CASE REPORT

Palliative care for chronic neurological disorders: A case series and literature review

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ABSTRACT

Background: There has been increased interest in palliative care for Individuals with chronic neurological disorders, yet there are no specific case reports or illustrations on detailed palliative care practices. Palliative care services for neurological disorders in India are limited. *Aim:* To illustrate the generalist palliative care practice for persons with chronic neurological disorders in a tertiary care hospital. *Materials and Methods:* A case study design was used to demonstrate generalist palliative care in neurological disorders using five case studies. CARE guidelines used for reporting case studies. *Results:* Degenerative neurological conditions such as dementia, motor neuron diseases, Parkinson's disease, multiple sclerosis, Duchenne muscular dystrophy and other conditions such as progressive supranuclear palsy, sub-acute sclerosing pan encephalitis, mitochondrial disease, multiple system atrophy, stroke with poor prognosis need immense palliative care. Early identification of palliative care needs from the beginning of diagnosis, and the barriers in facilitating palliative care in tertiary care settings were discussed. The psychiatric social workers provided generalist palliative care such as communicating prognosis, addressing caregiver burden, end-of-life care issues, advance care planning, and appropriate referral to hospice care and other palliative care services. *Conclusion:* Palliative care for chronic neurological disorders is in its infant stage in India. There is limited awareness about the need for palliative care for chronic neurological disorders among social work trainees, neurology trainees, and other health care providers. Hence, there is a strong need to increase awareness and access to palliative care for persons with life limiting or life threatening chronic neurological disorders. It is feasible to provide generalist palliative care for chronic neurological disorders in a tertiary care setting.

Keywords: Palliative care, neurological disorders, psychiatric social work interventions, end-of-life care

INTRODUCTION

Neurological disorders are the leading cause of disability and the second leading cause of death worldwide. Globally, neurological disorders accounted for 28.6% of disability-adjusted life years in 2010.[1] About 30 million people in India suffer from neurological disorders.[2] In India, DALYs due to non-communicable neurological disorders doubled from 4% in 1990 to 8.2% in 2019.[3] The largest contributors of neurological DALYs in India are Stroke (37.9%), headache (17.3%), epilepsy (11.3%), cerebral palsy (5.7%), and encephalitis (5.3%).[4,5]

Worldwide, about 40 million people require palliative care every year. There are variations in palliative care services available in developing countries compared to developed countries. People in need of palliative care are more (about 80%) in low and middle-income countries. Very few countries worldwide have well-integrated palliative care into their healthcare systems.[6] Palliative care improves the quality of life of patients with a life-threatening (neurological) illness and their families through the prevention and relief of suffering using early identification,

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appropriate assessment and treatment, and other physical, psychosocial, and spiritual sufferings.[7] The prevalence of patients with palliative care needs in India was estimated to be around six million in 2012.[8] NIMHANS started specialist palliative care for chronic neurological conditions in 2020 with CSR funding support from SUN Pharma.

Palliative care for chronic neurological disorders aims to provide overall symptom management, mitigate pain, and improve the quality of life for people suffering from a chronic life-limiting illness.[9] It is essential to provide palliative care for patients with chronic neurological conditions and their caregivers in hospitals, nursing homes, at home, and in the community. Few neurological conditions require immense palliative care, which is unnoticed from a palliative care perspective. Neurological conditions such as Parkinson's disease, dementia, stroke, sub-acute sclerosing pan encephalitis, mitochondrial disease, demyelinating disorders, neurocognitive disorders, and Duchenne muscular dystrophy require palliative care from the time of diagnosis. Most persons with chronic neurological illness would benefit from palliative care in terms of addressing their end-of-life wishes. Palliative care would benefit individuals with neurological disorders in terms of better quality of life, lower symptom burden, reduced caregiver burden, and improved health-related decision-making.

