 2028 households screened, 24 patients were found to have the need for palliative care; all 24 patients were from different households. The need for palliative care was found to be 1.5/1000 population (95% CI: 0.9–2.1). The mean age (SD) of patients who need palliative care was 60 years (SD–12.9). The median years of education of patients were 0 years (IQR 0–8). Fifty percentages of the patients were female. The majority of the patients belonged to the upper-lower socioeconomic class (58.2%). The common conditions which required the need for palliative care were stroke with a focal neurological deficit (45.8%), osteoarthritis with marked dependence (20.8%), cancer (12.5%) and



**Figure 2:** Flowchart showing the population screened and excluded in the study.

old age-related weakness with marked dependence (8.3%) [Table 2]. Three patients had cancers, that is, oral cancer, lung cancer and colorectal cancer. Three patients were completely bedridden and one patient had bedsores. The severity of the symptoms was assessed for 23 patients, as one patient had died. All the patients reported poor well-being with the median (IQR) score of 7 (IQR – 4–9) [Table 3]. Most of the patients had caregivers (66.7%) and were females (81.2%). The mean age of the caregivers was 42.6 years (SD–15). The median score for the median caregiver strain index was 12 (IQR 8.5–17). None of the patients was receiving palliative care as patients and their caregivers were not aware of the term palliative care/end of life care/home care for bedridden people/community-based care. Among the patients, the problems faced by the patients were related to financial strain (43.4%), psychological issues (21.7%), spiritual crisis (8.7%) and lack of caregiver/support (5.1%). Among the caregivers, the problems faced were related to financial strain (53.8%), mobility/transfer of patient (26.7%) and psychosocial (20%).

## DISCUSSION

We found the prevalence of need for palliative care to be 1.5/1000 population, of which half of them were female. This prevalence was comparable to a study done in Chandigarh (2/1000 population).<sup>[7]</sup> It was lower compared to the studies done in Puducherry (3.3/1000 population,<sup>[6]</sup> 6.1/1000

**Table 1:** Details of the study population included and excluded.

	Included population (n=16,238) (%)	Excluded population (n=561) (%)
Sex		
Males	8267 (50.9)	292 (52.1)
Females	7971 (49.1)	269 (47.9)
Age group*		
0–10	2102 (13.1)	57 (10.2)
11–20	2856 (17.7)	97 (17.3)
21–30	3227 (20)	130 (23.3)
31–40	3187 (19.8)	110 (19.7)
41–50	2409 (14.9)	84 (15)
51–60	1148 (7.1)	47 (8.4)
61–70	783 (4.9)	25 (4.5)
>70	397 (2.5)	9 (1.6)
Married status		
Never married	7527 (46.4)	271 (48.3)
Ever married	8711 (53.6)	290 (51.7)
Years of education		
0	3725 (22.9)	108 (19.3)
1–6	3110 (19.2)	93 (16.6)
7–10	5344 (32.9)	205 (36.5)
11–12	2285 (14.1)	90 (16)
>12	1774 (10.9)	65 (11.6)

\*Age data were missing for 129 participants in the included population and 2 participants in the excluded population

**Table 2:** Details of the patients in need of palliative care ( $n=24$ ).

Variable	n (%)
Sex	
Male	12 (50)
Female	12 (50)
Socioeconomic class (Modified Kuppaswamy's scale)	
Upper	0 (0)
Upper middle	0 (0)
Lower middle	3 (12.5)
Upper lower	14 (58.3)
Lower	7 (29.2)
Disease	
Stroke with focal neurological deficit	11 (45.8)
Osteoarthritis with marked dependence	5 (20.8)
Cancer	3 (12.5)
Old age weakness with marked dependence	2 (8.3)
Alzheimer's disease	1 (4.2)
Severe Chronic obstructive pulmonary disease	1 (4.2)
Spinal injury	1 (4.2)
Treatment facility	
Private	16 (66.7)
Government	7 (29.1)
No treatment	1 (4.2)
Presence of caregiver	
Yes	16 (66.7)
No	8 (33.3)

**Table 3:** Edmonton symptom assessment of patients with need of palliative care ( $n=23$ ).

Symptoms	Median score (IQR)*
Pain	2 (0–5)
Fatigue	0 (0–2)
Nausea	0 (0–0)
Depressed	4 (0–6)
Anxiety	0 (0–0)
Drowsiness	0 (0–4)
Shortness of breath	1 (0–4)
Appetite loss	0 (0–4)
Poor well-being	7 (4–9)
Sleep-related issue	2 (0–7)

\*Higher score means the high intensity of symptoms. For each symptom, the score ranges from 0 to 10

population<sup>[4]</sup>) and Tamil Nadu (4.1/1000 population).<sup>[5]</sup> This difference could be due to the difference in the study setting and the study population as the study population in our setting is mostly young. This could be also a reason for the lower cases of old age-related weakness, cancers and other NCDs. Most of the previous studies had reported old age/old age-related weakness as the most common condition for the need for palliative care.<sup>[4,5]</sup> We had quantified this through the Barthel Index and had used a cut-off for marked dependence which was considered for palliative care need.

