

A Qualitative Study on Palliative Needs of Stroke Patients in an Indian Tertiary Care Setting - Doctors' Perspective

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Abstract

Introduction: Stroke is the development of a focal neurological disturbance lasting >24 h, of vascular origin. In India, stroke is one of the leading causes of morbidity and mortality. Most stroke patients, during their duration of treatment and posthospitalization, want relief of suffering, a sense of control and minimized burden on the family. **Aim:** The aim of this study is to describe treating doctors' perspectives on the palliative needs of stroke patients in India. **Methodology:** This qualitative study was conducted at a tertiary care hospital in South India. A total of 17 doctors involved in the care of stroke patients were interviewed, using an interview guide. The interviews were audio recorded simultaneously. The audio recording was transcribed verbatim, and the data were coded using a grounded theory approach. An inductive approach using thematic analysis was used to manually analyze the data. **Results:** Eight themes emerged. (1) Functional disability: loss of independence due to immobility, speech deficits, visual disturbances, feeding difficulties, and incontinence cause immense distress. (2) Physical burden: pain in the form of central poststroke pain, periarthritic shoulder, psychogenic pain, and various sequela of chronic bed bound state like bed sores and pneumonia add to the burden. (3) Psychological needs: depression is common in stroke patients along with other psychological issues such as anxiety, agitation, apathetic state, and behavioral disturbances (4) Social issues: Cost of treatment of stroke patients coupled with their loss of employment leads to huge economic burden. They also face abandonment by children or spouse, in all sections of socioeconomic strata. (5) Caregiver burden: caregiver has a major role in a setting of stroke and in the long-term affects all domains of their lives, compromising their psychological and physical health. (6) Counseling-an unmet need: counseling is particularly important in a setting of stroke for the patient as well as the caregivers and results in a better patient outcome. However, clinicians expressed that it was inadequate due to the huge patient load, time constraints, and lack of effective counseling skills. (7) Spiritual needs: few clinicians stated that existential distress and spiritual struggle are seen in debilitated stroke victims and are often unaddressed. (8) Issues at the end of life care: patients with massive stroke, multiple comorbidities, and poor rehabilitative potential requires end of life care. **Conclusions:** From the interviews of the clinicians, we can conclude that care of a stroke patient is more than medical management and rehabilitation, as several other aspects of the patient's life are affected by the condition. The quality of life aspect has to be looked upon as an area that requires active intervention in a setting of stroke. Physical disabilities were viewed as the most significant factor in reducing the quality of life. Spiritual needs have a low priority in comparison to other physical needs. Due to high patient load and time constraints, many of the needs are unaddressed. Two important areas where palliative medicine has a major role in a setting of stroke are counseling and alleviating caregiver burden. However, referral of stroke patients to palliative medicine is low and further research to identify barriers to specialist palliative care of stroke patients will help in promoting the referrals to palliative medicine.

Keywords: Care, needs, palliative, stroke

INTRODUCTION

Stroke as defined by the WHO is “the rapid development of clinical signs and symptoms of a focal neurological disturbance lasting >24 h or leading to death with no apparent cause other than the vascular origin.” In India, stroke is one of the leading causes of morbidity and mortality, with an estimated age-adjusted prevalence rate of 84–262/100,000 in rural and 334–424/100,000

in urban areas. According to recent population-based studies, the incidence rate is 119–145/100,000.^[1]

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Access this article online

Quick Response Code:



Website:
www.jpalliativecare.com

DOI:
10.4103/IJPC.IJPC_161_18

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How to cite this article: Lloyd J, Pinto AM, Nair S, Tarey S. A qualitative study on palliative needs of stroke patients in an Indian tertiary care setting - Doctors' perspective. *Indian J Palliat Care* 2019;25:84-91.

Management of stroke chiefly consists of thrombolysis and secondary prevention. Formation of organized stroke units in developed countries has led to a decrease in stroke mortality.^[2] However, in low- and middle-income countries like India, a lack of resources leads to inadequate organized care of stroke patients.^[3] Along with the increase in survival rates among stroke victims, there is an increase in the number of debilitated stroke patients who have a prolonged stay in the hospital, bed bound at home or institutionalized in hospice care. The quality of life poststroke is drastically reduced.