Need for palliative care in neurological conditions

Few patients with Parkinson's disease and motor neuron disease face psychosocial problems such as anxiety, depression, fatigue, distress, communicating illness to the family, unresolved personal and family conflicts, and so on. Palliative care for motor neuron disease and Parkinson's disease is limited globally and is alarming in India and other developing countries. Most citizens cannot afford nursing care and require professional palliative care. This category of people is often forced to choose home-based care for their family members with palliative care needs.[10]

Palliative care starts when the diagnosis has a poor prognosis and is fatal. It takes a shift from rehabilitation to an end-of-life care approach. The treatment of fatal neurological conditions starts with a rehabilitative approach focusing on the strength of the patient and family. The health care professionals care for patients and family members in the initial and middle phases. Follow-up. The patient is at the end of the end-of-life stage, and follow-up visits and medical management are limited at this phase. This period brings in a lot of palliative care needs, and unfortunately, these needs are not focused much on a tertiary care hospital. This paper illustrates the indicators of palliative care and describes generalist palliative care for chronic neurological conditions in a tertiary care hospital setting. The usual care providers provide generalist palliative care for the patient and family with low to moderate complexity of palliative care needs. It is a vital and integral part of their routine clinical practice. Focusing on quality of life includes symptom control and a whole-person approach, considering the patient's past life experiences and situation. It encompasses the patient with a life-threatening illness and family members, respects patient autonomy and choice, and emphasizes open and sensitive communication, which extends to patients, families, and professional colleagues.

This case series enhances clinicians' understanding of the importance of palliative care for chronic neurological conditions, illustrating palliative care indicators for neurological disorders through five different case reports.

MATERIALS AND METHODS

A case study design was used to illustrate the palliative care for persons with chronic neurological disorders. Case reports were prepared using CARE (CAse REport) guidelines. A case report is a narrative that describes a medical problem experienced by one or more patients and is used for medical, scientific, and educational purposes. Case reports written with guidance from reporting standards are sufficiently rigorous to guide clinical practice and inform clinical study design. CARE is a consensus-based clinical case reporting guideline developed by Gagnier et al.[11] The checklist has 13 items: title, keywords, abstract, introduction, patient information, clinical findings, timeline, diagnostic assessment, therapeutic interventions, follow-up and outcomes, discussion, patient perspective, and informed consent. It improves the completeness and transparency of case reports, and the systematic aggregation of information from case reports informs early signs of effectiveness and harms and improves healthcare delivery. The case reports were collected from Dec 2019 - June 2020 by the first author (CVK). The first and second authors provided generalist palliative care for individuals with chronic neurological disorders in outpatient and in-patient settings.

Case vignette 1

A 61-year-old male, married, illiterate, with a low socioeconomic status from a rural domicile, had his first visit to a tertiary care teaching hospital. He presented with complaints of memory disturbances, wandering behaviour, apathy, difficulties in daily activities for the past year, and worsening of symptoms in the last six months. He was diagnosed with frontotemporal *dementia.* Addenbrooke's cognitive examination showed 32/100, and the MMSE score was 14/30, indicating moderate impairment. He was referred in an outpatient setting to a psychiatric social worker, and palliative care was provided in terms of addressing the caregiver burden and educating him about the illness.

The psychosocial assessment revealed that the family has a poor support system. The patient's wife is the family's sole breadwinner and primary caregiver. She was highly burnt out with difficulty in handling patients' wandering behaviour and assisting the patient in activities of daily living (ADL). She expected to cure the illness and to make the patient independent in ADL. She could not maintain a cordial relationship with neighbours due to the patient's inappropriate behaviours. She demanded in-patient admission as no one was there to support her to reduce her physical, emotional, and financial burden. The treating team informed that the patient might not reach the premorbid level; further, the patient needs continued care, periodical follow-up, and nursing care. In this case, the indicators of palliative care are dependency on ADL, progressive nature of the illness, patient's behavioural symptoms, caregiver burden, loss of functioning, poor social support, disadvantaged social situation (as they do not have children or any relatives to take care), caregiver asking for admission when the patient does not require hospitalization. Intervention focused on Home base care and referred to Sihab thangal home care unit for Hospice and palliative care services and coordinated with Sihabthangal team.

We both are alone; please admit the patient here and offer a job for me in the hospital itself as I am not able to handle it alone, and being in the hospital makes me feel better than taking him back to the home where not much support is available".

Themes emerged: Help-seeking, loneliness, need for medical help, helplessness, difficulty, tertiary support and caregiver burden in managing the patient at home.