This could have led to the low need for palliative care in our study compared to other studies.<sup>[4,5]</sup> Most of the patients requiring palliative care had a stroke with neurological deficit, osteoarthritis with marked dependence, cancer and old age-related weakness with marked dependence similar to other studies.<sup>[4,5,7]</sup> The median age of patients requiring palliative care was 60 years, this was consistent with studies done at Puducherry<sup>[4]</sup> and Tamil Nadu.<sup>[5]</sup> This could be because the morbidity and incidence of NCDs are higher among this age.<sup>[12,13]</sup> We found that the awareness regarding palliative care among the patients and caregivers was zero. There is a need to generate awareness regarding palliative care.<sup>[6,7]</sup> A study in Kerala found the awareness among the general population to be 13.4%.<sup>[14]</sup> This could be due to the high number of active palliative care units in Kerala and with support from the government and local bodies. Furthermore, there is a concentration of palliative care services in Kerala compared to other parts of India.<sup>[15,16]</sup>

It has been more than a decade since India launched National Programme for Palliative Care in the 12<sup>th</sup> 5-year plan. It aimed to generate awareness and to provide palliative care as an integral part of all the levels of healthcare.<sup>[17]</sup> The progress seems to be unsatisfactory. Our study setting was an urban resettlement colony in New Delhi, which is a part of a metropolitan city filled with various resources and facilities. Despite our study setting being catered by several health facilities (government and private), none of the study patients requiring palliative care were receiving palliative care. The reason could be the lack of awareness and training of health-care providers for palliative care as the focus of providing palliative care services under the national programme is mainly at the district hospitals. Furthermore, studies done in various settings of India have found a substandard awareness and knowledge about palliative care among health-care providers.<sup>[18-21]</sup> As there is an unmet need for palliative care in the community, there is a need for tremendous efforts to generate substantial awareness regarding palliative care and training of health-care providers for providing palliative care services at all levels. The escalating burden of NCDs and increase in morbidities is an early rising alarm for India to prepare and address the palliative care need.<sup>[22,23]</sup> Most of the NCDs and their complications need palliative care. Palliative care cannot only be provided through a hospital or clinic but also through a community or home-based setting.<sup>[1]</sup> There are various models for palliative care that have proven to be effective in a setting with limited resources and minimal infrastructure. It's one of the examples in India is Neighbourhood Network in Palliative Care as it relies on the community to identify the needs, plans strategy and helps them with active support from health professionals.<sup>[24]</sup> Findings from this study cannot be generalised to North India, further studies are required to assess the needs and awareness for palliative care.

## Strengths and limitations

We were able to estimate the prevalence of the need for palliative care in an urban setting of North India with a household-to-household survey having a large sample size and with a high response rate. The population excluded were similar to the population included in terms of age, sex and education. We had used a team approach (trained physician and medical social officer) to confirm the need for palliative care. We assessed the dependency, symptom score for patients and caregiver strain using standard tools. We interviewed only one adult person in a household to collect information about other household members. We did not collect the data on the prevalence of chronic illness and comorbidity, which could have underestimated the need as various studies have used the data for chronic diseases and deaths to estimate the need for palliative care and found a substantially higher need for palliative care.<sup>[25,26]</sup>

## CONCLUSION

The need for palliative care was found to be 1.5/1000 population in an urban resettlement colony of North India. The most common conditions in an urban community requiring palliative care were stroke with focal neurological deficit and osteoarthritis with marked dependence. Further studies are required from North India to generalise the findings.

## Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent.

## Financial support and sponsorship

Nil.

## Conflicts of interest

There are no conflicts of interest.