Palliative care is defined as an approach that improves the quality of life of patients and their families facing the problem associated with a life-threatening disease. Palliative care in the past was mainly associated with cancer patients, but today palliative needs of individuals with other noncancer diseases, especially neurological diseases are increasingly being recognized.^[3]

Stroke care is influenced by decisions that are clinically challenging, emotionally taxing, and ethically complex. Most stroke patients, during their duration of treatment and posthospitalization, want relief of suffering, a sense of control, and minimized burden on the family.^[4] Palliative care seeks to improve the quality of life of patients and families through the identification, prevention, and relief of pain and suffering in body, mind, and spirit. However, the palliative needs of stroke patients are often poorly investigated.^[5]

Many stroke survivors are often unable to state and describe their needs and concerns, and clinicians need to be aware of their palliative needs and ensure that these needs are met. Studies show that an average Indian patient with moderate-to-severe pain from a disease is unaware that there are effective medications to relieve the pain.^[6] Many patients continue to have poor symptom control and unmet palliative needs, long after the onset of the stroke.^[7]

Previous studies have identified pain, dyspnea, anxiety, depression, agitation, incontinence, fatigue, poststroke seizures, sexual dysfunction, and sleep-disordered breathing as common palliative needs among stroke patients.^[8,9]

Ntlholang *et al.* said that in stroke patients with progressive chronic comorbidities, intensive palliative care is the predominant focus, and goal for the remainder of their lives.^[10]

In India, the awareness regarding the scope of palliative care is low among professionals as well as the patients,^[11,12] and only limited information is available on the number of stroke patients who received palliative care.^[13]

This study aims to assess physicians' perspectives on the palliative needs of stroke patients and to identify these needs.

This is a very important area of research that has not been undertaken in our country. A physician's understanding of the palliative needs of stroke patients will promote the number of references to specialist palliative care.

METHODOLOGY

Design

This study follows a qualitative design, utilizing an interview guide. Inductive qualitative research guidelines were used to conduct this study.

Participants

The study was conducted at St. John's Medical College Hospital, a tertiary care hospital in South India. The sample comprised 17 qualified doctors involved in the care of stroke patients from Departments of Internal Medicine, Neurology, and Physical and medical rehabilitation. Convenience method of sampling was employed. Interviews were conducted until data saturation was achieved. The sample size was determined using this method.

Procedure

The participants were approached individually and primed regarding the study. A convenient time and place were arranged with each doctor, to conduct the interview. Written informed consent was taken before the interviews. Two investigators conducted the interviews which were face-to-face, in-depth, and semi-structured. Open-ended questions were asked using an interview guide designed by the authors. The interview was audio recorded simultaneously. Privacy and confidentiality were maintained throughout the process. Pilot testing of the interview guide was done over the course of three interviews, which were noninclusive. The average duration of an interview was approximately 40 min. The audio recording was transcribed verbatim and independently coded by the two investigators manually.

Analysis of data

The transcripts were analyzed using iterative and interpretative approach. Two analysts independently coded the entire data set manually. An inductive approach using thematic analysis was employed wherein new ideas and themes were allowed to emerge without any prejudice. The emerging themes, categories, and subcategories were identified. This was followed by in-depth discussions and sharing of coding patterns between the analysts so that there was a common understanding of the categories generated. This gave way to a final coding template, and the entire data set was then coded and analyzed.

RESULTS

Eight themes emerged:

1. Functional disability
2. Physical burden
3. Psychological needs
4. Social issues
5. Caregiver burden
6. Counseling-an unmet need
7. Spiritual needs
8. Issues at the end of life care.

Functional disability

Loss of independence due to various functional disabilities was considered the most important factor that reduces the quality of

life of stroke patients, according to the clinicians. Among the various functional disabilities, immobility due to hemiparesis or hemiplegia was considered the most significant one. Other disabilities include speech deficits, visual disturbances, feeding difficulties, and incontinence.

Speech deficits due to aphasias and dysarthrias, visual disturbances mostly due to hemianopsia, reduced visual acuity and diplopia, feeding difficulties due to dysphagia and nasal regurgitation are commonly seen. Patients with a large stroke might also have cognitive impairment and delirium.

Most participants also stated that bowel and bladder incontinence is a major issue seen in many stroke patients. Patients with bladder incontinence require catheters, which increased the risk of urinary tract infections and catheter-related injuries. Bowel incontinence requires the use of diapers. However, in bedridden patients, constipation is also seen and may require enemas.