Case vignette 2

A 58 years old female, widow, illiterate, belonging to low socioeconomic status, hailing from a rural area, presented with the symptoms of difficulty in walking, upper limb weakness, slurred speech, difficulty in swallowing, tongue fasciculation, slowness in performing ADL with eight months illness duration. She was diagnosed with motor neuron disease, evolving into ALS. She was referred to the psychiatric social worker in an outpatient setting, and generalist palliative care was provided in terms of breaking the bad news, addressing her psychological distress, advance care planning, and coping with illness. The psychosocial assessment revealed that she lives alone. Both of her sons are married and living separately. She is a daily wage earner and has been unemployed for six months. Depressive cognition was present, along with hopelessness, worthlessness, and biological dysfunctions. *Neurological examination* revealed more weakness in the left side of the lower and upper limbs. Severe weakness was noted in the left shoulder, elbow, wrist, fingers, left lower limb, hip, and knee with grade 2 power. The indicators of palliative care in case 2 are rapidly progressive, deteriorating, disabling nature of the illness (motor neuron disorder), life-limiting, unfavourable prognosis; cure is not available.

I'm not even able to wear my saree properly, I am living alone, hesitant to seek help to wrap my saree properly. I am scared. My children would see me as a burden now. How long my children would take care of me, I don't know. I don't want to be dependent on them for my daily needs. When will I get better?

Themes emerged: Loneliness, painful living with disability, being a burden to others, hope and optimism about recovery, and not seeking help due to self-stigma

Case vignette 3

A 43-year-old female diagnosed with relapse remitting multiple sclerosis, presented with complaints of blurred vision, burning sensation in her body, fatigue, and difficulty in performing daily activities with an illness duration of 11 years and a history of three similar episodes and is on medication. Symptoms worsened in terms of gait imbalance and urinary incontinence. She was referred to the psychiatric social work team in an in-patient setting. The goal was to counsel the patient to cope with illness, improving her quality of life through home-based palliative care. Psychosocial assessment revealed dysfunctions in daily activities, low self-esteem, and dependence on ADL; her husband assisted her in ADL after her gait disturbances increased. She can walk with support but is unable to do any tasks. She feels guilty for not performing her role as a mother of an eight-year-old child. The child seems not to comprehend the situation and keeps enquiring about her recovery. This triggers the patient emotionally and results in crying spells. She has adequate social support. Palliative care focuses on educating about the nature of the illness, fatigue management, home-based rehabilitation, and positive coping.

In this case, the palliative performance scale was administered and the score ranged from 60 – 70%. Palliative care indicators in this patient are ADL dependency, urinary incontinence, chronic, progressive, incurable nature of the illness, and disabling condition.

Anyway, one day I'll die; all these medications would help me in delaying my death. Then why should I be alive when I am unable to take care of my children as a mother?

Themes emerged: Acceptance of prognosis, pessimistic view about the future, death wishes, child care needs, helplessness in fulfilment of her roles and responsibilities,

Case vignette 4

A 38-year-old female diagnosed with young-onset Parkinson's disease, dependent on ADL. She was referred to the psychiatric social work team in an in-patient setting. Palliative care focuses on addressing the caregiver's burden.

Indicators for palliative care: Caregiver burden, ADL dependent, deteriorating, disabling, irreversible nature of illness, end-of-life care issues.

Though we understand the illness, accepting the fact is hard. Three years ago, her sister died due to a duplicate condition. We could see her almost reaching that stage. We could not afford to keep her in our nearby hospital, which is *very expensive. That is why we have brought her here. This place is familiar to her and to us. So that she feels comfortable in continuing treatment and we temporarily feel relieved from this pain.*

Themes emerged: Grief, denial, affordable tertiary care, temporary relief in continuing the care, and near-death experiences.

Case vignette 5

An 18-year-old female, married and diagnosed with a postpartum stroke, lost her newborn baby due to medical complications within three days. The patient was taken to a nearby hospital and then referred to a stroke-ready hospital. The patient underwent surgery; her prognosis was poor. The patient was referred to the psychiatric social worker from in-patient care to communicate the prognosis and to handle end-of-life care issues. Her husband was 19 years old. She had a lesser understanding of the illness and was highly distressed due to the death of a baby. The patient was in a critical situation with a poor prognosis. She expired in the hospital.

We lost our child, and I'm not able to grieve also properly. My wife is serious now, and I am running here and there to arrange for her medical support, at least I want my wife alive.

Themes emerged: Loss, Grief, helpless, unrealistic expectation

Out of 33 quality indicators for palliative care,[11] 24 were relevant for chronic neurological conditions, and most of these indicators were illustrated in the above five case series reports.

