

Original Article

Needs Assessment of Patients Requiring End-of-Life Care: A Community-based Cross-sectional Study

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ABSTRACT

Objectives: The first step in implementing comprehensive palliative care is to assess the need for it within the community. Therefore, our study aimed to determine the number of individuals requiring end-of-life care in the rural sectors in the peri-urban area and to evaluate the unmet needs of the identified patients.

Materials and Methods: Data triangulation was conducted using information from health workers in the respective villages, cancer registry data from the District Headquarters Hospital, and snowball sampling. The identified patients were interviewed using a semi-structured questionnaire that included socio-demographic information, disease details and assessments across four domains of palliative care.

Results: A total of 225 patients were identified. Among these patients, 55.9% were over the age of 60 years, while 8.0% were children and adolescents. The most common diseases identified included cerebrovascular disease, heart disease, frailty, cancer and chronic kidney disease among adults and cerebral palsy among children. The prevalent physical issues reported were immobility, pain, fatigue, breathlessness and constipation. Approximately two-thirds of the patients expressed concerns regarding their future and financial issues. Three out of four patients reported difficulties in performing daily activities. Most of the patients attributed their source of strength to their relationships with others, followed by their faith in God. Socioeconomic factors such as education, occupation, family type and income were found to influence various domains of palliative care, except the spiritual domain.

Conclusion: In the studied population, 4.3 individuals/1,000 required end-of-life care. In addition, all four domains of care exhibited unmet needs. These needs can be addressed through policy implementation and the integration of palliative care into primary care services.

Keywords: End-of-life care, Needs assessment, Palliative care, Prevalence

INTRODUCTION

Palliative care is the care provided for individuals with incurable diseases, aiming to improve their quality of life. According to the World Health Organization (WHO), 'Palliative care is 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] Unfortunately, an estimate for lower-middle-income countries shows the distributed opioid equivalent is sufficient for <1% of those in need.^[2] This type of care, which is essential for both chronic and life-threatening

conditions, should be need-based and provided at all levels of healthcare. End-of-life care is a component of palliative care. 'It is considered as care given to people who are near the end of life and have stopped treatment to cure or control their disease.'^[3] In addition to enhancing quality of life, end-of-life care has been shown to reduce acute hospital admissions and is cost-effective.^[4] Furthermore, it assists patients and families in making difficult decisions, planning for the future, promoting healthcare utilisation and improving satisfaction for both patients and caregivers.^[4]

The WHO has identified several terminal diseases that require palliative care at the end of life, including Alzheimer's disease and other dementias, cancer, cardiovascular diseases, cirrhosis of the liver, chronic obstructive pulmonary disease,

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diabetes, human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome, kidney failure, multiple sclerosis, Parkinson's disease, rheumatoid arthritis and drug-resistant tuberculosis.^[5] Given the increasing prevalence of these chronic conditions that necessitate end-of-life care, the demand for such services in the community could be substantial. Understanding the extent of this issue is crucial for planning adequate resources and enhancing the capacity of healthcare providers. There is an unmet need assessment in the four domains of end-of-life care in the eastern part of India. Therefore, we aimed to determine the number of patients in need of end-of-life care in the rural block of the district and to assess their needs across all four domains of palliative care.

MATERIALS AND METHODS

An analytical cross-sectional study was conducted in two of the five sectors of the district subdivision. All the patients with a terminal illness identified in the sectors, regardless of age, were included in the study. Participants who did not provide consent were excluded from the study. Data collection took place from January 2020 to July 2020.

Approval was obtained from the Institute Ethical Committee and the State Ethical Committee. Informed verbal consent was obtained after providing the patient information sheet. The identities of the participants were kept confidential and data analysis was done without identifiers.

The patients were identified through multiple sources and triangulated. The sources were the cancer registry, the stroke registry in the district public health institutions, key information from Accredited Social Health Activists (ASHAs) and snowball sampling. The ASHAs were educated on palliative care and provided with a surprise question, 'If you would be surprised if the patient dies within 1 year'^[6] and disease cues to help identify patients. The cues for symptoms and diseases included paralysis, heart disease, kidney disease, liver disease, breathlessness, limiting mobility, swollen body, chronic diseases such as HIV, multidrug-resistant tuberculosis and bedridden patients. The names of the patients and details of their conditions were collected from them. Data from these two sources were utilised to initiate the snowball sampling to find any other patients in the vicinity. Each referred household was visited with the help of ASHAs by the health worker trained in palliative care to include based on inclusion criteria. The patient's diagnosis was validated through assessment and a review of medical records to verify disease details.