These functional disabilities, resulting from stroke, prevent them from doing activities of daily living and become dependent on a caregiver, causing immense mental distress in them.

“There are many disabilities stroke patients suffer from, but I think the most significant one is immobility, which affects their independence and their daily activities. Then there are swallowing difficulties and speech difficulty. Patients with aphasia have more problems. Many have problems of bowel and bladder incontinence, cognition and behavioral disturbances.”– (P7)

Physical burden

The physical burden in stroke patients emerged as a major theme, of which pain was viewed as a prominent issue.

Pain

Most physicians stated that pain is a common symptom that affects the quality of life of stroke patients. Based on the views of the participants, pain in stroke victims can be broadly categorized into the following:

Central pain

The clinicians stated that this is mostly seen in a thalamic stroke, where the patient usually describes it as a burning pain or “pins and needles” sensation on the side affected by stroke. Most clinicians were aware of the nature of central poststroke pain, but most of them concurred that in a clinical setting it is often difficult to elicit the exact nature of the pain due to the patient’s cognitive dysfunction or aphasia. Often the doctors consider it to be a peripheral pain, which is more common than central pain and start them on NSAIDs or opioids. These medications are not very effective for central pain. All the participants were aware that central poststroke pain is to be treated with medications such as Amitriptyline, Pregabalin, or Gabapentin, but admitted to rarely starting them on these drugs until very late.

“When a stroke patient complains of pain, we usually start them on paracetamol, and then move up the WHO ladder for pain management”– (P4)

Peripheral pain

- **Shoulder pain:** All the participants unanimously agreed that the most common form of pain seen in stroke patients is shoulder pain. Participants stated that the etiology of the pain is not clearly understood and multiple factors may contribute to it. Most participants had not tried anything other than Nonsteroidal anti-inflammatory drugs (NSAIDs) and opioids. Many said that physiotherapy could help improve the condition. Few of the physiatrists who were interviewed stated that uncontrolled pain often interferes with the rehabilitative process
- **Multiple aches and pain:** many clinicians encountered complaints of nonspecific aches and pains over different parts of the body, commonly occurring a few weeks to months after the onset of stroke. Most of the patients who experienced this were the elderly. Some participants attributed it to other underlying conditions unrelated to stroke, such as osteoarthritis. *“... most of these patients had similar mild pain symptoms even before the onset of stroke, but once they are in a bed bound state, they don’t have any distractions and tend to concentrate more on the pain, and they feel that their pain is more now.”*–(P8)
- Other factors contributing to peripheral pain include:
 - Allodynia, which is an exaggerated response to normal stimuli
 - Deep bed sores eroding the nerves
 - Catheter infections.

Psychological pain

Many clinicians stated that there is a psychological component of pain.

“...Stroke patients are in a lot of psychological distress and this can sometimes manifest as physical pain.”–(P9)

However, most of them stated that they do not put this knowledge of “psychological aspect” of pain into clinical practice while managing pain in a patient.

“...Most of the time, we fail to look into the psychological component of the pain. When a patient complains of pain, we start them on some analgesics and wait for them to respond.”– (P12)

- Other factors contributing to physical burden:

Patients with long-term deficits and bed bound for prolonged periods have numerous other problems as stated by various participants.

- Pneumonias due to aspirations, requiring frequent hospitalizations
- Bedsores due to prolonged bedridden state
- Contractures
- Frequent urinary tract infections
- Discomfort caused by the use of Ryle’s tube, catheters
- Superadded infections
- Deep vein thrombosis.

Psychological needs

From the interviews of clinicians, psychological effects of stroke were a major theme that emerged, of which depression was viewed as the most common.

Most clinicians were of the opinion that the psychological effects stemmed from the sudden change from being a fully functional individual to one who is dependent on others for activities of daily living. Loss of employment and financial issues also added to the psychological burden on the patients.

All the participants stated that depression is very commonly seen in stroke victims. Few neurologists mentioned that nearly 20%–30% of stroke patients develop clinical depression over a period of 2–3 years if they are not rehabilitated well. Some doctors mentioned that patients have difficulty in adjusting their expectations to fit their disability and often lash out at family members or withdraw. The lack of counseling and motivation can also worsen psychological conditions.