Palliative care indicators for neurological disorders

1. ADL dependent
2. Advanced stage of illness
3. Burden among caregiver
4. Bedridden
5. Chronicity of illness

6. Cognitive decline
7. Deteriorating condition
8. Disabling condition
9. Degenerative conditions
10. Progressive nature of illness
11. Incurable illness
12. Life-limiting disorders
13. Loss of functions
14. Poor prognosis
15. Muscle mass decline
16. Non-responsive to active treatment
17. Rapid Progression
18. Reduced oral intake
19. Swallowing difficulty
20. Speech difficulty
21. Treatments are no longer beneficial
22. Uncertain recovery and uncertainty of living
23. Urinary incontinence
24. Weight loss (10%) in the last six months.

DISCUSSION

These five case reports shed light on various psychosocial issues in dealing with individual, family, and palliative care aspects of persons with chronic neurological disorders. Patients who need palliative care go through multiple psychosocial issues, such as emotional symptoms such as anxiety, depression, fear of death, limitation in social functioning, work-life, role changes in the family, dissatisfaction with life, poor quality of life, and financial constraints.

This case series analyse the gap between providing generalist and specialist palliative care, rehabilitation, and end-of-life care. There are several indicators for palliative care for individuals with chronic neurological disorders. However, the commonly observed indicators are ADL dependent, advanced stage of illness, caregiver burden, bedridden (reduced oral intake, urinary incontinence), and chronic nature of the illness. The services provided are generalist palliative care at the initial phase, and very few got end-of-life care services. Thus, initiating palliative care services is strongly recommended to address the palliative care needs of patients in neurology. It is crucial to have a multi-disciplinary approach to integrate palliative care in tertiary care settings.

Multi-disciplinary team approach

Effective palliative care in neurology requires a multi-disciplinary approach that includes the family's use of available community resources. It can be successfully implemented even if resources are limited. It can be provided in tertiary care facilities, community health centres, and even at home.[6] The teams usually consist of doctors, social workers, nurses, occupational therapists, physiotherapists, speech therapists, psychologists, and dieticians.

Palliative care not only provides relief from pain but also enables access to other services such as counselling for caregiver burden, psychological suffering of patients and family members, and coping with a life-threatening illness. Most importantly, to ensure that a person dies with dignity. The implementation of palliative care goals and procedures in neurology needs to be considered according to the specific neurological conditions in terms of symptoms, clinical course, disability, and prognosis. The practical palliative approach to neurological diseases requires particular skills and expertise to adapt the concept of palliative care to specific disease conditions.[13][14]

The complex needs of neurological patients can be managed with a comprehensive multi-disciplinary team that addresses the physical, psychological, social, spiritual, and existential needs to reduce suffering. Early discussions about prognosis, goals of palliative care, and advance care planning are critical as they can guide treatment decisions and allow patients to regain a sense of autonomy despite progressive cognitive or functional decline.[15]

There are specific, less recognized needs in neuro-palliative care, such as caregivers' helplessness in handling the death of their loved one without any external support, which brings lots of ambiguity and unaddressed grief among caregivers. Caregivers demand medical management for a patient's pain relief. Caregivers often share the experience at the end of the phase with their loved ones as traumatic. Multi-disciplinary teams are unavailable at the end phase, requiring more nursing or hospice care. This often brings a sense of not terminating the cases as patients' and families' expectations add to their confusion and worries. This signifies the importance of integrating all available services to meet the palliative care needs of the patients as well as dealing with the caregiver's emotional distress at the end of the life stage.

More studies are needed on palliative care for patients with neurological conditions.

However, few studies highlighted palliative care for degenerative diseases. Palliative care needs were higher among family members who had a more significant burden due to neurodegenerative conditions. Few studies have shown that professional palliative care in dementia by a multi-disciplinary team brings differences in advanced dementia while treated in a hospital.[16],[17] Home-based palliative care consists of identifying and addressing motor and non-motor symptoms, medication errors, home safety issues, and unmet psychosocial needs and implementing assessment and care plans, including referrals to in-home therapies and community resources.[18]

Cochrane review of three RCTs of palliative care interventions was uncertain in benefitting people with multiple sclerosis (MS). There is insufficient evidence regarding the difference between palliative care versus usual care for long-term health-related quality of life, adverse events, and hospital admission in patients with multiple sclerosis. Following palliative care, outcomes such as fatigue, anxiety, depression, disability, cognitive function, relapse-free survival, and sustained progression-free survival may be measured in MS.[19]

Psychiatric social workers play a vital role in palliative care in communicating bad news, pain assessment and management, advance care planning, addressing caregiver burden, end-of-life care issues, and appropriate referral to hospice care and other palliative care services.