The patient or the informant was interviewed using a semi-structured questionnaire. The operational definition of individuals requiring end-of-life care was that of terminal illness and end-of-life care definition 'patients suffering from a disease from which recovery cannot be expected with the available treatment, and death is unavoidable in the foreseeable future'.^[7] The diseases included were based on

the Global Atlas of Palliative Care.^[5] In situations where the patient was unable to respond, or in the case of children, data were collected from caregivers.

For children and adolescents under 18 years of age, only socio-demographic and physical assessments were conducted, as the psychological, social and spiritual evaluations for children differ from those for adults. Of the 225 identified patients, 203 patients were interviewed. Among the remaining twenty-two, nine were from a containment zone, making it impossible for health workers to reach them. The others were non-responders. Physical symptom assessment was done for all the patients, while the psychosocial and spiritual assessment was done for adults aged 18 years and above (187 patients).

A semi-structured questionnaire was created for terminally ill patients, focusing on socio-demographic data, disease details, service accessibility, and four domains of palliative care: physical, social, psychological, and spiritual. It was adapted from the Palliative Care Needs Assessment Guidance provided by the Irish government.^[8] Physical symptoms were assessed using a ten-point Likert scale, with a score above three indicating the presence of a physical problem, arbitrarily considering <3 as a mild symptom. Social, psychological and spiritual unmet needs were considered present if any responses in the respective domains were negative.

We collected data using Epi-Collect 5, imported it into Microsoft Excel 2010 and analysed it with the Statistical Package for the Social Sciences version 20.0. The variables were expressed as means with standard deviation, median with interquartile range (IQR) or frequencies with percentages appropriately. Chi-square test was used to test the association of categorical variables.

RESULTS

We identified 225 patients from the two sectors. The total population of both sectors, based on the household register of ASHAs, was 60,575 across 39 villages. The prevalence of end-of-life care needs within each village ranged from 0.2 to 13.5 patients/thousand population. The median prevalence was 4.3 patients/thousand, with an IQR of 2.1–5.9 patients/thousand.

Most of the patients belonged to the age group of 61–80 years (93, 45.8%), and 16 patients were under 18 years of age (8.0%). Two out of five patients (84) were illiterate. In contrast, three-fourths (158) of the heads of families were literate. The joint family structure was the most prevalent, observed in 102 families (50.2%). Nearly half of the families had five or fewer members (95, 46.8%). The median income of the families was Rs. 14,500, and one-third (68, 33.7%) had an income between ten and twenty thousand rupees [Table 1].

Disease patterns among adults (≥ 18 years of age).

The most prevalent condition among the patients was cerebrovascular disease (54, 24.0%), followed by heart

| Table 1: Socio-demographic details of patients. | |
|---|-----------------|
| Variable | Frequency n (%) |
| Gender | |
| Male | 111 (54.7) |
| Female | 92 (45.3) |
| Age (years) | |
| <18 | 16 (8.0) |
| 18–40 | 16 (8.0) |
| 41–60 | 58 (28.6) |
| 61–80 | 93 (45.8) |
| >80 | 20 (9.9) |
| Education of the patient | |
| Graduate and above | 7 (3.4) |
| Matric | 40 (19.7) |
| Primary | 72 (35.5) |
| No formal education | 84 (41.4) |
| Education of the head of the family | |
| Graduate and above | 16 (7.9) |
| Matric | 58 (28.6) |
| Primary | 84 (41.4) |
| No formal education | 45 (22.2) |
| Occupation of the head of the family | |
| Unemployed | 65 (32.0) |
| Unskilled work | 55 (27.1) |
| Semi-skilled work | 37 (18.2) |
| Skilled work | 46 (22.7) |
| Income (rupee) n=202 | |
| Median (interquartile range) 14,500 (8,000, 20,000) | |
| ≤5,000 | 36 (17.8) |
| 5,001–10,000 | 53 (26.2) |
| 10,001–20,000 | 68 (33.7) |
| 20,001–30,000 | 21 (10.4) |
| >30,000 | 24 (11.9) |
| Type of family | |
| Nuclear | 49 (24.1) |
| Extended | 51 (25.1) |
| Joint | 102 (50.2) |
| Single | 1 (0.5) |
| Size of family, n | |
| ≤5 | 95 (46.8) |
| 6–10 | 81 (39.9) |
| >10 | 27 (13.3) |

disease (42, 18.7%), frailty (32, 14.2%) and chronic kidney disease in 29 patients (12.9%) [Figure 1]. Cerebrovascular accidents (CVAs), frailty and heart disease were more prevalent in older patients, while cancer, chronic kidney