“... if the affected person is the sole breadwinner of the family and the entire family is dependent on them and then they become bedridden, they go into a severe state of depression...”–(P10)

Other psychological issues mentioned were anxiety, apathetic states, agitation, emotional lability, guilt, lack of confidence, fatigue, behavioral disturbances, decreased attention span and sleep disturbances.

“Some of them have anger towards their illness and refuse to continue care. Then there are those who are apathetic. They have a feeling that what is the point of doing all this and they go into a negative apathetic state”–(P3)

Social issues

Many participants stated that stroke, being a cause for long-term disability, can give rise to many social problems faced by the patients and their families.

Social issue that recurrently came up during the interviews was the financial burden of caring for a stroke patient, especially if an earning member of the family was affected.

Caring for a stroke patient who is bed-bound also forces the caregiver into unemployment or loss of work hours. Cost of medication, visits to the doctor, physiotherapy sessions, and travel to a tertiary center increases the expenditure of the family. Many clinicians highlighted that stroke patients require hospitalization and follow-up for long durations and most patients in an Indian setting cannot afford prolonged hospital care.

“Lots of these patients are from a poor socioeconomic background. They cannot afford treatment for such long periods. Money becomes a big issue.”–(P14)

“The attender is needed to bring the patient to therapy. That itself is a big constraint. He will have to leave his job or take off for a week or two, and then also they are not hopeful. They know it is not going to change much.”–(P11)

Few participants mentioned that patients suffering from stroke have also faced abandonment and institutionalization by spouse or children, in all sections of society.

“Lots of patients who are married go through divorce and children leave them. Nobody can leave everything else in the world and just be with the patient.”–(P7)

Some clinicians were of the view that neglect of a stroke patient exists in all sections of society, irrespective of their financial status. It was suggested that individuals from higher strata of society do not have enough time to take care of the patient, while those from a lower strata of society do not have the means to take care of them.

“People from lower socioeconomic strata, they will be there to take care of the patient but they won't have money because most of them may be farmers and unemployed. People from the higher strata, the children are not there to look after them, to give them moral and emotional support.”–(P6)

Gender bias was a point brought up by few of the participants which highlighted that the amount of care given to a male stroke patient was more than that given to a female.

“In an Indian scenario, the female will look after her husband if he gets a stroke. In a similar way, the parents will look after the son. But if a married female has a stroke and someone has to take care of her, then it is very difficult. In the Indian scenario, the support system is not so strong for the female who suffers a stroke. Otherwise it is her parents who look after her. But after marriage with children it becomes very difficult.”–(P7)

Caregiver burden

All the participants were of the view that, caregiver burden is unacceptably high in a setting of stroke, compared to other chronic conditions. They attributed it mainly to the long-term disability.

“...During the first week, the family members are mostly worried about the disability, they ask questions like, “when will he start walking again?”, “When will he start talking”.”–(P14)

From the information gathered from the clinicians, it was suggested that:

- During the initial phase, the main factors that contribute to caregiver burden are patient-centric, which may include:
 - Distress due to the current state of the patient
 - Unaddressed queries regarding the condition and management plan
 - Assisting the patient with activities of daily living-toiletry, bathing, feeding and ambulating
 - Apprehension about the recurrence of the stroke.
- However, in the long term, the factors contributing to caregiver burden are mostly caregiver centric:
 - Mental exhaustion
 - Time constraints
 - Loss of employment
 - Financial issues

- Restraints in social life
- Depression in caregiver.

The participants stated that, in an Indian setting, it is almost always a family member who takes care of the patient, and professional caregivers are rarely employed. Many a time, the caregiver has to give up his/her job to look after the patient. Over a period of time, this affects all domains of the caregivers' life and even cause clinical depression in them.

Although the clinicians are aware of the caregiver burden, most of them stated that they do not adequately counsel the family nor discuss the caregiver issues with them. All of them attributed it to the huge patient load, time constraints and inexperience at counseling.

All the clinicians strongly agree that the palliative care team can be highly beneficial in counselling the caregiver and alleviating the burden. A few suggested a long-term follow-up plan with palliative care team, as an option that can be considered, for the patient and the caregivers to discuss and address their issues.

