

Perspectives of Physicians Looking After Patients with Neurological Disorders Towards Palliative Care in West Bengal, India

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Abstract

Introduction: The proportion of hospitals providing specialist palliative care has increased considerably all over India. However, palliative care is yet to be integrated with services provided to patients with neurological impairment. Here, we present survey results describing the current levels of collaboration between neurology and palliative care services and exploring the views of professionals towards the integrated Neuropalliative care service.

Methods: Physicians (Internal Medicine, Neurology and Neurosurgery) looking after patients with neurological disorders at Medical Colleges in the state of West Bengal, India were approached via email to complete a comprehensive online survey.

Results: The survey received responses from 75 physicians. Overall, palliative care needs of neurologically impaired patients were considered different from patients in other specialities.

Conclusion: Our results demonstrate the opportunity to increase collaboration between neurology and palliative care services for people with progressive neurological conditions.

Key words: Palliative care, neurosciences

from neurological impairment. The ideal model of palliative care is still unknown although it is being considered as essential. Although neurosciences has grown rapidly with many subspecialties it has not been paralleled by studies or guidelines regarding how best to integrate palliative care into this unique patient population. Here, we present survey results describing the current levels of collaboration between neurology and palliative care services and exploring the views of professionals towards the integrated Neuropalliative care service.

Methods

Physicians (Internal Medicine, Neurology and Neurosurgery) looking after patients with neurological disorders at Medical Colleges in the state of West Bengal were approached via email to complete a comprehensive online survey. The survey was launched in August 2020 and closed on December 2020. It consisted of multiple choice or open comment questions with responses collected using online forms. Professionals were informed that by completing the survey, they provided informed consent for use of their anonymised data. The 10 item survey assessed a) Collaboration with Neuropalliative care services b) Barriers to Referral to Neuropalliative care Services. SurveyMonkey (www.surveymonkey.com) was used for survey distribution. The study protocol was approved by the Institute of Neurosciences Kolkata and Tata Medical Centre Institution Review Board.

Statistical Analysis

The primary aim of this study was to provide descriptive information about perceptions, practices and preferences of Neurophysicians. Categorical data are presented as numbers (%).

Results

The survey received responses from 23 Neurology, 15 Neurosurgery and 37 Internal medicine Professionals out of total 225 list serve members. Two-thirds of respondents had over 10 years of experience in their respective fields. Overall, palliative care needs of neurologically impaired patients were considered different from patients in other specialities by the majority of respondents (66%). Regarding the issue of collaboration with

Introduction

Palliative Care aims at improving the quality of life of patients and family by alleviating the patient's pain and other symptoms, providing psychosocial and spiritual support through a multidisciplinary approach. Unfortunately, palliative care has major focus on oncology in which there is convincing evidence 1 other specialties are just recognizing the essence of palliative care in principle where the results regarding integrating palliative care into the intensive care unit setting are mixed 2. Evaluations of services for palliative care in non-cancer conditions are few 3. Even less is known about the utilization of palliative care in the management of patients who are suffering

palliative care services majority of the respondents agreed (66.6%) that they preferred to work hand in hand with palliative care right from the time the patient is diagnosed with the neurological disease. The most common indications for palliative care consult was “ to manage symptoms - physical , psychological and spiritual, discuss goals of care and advance care planning” (66.7%) followed by ‘care of terminally ill patients’(50%). Majority of the respondents (80%) felt that they were neither uncomfortable nor indecisive in referring the patients for palliative care services. However (50%) of the respondents felt that referral to palliative care might have some negative effect on the psyche of the patients and their relatives who consider this as an act of abandonment on the part of the primary consultant. The concept of loss of autonomy in patient care as a barrier to referral to palliative care services was brushed aside as absolutely false by majority (80%) of respondents.

Discussion

Our data suggest that neurophysicians identify distinct palliative care needs in their patient population, value palliative care services, and have different views regarding the preferred way to integrate palliative care services to the treatment of patients suffering from neurological ailments. Despite substantial research into prognostic models after severe acute brain injury, prognostic uncertainty remains one of the most challenging issues in the field of neurosciences. In our study the most common indications for palliative referral were symptom management including both physical and psychological while issues related to care of terminally ill patients were less common. These observations were opposite to the available

literature 4 . This is probably due to the fact that most of the studies involving integration of palliative care into the management of patients who are neurologically impaired had been carried out in Neuro – ICU where neurologic catastrophe leading to a loss of neurologic function is more predominant than discomfort and pain. Our study therefore demonstrates that palliative care services in the form of symptom management may prove beneficial not only for terminally ill but also for all neurologically impaired patients as a whole. It is equally important for professionals caring for the neurologically impaired to have the right understanding of palliative care and to recognize the potential benefit of Neuropalliative care for their patients. Several limitations need to be considered in interpreting the results of our study. First, this was a survey study thus we do not know how accurate the questions relate to actual practice patterns. Second, the small number of respondents highlights the challenges of conducting research among busy health professionals.

Conclusion

Our results demonstrate the opportunity to increase collaboration between neurology and palliative care services for people with progressive neurological conditions. Future studies should consider evaluating the perceptions of palliative care specialists regarding consultations from neurophysicians. Other areas that should be explored include any differences in the perceptions of surrogate decision makers to help identify optimal outcome measures to evaluate the effects of palliative care interventions.