There are five primary goals in providing palliative care for chronic neurological conditions. They are improving the coping skills of the individual and his or her family, Screening for psychological distress, Enhancing the self-worth of the family system as well as the individual, providing specific symptom relief, enhancing the responsiveness of the environment.

Social Casework

The social workers provide palliative care using social work skills such as active listening and empathizing with individuals' physical, emotional, and psychological problems. Patients often have death wishes, suicidal thoughts, depression, and anxiety. The person may suffer from pain due to illness, psychological problems like fear of dealing with illness, disability, unemployment, limitation in mobility, lack of coping with the illness, which would trigger death wishes or suicidal thoughts, and other unaddressed psychosocial stressors that may lead to anxiety and depression. Working on individuals' coping strategies and pain management techniques and identifying the individual's strength by looking at things from strength perspectives would relieve them from physical and emotional pain and help them deal with illness and cope spiritually.

Pain management

The source of the pain is not always due to illness. It gets aggregated for various physical, social, psychological, and emotional reasons. It requires a multi-disciplinary approach to reduce pain caused by physical symptoms. Art therapy, music therapy, yoga, touch therapy, diversion therapy, and psychological support would help in reducing the pain.

Spirituality

Spirituality is another culturally accepted form of therapy that responds well to life-threatening illness at the individual and familial level. The goal is to help patients cope with their depression or anxiety related to illness. Reassuring them helps them focus on good memories, achievements, and existing strength, directs them toward finding meaning in their life, and helps them live with dignity.

Family Casework

The chronic nature of neurological illness affects the entire family's functioning from providing care, financial support, and caregiving. Socioeconomic status often interrupts providing care, causes a lack of support in physical caregiving, causes property issues, and changes the family structure. The primary challenge is communicating the prognosis to the family about the patient's diagnosis, disability, and prognosis, preparing the family members to face the crises (acceptance of death). The communication skills needed to convey negative information about patient health conditions need to be simple enough that families understand it without harming their cultural sentiments when revealing the prognosis to the individual.

Addressing caregivers' burden

Caregiver's burden and mental health concerns due to the chronic nature of the illness, disability, providing care for patients, and fear of losing patients would bring loss of negative emotions, grief, and depressive feelings among caregivers. Reassuring them and addressing their stressors, mental health concerns, and role reversal in caregiving is important. Mobilizing resources, networking, facilitating legal discussion, and providing appropriate aid would enable the family to reduce the burden of family caregiving and ensure patients' quality of life. Most families are unable to afford aids, waterbeds, and catheter management. Preventing infections and bedsores requires supervision and training. Thus, institutional palliative care provides a way for it and reduces anxiety among families to deal with it with guidance.

Communicating Prognosis

Communicating prognosis is the most challenging interaction between the patient and the health care professionals as it conveys negative news about illness, chronic illness, disability, and death. Acquiring all information from the patient's medical record, interacting with patients and family, and understanding illness and what outcome they expect from treatment are essential in planning the layers of breaking the bad news. Understanding the cultural background, how death is treated in their culture, and having a genogram of who is close to the patient would help communicate the prognosis. Especially in the Indian scenario, death, disability, or poor prognosis is not encouraged to be discussed with patients directly, though it is ethical. Hence, the bad news is often broken into the patient's plans after considering the family's interests and preferences. Breaking the bad news is a must to communicate in a patient's native language, which makes it easier for them to understand, comprehend, and express their feelings.

Palliative care assessment tools:

Tools that can be used in the assessment of palliative care are the Edmonton Symptom Assessment Scale (ESAS)[20], the palliative performance scale (PPS),[21] the palliative outcome scale (POS),[22] and Support and palliative care indicator tools (SPICT).[23]

Breaking *the bad-news*

SPIKES[24] Model is followed to break the bad news. Setting up the environment, Perception of the family members regarding illness, Invitation: Allowing the patient and the family members to discuss more about the illness. Knowledge: the information can be shared with patients and family members based on their knowledge of illness. Emotions: empathize and acknowledge their emotions, such as anger, denial, sadness, and bargaining; listen to their agony and validate their reason. Summarize the content of the session at the end.