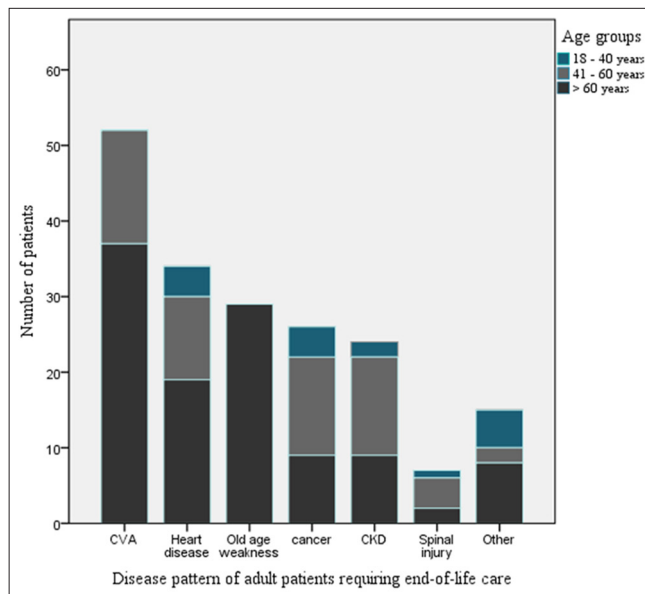


Figure 1: Illness distribution among adult patients identified as requiring end-of-life care. CVA: Cardiovascular accidents; CKD: Chronic kidney disease.

disease and spinal injuries were more frequently observed in the younger age group. Around one-third of patients (31.5%) were bedridden.

Four domain assessments of the adult patients

The most common symptoms were immobility, pain, fatigue, breathlessness and constipation. The symptoms which were graded as above 3 in the Likert scale, were immobility, fatigue, breathlessness, diarrhoea and hearing difficulty [Table 2]. In social assessment, support from the family was received by 180 (96.3%) patients, but only 104 (56.1%) received support from their friends/relatives. Three-fourths of patients (142, 75.9%) found it difficult to do day-to-day activities, hence needed assistance from others. Concern for the future was reported by 121 (65.4%) patients, and financial concern was reported by 132 (71.0%). Most of the patients preferred to be cared for at home in their last days (172, 92.0%).

Psychological and spiritual well-being assessment showed that only two patients were treated for psychiatric disorders, one for anxiety, and the other diagnosis was not known. More than half of the patients (105, 56.1%) felt depressed, and 92 (49.2%) patients reported feeling hopeless regarding their lives. No form of counselling was provided to the patients. The source of strength for patients was mostly from people/family members (115, 61.2%), followed by faith in God (66, 35.3%). 151 (80.3%) patients regarded themselves as religious and 125 (66.8%) felt that their religion helped them in coping with their underlying condition [Table 3].

On assessing the adult patients, physical well-being unmet need was present in 150 (73.9%) patients who had any of the symptoms above score of 3, social well-being was affected

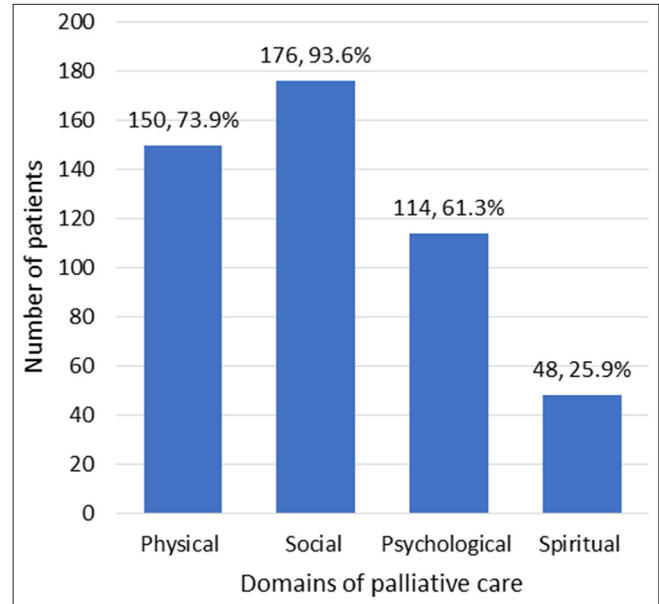
Table 2: Physical well-being of the adult patients, $n=187$.