Counseling-an unmet need

All the clinicians strongly agree that counseling is absolutely essential in a setting of stroke in view of the complex nature of the disease, sudden onset of several disabilities and the immense distress the patients and family experience. However, most of the participants felt that the counseling is inadequate, because of the huge patient load, time constraints, and lack of adequate training in counseling skills.

"In a hospital like this with a huge patient load, I don't really have that much time to give for each patient. I don't get the time to sit down, talk to them and counsel them about the condition and the outcomes"-(P11)

The participants stated that many patients and their family members are not completely aware of the nature of the condition. Doubts regarding how it happened, the duration of the debilitated state, outcome of therapy, recovery, recurrence, etc., are common. In an Indian tertiary hospital setting, a majority of the patients are of poor literacy and from various linguistic and cultural backgrounds. Often the physicians, due to their time constraints, are unable to look at the various aspects of their background, i.e., cultural and social factors, and tailor the explanation and counseling to their level of understanding.

One of the physicians said:

"I don't think I'm adequately trained to do counselling at this level, to make the patient accept and adjust to the condition, and to explain to them at their level of understanding".- (P6)

Few of the participants stated that many patients are in an apathetic state and require extensive counseling to put them in the "right frame of mind" to focus on improving. Physiatrists stated that counseling and motivating them are needed to help them go through their rehabilitation exercises.

Spiritual needs and existential distress

Few clinicians stated that existential distress and spiritual needs are seen in debilitated stroke victims and are often unaddressed.

"Following an event like stroke, the patient may not be able to withstand that kind of an onslaught and this causes a lot of spiritual struggle and existential distress in them."-(P16)

"Frequently they ask questions like, "What have I done to deserve this", "Why has God punished me, I have never harmed anyone"."-(P8)

However, most clinicians did not view spiritual needs as a significant issue.

Issues at the end of life care

Many participants stated that patients with massive stroke, multiple comorbidities, and poor rehabilitative potential may require end of life care. Although most participants felt the need for the end of life care in severely affected stroke patients, there was a lack of clarity about the stage at which it has to be provided.

One of the neurologists said:

"... only severely affected patients with other co morbidities, where their life span is reduced and quality of life is reduced, and the family doesn't want any active medical management, then we refer to palliative medicine."-(P11)

Few clinicians mentioned that palliative care was sought when family members had to be counseled about decision making for stroke patients with a poor prognosis.

Few participants mentioned that due to the high turnover of patients, they were unable to provide adequate counseling to patients requiring end of life care and had advised them to be transferred to a local hospice facility.

DISCUSSION

Along with the decline in mortality in stroke patients, there has been an increase in the number of stroke survivors with residual disabilities and impairment. These disabilities interfere with quality of life poststroke.^[14] Studies have shown that the prevalence of disability among stroke patients between 24% and 54%.^[15] Physical inactivity has also shown to be linked to the prevalence of poststroke depression (PSD).^[16]

Although all the doctors acknowledged the prevalence of pain in stroke patients, most of them suggested that they do not consider pain as a significant medical symptom in a setting of stroke. There seems to be a lack of clarity on the appropriateness of following the WHO ladder for pain management in stroke, as it does not cover the management of central pain at least in the initial steps.

Clinicians need to be more aware and be able to differentiate a central poststroke pain from peripheral pain and administer the appropriate form of treatment.

Physiatrists stated that pain often interferes with the process of rehabilitation leading to discontinuation and poor outcome.

Studies have shown that early rehabilitation is required in stroke for a better functional outcome.^[17,18] Therefore, pain management should be carried out from the initial phase of treatment in stroke patients to produce a better outcome.

Previous studies suggest that there is an association between pain and increased levels of anxiety, agitation, and depression in stroke patients.^[19] Clinicians are aware of the psychological aspect of pain but measures taken to address the issue is inadequate.

According to a study by Kim, the major psychological issues that arise are PSD, poststroke anxiety, poststroke fatigue, poststroke anger proneness, and poststroke emotional lability.^[20] In our study, PSD was the most common psychological issue discussed.