## REFERENCES

- World Health Organization. WHO Definition of Palliative Care. Geneva: World Health Organization; 2019. Available from: <https://www.who.int/cancer/palliative/definition/en> [Last accessed on 2019 May 22].
- World Health Organization. NCDs Global Atlas of Palliative Care at the End of Life. Geneva: World Health Organization; 2019. Available from: <https://www.who.int/cancer/publications/palliative-care-atlas/en> [Last accessed on 2019 Jun 13].
- Etkind SN, Bone AE, Gomes B, Lovell N, Evans CJ, Higginson IJ, *et al.* How many people will need palliative care in 2040? Past trends, future projections and implications for services. *BMC Med* 2017;15:102.
- Daya AP, Sarkar S, Kar SS. Estimation of palliative care need in the urban community of Puducherry. *Indian J Palliat Care* 2017;23:81-7.
- Elayaperumal S, Venugopal V, Dongre AR. Identifying people in need of palliative care services in rural Tamil Nadu: A survey. *Indian J Palliat Care* 2018;24:393-6.
- Chandra A, Sarkar S, Adinarayanan S, Balajee KL. Impact of health awareness campaign in improving the perception of the community about palliative care: A pre- and post-intervention study in Rural Tamil Nadu. *Indian J Palliat Care* 2016;22:467-76.
- Kaur S, Kaur H, Komal K, Kaur P, Kaur D, Jariyal VL, *et al.* Need of palliative care services in rural area of Northern India. *Indian J Palliat Care* 2020;26:528-30.
- Shah S, Vanclay F, Cooper B. Improving the sensitivity of the Barthel Index for stroke rehabilitation. *J Clin Epidemiol* 1989;42:703-9.
- Hui D, Bruera E. The Edmonton symptom assessment system 25 years later: Past, present, and future developments. *J Pain Symptom Manage* 2017;53:630-43.
- Onega LL. The modified caregiver strain index (MCSI). *J Gerontol Nurs* 2013;33:19-26.
- Imperial College London. Epicollect 5; 2018. Available from: <https://www.five.epicollect.net> [Last accessed on 2020 Aug 16].
- Paul K, Singh J. Emerging trends and patterns of self-reported morbidity in India: Evidence from three rounds of national sample survey. *J Health Popul Nutr* 2017;36:32.
- Verma VR, Dash U. Horizontal inequity in self-reported morbidity and untreated morbidity in India: Evidence from national sample survey data. *Int J Equity Health* 2021;20:49.
- Joseph N, S J, Kotian S. A comparative study to assess the awareness of palliative care between urban and rural areas of Ernakulum district, Kerala, India. *Indian J Palliat Care* 2009;15:122-6.
- Azeel EP, Anbuselvi G. Is the Kerala model of community-based palliative care operations sustainable? Evidence from the field. *Indian J Palliat Care* 2021;27:18-22.
- Khosla D, Patel FD, Sharma SC. Palliative care in India: Current progress and future needs. *Indian J Palliat Care* 2012;18:149-54.
- Ministry of Health and Family Welfare, Government of India. National Programme for Palliative Care (NPPC): National Health Mission. Available from: <https://www.nhm.gov.in/index1.php?lang=1&level=2&sublinkid=1047&lid=609> [Last cited on 2022 Mar 07].
- Butola S. A study on knowledge, attitude, and practices regarding palliative care among doctors in border security force. *Prog Palliat Care* 2014;22:272-9.
- Patel A, Deo S, Bhatnagar S. A survey of medical professionals in an apex tertiary care hospital to assess awareness, interest, practices, and knowledge in palliative care: A descriptive cross-sectional study. *Indian J Palliat Care* 2019;25:172-80.
- Bhadra K, Manir KS, Adhikary A, Kumar G, Manna A, Sarkar SK. Awareness of palliative care among doctors of various departments in all four teaching medical colleges in a metropolitan city in Eastern India: A survey. *J Educ Health Promot* 2015;4:20.
- Nair M, Kumar P, Mahajan R, Harshana A, Kurup KK, Moreto-Planas L, *et al.* Knowledge, attitudes, and practices regarding palliative care: A mixed-methods study from Bihar, India. *J Palliat Care* 2021;36:9-11.
- Arokiasamy P. India's escalating burden of non-communicable diseases. *Lancet Glob Health* 2018;6:e1262-3.
- Dandona L, Dandona R, Kumar GA, Shukla DK, Paul VK, Balakrishnan K, *et al.* Nations within a nation: Variations in epidemiological transition across the states of India, 1990-2016 in the global burden of disease study. *Lancet* 2017;390:2437-60.
- Kumar S, Numpeli M. Neighborhood network in palliative care. *Indian J Palliat Care* 2005;11:6.
- Murtagh FE, Bausewein C, Verne J, Groeneveld EI, Kaloki YE, Higginson IJ. How many people need palliative care? A study developing and comparing methods for population-based estimates. *Palliat Med* 2014;28:49-58.
- Morin L, Aubry R, Frova L, MacLeod R, Wilson DM, Loucka M, *et al.* Estimating the need for palliative care at the population level: A cross-national study in 12 countries. *Palliat Med* 2017;31:526-36.

**How to cite this article:** Chandra A, Bhatnagar S, Kumar R, Rai SK, Nongkynrih B. Estimating the need for palliative care in an urban resettlement colony of New Delhi, North India. *Indian J Palliat Care* 2022;28:434-8.