| Physical symptoms | Frequency n (%) | Pain scale score more than 3 (moderate to severe) Frequency n (%) |
|--------------------|-------------------|---|
| Pain | 75 (40.1) | 36 (19.8) |
| Immobility | 81 (43.3) | 73 (34.8) |
| Fatigue | 74 (39.6) | 52 (27.8) |
| Breathlessness | 43 (23.0) | 22 (11.9) |
| Constipation | 40 (21.4) | 15 (12.3) |
| Diarrhoea | 13 (7.0) | 7 (3.7) |
| Hearing difficulty | 15 (8.0) | 10 (5.3) |
| Nausea | 5 (2.7) | 2 (1.0) |
| vomiting | 5 (2.1) | 0 (0.0) |

Table 3: Spiritual well-being of identified patients, Total $n=186$.

| Questions | Frequency n (%) |
|---|-------------------|
| Which is your source of strength | |
| Faith | 66 (35.5) |
| People | 115 (61.8) |
| Hobbies | 5 (2.7) |
| Are you a religious person | |
| Yes | 151 (80.3) |
| If yes, do you think it helps in your condition $n=149$ | |
| Yes | 125 (83.9) |
| No | 15 (10.1) |
| Ways of hope from religious practices for the patients (total $n=105$) | |
| Family support | 32 (30.5) |
| Religious practice feels good | 31 (29.5) |
| Feel better (health) | 25 (23.8) |
| Gives hope and strength | 8 (7.6) |
| Motivation for daily living | 6 (5.7) |
| Peace and happiness | 3 (2.9) |

in 176 (93.6%) patients, psychological problems present in 114 (61.3%) patients and 48 (25.9%) patients had spiritual well-being unmet need [Figure 2]. Significant difference in the physical unmet need was found with the education of the head of the family ($p < 0.01$). Significant difference in dependency was found with age ($p < 0.01$), education of the patient ($p < 0.001$). A significant difference was found between the groups of occupation of the head of the family ($p = 0.04$) and type of family ($p = 0.03$) regarding concern for the future. A significant difference was found in financial concern with the education of the head of the family ($p = 0.03$) and monthly income ($p = 0.01$). A significant difference in the psychological unmet need was found with the occupation of the head of the family ($p = 0.03$) and monthly income ($p < 0.001$) and type of family ($p = 0.01$)

**Figure 2:** Patients with unmet needs across the four domains of palliative care.

[Supplementary material]. Physical gap was found to be significantly associated with psychological ($p = 0.04$) and spiritual ($p < 0.01$) unmet needs [Table 4].

Disease pattern among children and adolescents (<18 years). In children, the most common diagnoses were cerebral palsy (8) and congenital heart disease, affecting 4 children, which constituted 3.6% and 2.2% of the overall cases, respectively. Only physical assessment was done through interviewers among children under 18 with immobility as the predominant problem (8, 50%).

Treatment details of patients

The diagnosis occurred within 1 year before the interview for 79 patients (38.9%). Most diagnoses were made at government tertiary (79, 38.9%) or private tertiary centres (58, 28.6%), followed by private secondary care centres (30, 14.8%). Half of the patients (101) preferred government institutions for the treatment of their underlying conditions; among these, 33 patients (16.3%) received treatment at secondary institutions, while 68 patients (33.5%) were treated at tertiary institutions. In private institutions, 59 patients (29.1%) received treatment for their underlying conditions at tertiary centres, and 35 patients (17.2%) were treated at secondary centres. For minor illnesses, 86 patients (42.4%) preferred government primary healthcare institutions, followed by government secondary institutions (44 patients, 21.7%) and private primary (34, 16.7%) institutions.