A study done in India states that the prevalence of PSD is 35.29%, as defined by International Classification of Diseases-10. There was a significant correlation between male gender, being married, and living in a nuclear family with PSD.^[21] According to a study, among stroke survivors, depression is said to be the strongest factor influencing the poor quality of life.^[22] Studies have also associated PSD with the worse rehabilitative outcome, cognitive impairment, increased disability and risk of falls, as well as, increased mortality.^[23] PSD has also been linked to decreased efficiency in usage of rehabilitative services.^[24,25] PSD was also found to be predicted by baseline depressiveness and social support.^[26,27]

Caregiver burden is high in a setting of stroke. Studies show that caregiver burden often results in psychological and physical health compromise in the caregiver.^[28] Due to time constraints, most patients and family members are not counseled regarding caregiver burden and coping strategies during the hospital course or when they get discharged.^[29,30]

Studies show that educating caregivers about coping strategies and time management help reduce the burden.^[31,32]

Few physicians suggested a palliative care team input to the family members during the hospital stay, and a long-term follow-up plan with a palliative care specialist as an option that can be considered to address the caregiver issues.

Stroke is a cause of long-term disability and leads to many social issues. Studies have shown that the availability of social support was determined by gender, education, and pre-stroke employment.^[33] Quality of life poststroke was determined by social support, according to King.^[34]

A good counseling session with the patient and the family will help them to cope with the situation better, make them realize the importance of early physiotherapy and be more compliant with the medications and lifestyle modifications needed to prevent recurrence.

For patients with severe stroke, multiple comorbidities and poor rehabilitation potential, the primary focus should be to provide good palliative care. The palliative care team can assist

in counseling the patient and family, help in decision-making and alleviate psychological and existential distress in the patients.^[35]

There are limited data on end of life care in stroke patients, although it is a significant public health issue. Studies have shown that there is less communication from the physician about the transition to the end of life care in stroke patients, compared to patients suffering from cancer.^[36,37] Similarly, clinicians interviewed in our study stated that there was inadequate counseling regarding the end of life care, attributed to the lack of clarity, high turnover of patients as well as time constraints.

Based on the themes that emerged, a few ways palliative care can help in a setting of stroke is outlined below:

- **Functional disability:** the huge increase in the number of stroke survivors with residual functional disabilities and impairment puts a huge burden on the primary care team and often these patients have a prolonged stay in the hospital without much intervention. Palliative care team has a potential role in helping them with transitioning to a life outside the hospital with these disabilities, by offering education and psychological support, which the primary care team due to their time constraints, may not be able to offer
- **Physical burden:** physicians and physiatrists expressed that pain is commonly seen in post-stroke patients and are often not given enough attention. Palliative care specialists are trained to look out for and effectively manage pain. They can be of great help especially when dealing with thalamic pain which may require careful evaluation and trial of different pain medications
- **Psychological needs:** though the physicians were aware of the psychological issues like depression and anxiety, the measure taken to address these issues were not adequate. Palliative care consult can particularly be helpful in addressing these issues and offering psychological relief
- **Social issues:** palliative care specialists are trained to look at how the disease affects the social dynamics within the family and community and their involvement would benefit the patient and the relatives to deal better with social issues like a financial burden, long-term follow-up and neglect
- **Caregiver burden and counseling:** caregiver burden is very high in a setting of stroke. Clinicians stated that they do not adequately counsel the relatives regarding caregiver burden and fatigue. Physicians strongly recommended that the involvement of palliative care team would help alleviate caregiver burden and provide an opportunity to discuss and address issues leading to caregiver burden and fatigue
- **Spiritual needs:** spiritual needs were not viewed as a significant issue by most clinicians. However, spirituality is an important component of quality of life and may be a key factor in how people cope with illness and achieve a sense of coherence. Addressing spiritual needs is one

of the important domains of palliative care, and their involvement would help alleviate spiritual distress that many patients may experience

- Issues at the end of life care: for stroke patients with a poor prognosis, counseling regarding the end of life care and transition to a hospice facility is another important area which palliative care team can address in a setting of stroke.

CONCLUSIONS

The physicians who were interviewed agree that stroke, being a condition causing high morbidity, requires a multidisciplinary approach. The needs of stroke patients that emerged are the management of functional disability, appropriate and adequate pain management, psychosocial support, adequate counseling, and addressing caregiver issues. Due to high patient load and time constraints, many of these needs are unaddressed. Palliative care has a definitive role in providing a holistic approach to the care of stroke patients as well as to alleviate caregiver burden. However, referral of stroke patients to palliative medicine is low and further research to identify barriers to specialist palliative care of stroke patients will help in promoting the referrals to palliative medicine.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

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