Grief therapy

Enabling clients to accept and cope with the loss due to neurological disorder, validating their painful emotions, helping them to find meaning in their life, and helping them to understand that kind of feeling is expected in an incurable illness.

Challenges: A few Challenges in providing palliative care in neurology are lack of dedicated bed availability, lack of referrals for palliative care, lack of palliative care special clinics/units, non-implementation of insurance coverage policy for palliative care, lack of infrastructure, trained professionals, less supportive policy and advocacy, and cost of palliative care services.

The other challenges are timelines of disease progression, communication barriers, variability across disease progression, a threat to personhood arising from functional and cognitive impairments, uncertainty in prognosis, non-availability of social support system and disease trajectory, and inconsistency in information, attitudes, and skills among care providers.[25]

Strategies to strengthen palliative care

In 1996, the American Academy of Neurology Ethics and Humanities Subcommittee recommended that neurologists apply the palliative care principles for neurological patients as many die after a prolonged illness. The Accreditation Council for Graduate Medical Education requires neurology residents to receive instruction in end-of-life and palliative care.[18] Training programs for neurologists, social workers, and nurses in palliative care for neurology. Improving access to opioid pain relief (including revising national legislation and prescribing rules). National health policy on integrating palliative care in the treatment of non-communicable disorders, mental health disorders, and neurological disorders. The International Neuro-palliative Care Society (INPCS) was launched to promote the integration of palliative care within neurological services. European Association for Palliative Care (EAPC) and the European Academy of Neurology (EAN) strongly recommended palliative care for neurological illness, particularly when communication and cognition are impaired.[26]

Neurologists need to know the potential benefits of palliative care for their patients. There is an emphasis on integrating palliative care for chronic neurological conditions.[27] Neurological services and resources are inadequate for patients in most parts of the world, and there are inequalities in accessing neurological care across different populations, especially in developing countries. New Policies, programs, and increased resources to establish neuro-palliative care are highly recommended to ensure the dignity of the death of patients and caregivers' mental health.

Strengths of the study

This study uses five unique case series reports to highlight the unmet palliative care needs of persons with neurological illness in a tertiary care setting. The authors described the range of palliative care services provided to patients with neurological disorders. The possible benefits of palliative care for neurological disorders would be avoidance of doctor stopping, further investigations, and unnecessary follow-up visits which are no longer beneficial, reduction in caregiver burden and unrealistic expectations, relief from psychological distress, acceptance, better coping with illness, knowledge about of outcome of the illness; few were informed to avail disability welfare benefits which they are entitled, prepared them for home-based palliative care, advanced care planning, making appropriate family-related decisions, discussion about their unfulfilled wishes, dealing the patient with dignity. No family members wanted to place the patient in an institutional care setup for palliative care. Many ventilated while communicating prognosis.

The unique characteristics of neurological disorders, such as chronicity, progressive, incurable, disabling, and life-threatening nature, warrant palliative care in these case reports. Few patients were linked with community agencies and resources that provide home-based palliative care in terms of physical care, physiotherapy, and other related services free of cost. Most patients received some components of palliative care, and mainly, their psychosocial issues were addressed, which most palliative care services lack. This study highlighted the need for access to palliative care resources and the range of palliative care services provided to patients and families in low-resourced tertiary care settings. The unique list of palliative care indicators for neurological disorders was outlined, though they were not specific and different from other disorders. Assessments in neuro-palliative care and social work interventions were tailored to neurological illness, which was the main strength of the study. Palliative care practice guidelines for neurological disorders were described.

Limitations

Most outpatients were provided palliative care in a single session. Many could not turn up for follow-up for various reasons, such as the treating team discouraging follow-ups, which are no longer beneficial, longer distance to travel, and issues related to patients' mobility. Hence, it is difficult to objectively assess the outcome of palliative care for neurological disorders. Complexities in providing specialized palliative care limited the patient's access to the needed care. For outpatients, critical palliative care services such as spiritual support and other supportive services could not be provided due to time limitations, infrastructure, and lack of a specialized, certified neuro-palliative care team.

CONCLUSION

Palliative care services in neurology are at the infant stage. There needs to be more awareness about the need for palliative care for chronic neurological disorders among social work trainees, neurology trainees, and other health care providers. Persons with chronic neurological disorders often have limited access to palliative care. Hence, there is a strong need to increase awareness about palliative care for persons with chronic neurological disorders.

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