The patients had to travel a median distance of 17 km (9, 20) for treatment of the underlying disease and approximately 4 km (1.63, 6.75) for minor illnesses. Regarding the treatment of the underlying condition, 160 patients (78.8%) expressed satisfaction, while 196 patients (96.6%) were satisfied with

Table 4: Association of physical unmet need with other unmet needs.

| Unmet needs in social, psychological and spiritual domains | Physical unmet need | | Significance* | Odds ratio (95% confidence interval) |
|--|---------------------|--------------|---------------|--------------------------------------|
| | Present n (%) | Absent n (%) | | |
| Social unmet need | 134 (76.6) | 41 (23.4) | 0.08 | 3.27 (1.00–10.68) |
| | 6 (50.0) | 6 (50.0) | | |
| Psychological unmet need | 91 (79.8) | 23 (20.2) | 0.04 | 1.98 (1.01–3.87) |
| | 48 (66.7) | 24 (33.3) | | |
| Spiritual unmet need | 43 (89.6) | 5 (10.4) | <0.01 | 3.80 (1.41, 10.28) |
| | 95 (69.3) | 137 (30.7) | | |

*Chi square test and Fisher exact test

the treatment of minor illnesses. The most common reasons for dissatisfaction included lack of improvement or cure of the disease and financial constraints. In spite of having high unmet needs, the record review of patients did not show any palliative care services availed by the patients.

DISCUSSION

A median of 4.3 persons/1,000 population needed end-of-life care in the study. According to the Global Atlas of Palliative Care, approximately 37.4% of all-cause deaths require palliative care, with over 60% occurring in developing nations.^[5] In light of this information, the number of patients requiring palliative care in the present study was lower than anticipated. This could be due to the exclusive focus on end-of-life care. Prior research in South India indicated a prevalence of 6.1 and 4.5 patients/thousand population,^[9,10] while in North India, the prevalence was 1–2/thousand population requiring palliative care.^[11,12] A community-based study in Spain reported 3.02 individuals/1,000 population necessitated palliative care,^[13] a figure comparable to the current study. Patients exhibited hesitance in disclosing their disease to the ASHAs and others within their communities. Research has indicated the prevalence of stigma surrounding cancer and other chronic illnesses,^[13–15] which also could have contributed to the discrepancies observed between villages and other studies.

The illness patterns exhibited minor discrepancies compared to the global atlas.^[5] CVAs followed by cardiac disease were identified as the predominant cause, as in other reports. We were unable to differentiate between old age and conditions such as dementia and Parkinson's disease, as most individuals had not undergone any medical evaluations and regarded these symptoms as typical aspects of aging. In contrast, a hospital-based study did not highlight frailty in old age, likely due to the absence of hospital care-seeking behaviour for this issue.^[16] The prevalence of renal disease (12.5%) exceeded the global atlas disease burden for palliative care (2.02%), even after accounting for the 50% pain prevalence adjustment applied to this assessment. In addition to these conditions, respiratory disease was found to be a common cause in Sudhakaran *et al.*^[17] and osteoarthritis by Chandra *et al.*^[12]

which could have been left in this study, as it focuses on end-of-life care and variation in local disease patterns. The study found that children and adolescents make up 8.0% of end-of-life care patients, slightly exceeding the global atlas age group distribution of 6.0%. This may be due to socio-demographic characteristics and the higher prevalence of cerebral palsy in comparison to other research studies.^[5]

The study found unmet needs in all four domains of palliative care among the identified patients. The common physical issues identified included immobility, pain, fatigue, breathlessness, and constipation. Similar studies have also recognised pain, fatigue, breathlessness and constipation as common symptoms among patients requiring palliative care.^[18–20] Anderson *et al.*'s study and ours differ from other research with higher mobility issues,^[21] which could be due to patients with CVA and frail individuals who tend to visit health centres less frequently.^[22] In our study, unmet physical need was identified in a high proportion, with immobility being the most predominant problem. Furthermore, the high prevalence of moderate to severe pain underscores the critical unmet needs of these patients. Approximately three-fourths of patients reported an unmet need concerning their physical well-being, corroborating an Australian study among stroke survivors, which identified a persistent unmet need in 86% of participants.^[23]

The study found that almost all patients experienced social well-being impacts, though most received familial support. Sixty-one per cent of patients expressed anxiety about the future, and two-thirds reported financial difficulties. Several patients had lost their jobs due to illness, in addition to incurring out-of-pocket expenses, which may have exacerbated their financial crisis. Doherty *et al.* and Chaturvedi documented the concerns of palliative care patients regarding pain, physical issues, future uncertainties and financial matters in their research.^[24,25]

