

## “More care, research and recognition” for neuro-palliative development

Neuro-palliative care is a newly emerging subspecialty in neurology and palliative medicine which as defined by World Health Organization, is the specialty that recognizes and attempts to alleviate physical, social, psychological, and spiritual suffering (1).

### “Holistic care” approach—mind, body and spirit

A critical element of neurologic disease monitoring and management is to understand and appreciate the core principles of palliative care, as the course of many neurologic illnesses is ever increasing and incurable (2). Neurologists are often regarded as consulting physicians due to their sympathetic nature towards their patients at the time of diagnosis or during acute illness and hospitalisation. Strong skill-set, practical experience and knowledge in the field is essential and critical when responding to the patient's wishes and needs and be able to handle challenging conversations and providing adequate symptom-based management response. It is often perceived by patients living with chronic neurologic diseases such as dementia, multiple sclerosis (MS), Parkinson's disease (PD), motor neurone disease (MND) and sequelae of stroke consider their neurologist as one of their main medical practitioners or physicians, thus positioning them both the outpatient and inpatient care settings. Apart from addressing the initial symptoms which are referenced to the disease or illness, it is also important to improve the overall quality of life for patients and easing the burden of the caregivers and to continue providing aid to the end of life care of the patient.

However, there are gaps or areas that require greater knowledge and understanding such as symptom control and psychosocial care to patients and support for the immediate family, such as other end organ failure diseases are also determined for palliative care (3). Patients with MND, advanced Parkinsonism and experience with serious stroke usually have major symptoms and complex psychosocial problems (4-6).

The significance of providing excellent care to failing patients and the necessity for improving symptomatic management to patients at the end of life have been acknowledged and understood by neurologists for many years (7). Despite this requirement, the neurologic practice has been limited to the widespread incorporation of palliative care and further challenges have been incorporated with the lack of knowledge with opioid dosing, titration and unease with prescribing analgesics (8).

A study was conducted in evaluating the pain medicine education and training among practising neurologists. It is noted, of the findings that 89% of respondents thought that more pain education was necessary in residency training, and 91% of respondents thought that more pain education was compulsory for practising general neurologists. General knowledge of the basic palliative care principles surrounding end-of-life care of neurologists' beliefs and attitudes was deficient and lacking in a survey founded and conducted in the United States (9). The study indicated that 37% of respondents thought it was illegal to administer analgesics in doses that endangered respiratory depression in terminally ill patients with MND, and 40% of respondents thought that legal advice was required to consider withdrawal of life-sustaining treatment. The American Academy of Neurology (AAN) educational programs have identified and have made efforts in addressing the knowledge gap among neurologists of palliative care.

Once a patient's diagnosis is recognized, the clinicians should then focus their diagnostic expertise toward early detection and management of the symptoms. Each neurologic disease has the profile of symptoms that can be addressed and managed even though for each disease may differ in characteristics. Any of the palliative care elements such as physical, psychological, spiritual, and social would provide for a better and deeper understanding of the sources of and contributions to an individual's suffering which are probing and continuing questions that needs to be addressed.

### Associated treatment with patient preferences

To assist the patient and the immediate family in establishing goals and objectives of present and future treatments (i.e.,

advance directives and procedures) principal aims in palliative care (in all of the medicine) are required in the process of shared decision-making (9). Equally important and imperative is to correctly diagnose the patient preferences for individual health outcomes and treatments besides correctly diagnosing symptoms and disease and together with knowing what the patient wants, needs and values should assist the clinician to provide suitable treatment and further recommendations to achieve successful results. The use of a “best case, worst case, most likely case” scenarios can be presented to patients and their families some insight into the range of possible outcomes, along with the most likely or expected results, which can help and establish a treatment with its potential trade-offs for both chronic and acute conditions such as MND and stroke respectively.

Along the disease cycle trajectory at various time points which these discussions occur, the need to renegotiate goals should also be anticipated when triggers of advancing disease advocate limited life expectancy or excessive suffering, due to the disease itself or from the high problems associated with life-sustaining involvements. Delaying such discussions can have profound and detrimental effects on the patients, the families and providers (9).

### **Lack of research and knowledge**

The lack of evidence-based knowledge and exploration is the primary factor restricting palliative care involvement in long-term neurological conditions on how this should be achieved. Models and templates of integration of neurology and palliative care or services have been very few and limited. Over a period of approximately 3 months, one Canadian palliative care study for patients with PD have shown their symptoms and well-being to have been improved (10). However, it is unclear exactly how and when the patients are referred and the exact intervention. An integrated model in advanced MS showed improvements in patients' symptoms, caregiver burden and costs after a 6 weeks intervention in which palliative care and neurology worked closely together which were revealed in the United Kingdom (11). However, whether this model together with its practicality and theories would also be appropriate and be successful in other neurological conditions and settings is still unclear and greater analysis is needed to be explored. There are only few research studies focusing on neuro-palliative care in comparison to cancer palliative care (#35168) and renal palliative care (#1954), according to Medline search (medical literature analysis and retrieval system online). Medical practitioners and specialist in this field recognizes the current advancement in research and development studies and continually strive to promote the highest professional standards and best practice of palliative care research and would support wide research distribution and work to assist the transformation of research evidence and findings impacting all aspects and phases of neuro-palliative care practice and policies. However, it is difficult and challenging to determine precisely the current status of neurology palliative care research due to many unknown variables on an international scale.

Therefore, “more care, research and recognition” should continue to develop at this stage to ensure greater understanding of advanced neurology diseases opted for palliative care and its after effects, thus hopefully ease the pain and suffering of the patient and lessen the burden to the immediate family and the caregivers.

### **Acknowledgements**

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