In the current study, almost two-thirds of patients felt hopeless or depressed. These figures are significantly higher than those reported in a meta-analysis, which found that only 29.0% of palliative care patients suffered from mood disorders.^[26] Another study in the Manchester Heart Clinic

showed that 61% of palliative care patients and 41% of heart failure patients had psychological problems.^[21] Karunanithi *et al.* stated 92% moderate and severe distress among patients.^[27] These variations could be due to the difference in definition. The psychological problems were higher when associated with socioeconomic factors such as an unemployed head of the family, lower monthly income and a nuclear type of family in our study. Similar findings were shown by Lewis *et al.* and Joshi *et al.* in their study.^[28,29] The depressed patients in this current study did not receive treatment or counselling, highlighting concerns about the neglect of mental health by both patients and healthcare providers.

This study found a unmet need in spiritual well-being among 25.9% of participants. One-fifth of the participants in this study reported a loss of faith due to their illness, and a smaller percentage indicated that they had lost hope in God. Spiritual well-being is often overlooked in palliative care, despite its importance.^[30] Studies have shown that many, though many believe in prayer,^[31,32] a high percentage of patients experience spiritual suffering.^[32] This highlights the importance of providing palliative care patients with better spiritual care.

Physical symptoms were found to be associated with psychological and spiritual factors in the study, which is similar to that reported by Doyle *et al.*^[33] The interrelationship among palliative care domains emphasises the need for holistic care, which is the core of palliative care.

Although there is enough evidence indicating palliative care can reduce all the unmet needs,^[4,34,35] none of the patients were receiving palliative care as per patient handheld records. In spite of the high need, the patients had no record of receiving palliative care on record review or were aware of palliative care at the time of interview. This reinstates the low availability of palliative care services to those in need in low- and middle-income countries. The patients were receiving services from primary, secondary and tertiary health centres, emphasising the integration of palliative care into all three levels of care. The factors that contributed most to treatment dissatisfaction in our study included lack of improvement or cure and financial constraint, which could be reduced by the provision of palliative care as per Ratcliff *et al.*^[4] The strength of this study lies in its coverage of a large population, comprising 60,545 individuals across 39 villages. To avoid recall bias, patient records were reviewed before confirmation. A needs assessment was conducted for patients across all four domains in the community setting. Limitations of the study include the potential decreased identification of cases in a few villages, with a wide range of cases identified between the villages. We included snowball sampling to increase the identification of cases to increase case identification. We employed non-probability sampling to select sectors from the block, which may not accurately represent the overall population in the block. Though the Irish palliative care assessment tool is

well established, it was not adopted for the local context or validated for India, which could produce information bias. Further, the disease classification was based on available records. This would miss diseases like dementia (expected in <3%), which is considered as frailty due to old age in the general population. In addition, a lack of privacy during patient interviews and interruptions from caregivers may introduce information bias.

Implications and recommendations

The study identified the need for end-of-life care at the community level and disease distribution, though diseases such as dementia are missed. This can be used to plan for service provision to reduce the unmet needs at the community level, like integration into the primary care level, as most of the symptoms are manageable at the primary care level. Further research is needed to identify a feasible, efficient method to address the unmet needs at the community level, such as immobility. A higher prevalence of CKD in the community found in the study needs further exploration.

CONCLUSION

A median of four individuals/1,000 in the study population required end-of-life palliative care. Among these patients, cardiovascular diseases accounted for the highest percentage of cases necessitating palliative care, followed by frailty, cancer and chronic kidney disease. A significant proportion of patients with chronic kidney disease and cerebral palsy highlights the need to investigate the factors contributing to these conditions in the study area. The physical, psychological, social and spiritual well-being of the patients was affected and influenced each other. Physical symptoms such as immobility, pain, fatigue, breathlessness and constipation are prevalent. Addressing these needs requires effective implementation of national programs, palliative care integration, reducing social unmet needs and improving rehabilitation and symptom management.

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Ethical approval: The research/study was approved by the Institutional Review Board at All India Institute of Medical Sciences, Bhubaneswar, approval number IEC/AIIMS BBSR/PG Thesis/2018-19/23(Amendment-1), dated 16th December 2019.

Declaration of patient consent: The authors certify that they have obtained all appropriate patient consent forms. In the form, the patients have given their consent for their images and other clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

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