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NEURO-PALLIATIVE MEDICINE

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Most of the patients presenting to neurology services suffer loss of function in activities of daily living to variable extent, be it a diagnosis as acute as stroke, or one with natural course as insidious as myasthenia gravis. They need assistance with daily life activities, from mobility to swallowing to speech and much more. There is significant role of rehabilitation and physical exercises in movement disorders like dystonia, Parkinson disease in addition to those with stroke. Patients with demyelinating diseases are diagnosed at young ages and do exhibit some limitation in their activities of daily living.^{1,2}

It is observed that many chronic patients in neurology are advised the nation's most popular combination of paracetamol and orphenadine, and the magic red potion, injectable vitamin B complex because they didn't have any cure and this offered symptomatic management. In a regular clinic, I came across a family who kept their father chained in day hours, as he had advanced dementia and would physically manage to escape out of the house, while his sons would be away at work. They had to keep him locked up lest he harmed himself. The department's head was upset about it as he knew the patient from his early years, when he was an employee at the hospital and had a dynamic personality. Such instances made me wonder if there is some specialty taking care of these clinically negligible yet such significant patient issues.

The transition of a fully active human to a person with limited function is extremely distressful for the patient and their family, to say the least. As an outsider, nobody can imagine their plight, but being a physician caring for them primarily, one may imagine the challenges they have to face in daily life.³ Minor techniques related to feeding strategies help patients with neuromuscular junction disorders, motor neuron disease and chronic neuropathies.

As a neurology trainee, I counselled my patients with seizure disorder about the general precautions they must take, and triggers to avoid. I would be ecstatic when/ if some of them reported back with decrease in seizures by mere following of instructions and adhering to medicine timings. The feeling of making a difference to them, being able to provide some comfort in their lives, is always very accomplishing

Experience in clinical neurology makes one realise the burden of the unresolved concerns of neurology patients related to daily life, how to lead a life with any given functional status, and the lack of specialists to deal with them in our region. According to the 6th Population and Housing Census of 2017, the population of Pakistan is around 207 million. Considering the World Health Organization (WHO) estimate of 15 percent prevalence of global disability, around 31 million people in Pakistan are expected to be living with some form of disability.⁴ The care strategies are all documented in books and on the internet for specific symptoms, but how to make them work for our patients. So many options are unavailable here, how to figure out a way to help them, and most importantly, to generate time to hear and then address their issues in the busy clinics filled with critical examination findings, challenging imaging modalities and neurophysiology studies.

CPSP notification in early 2022 about Palliative Medicine being added amongst fellowships offered by the college, to me, felt like a prayer answered. This seemed to be the missing link in the chain, the specialty offering time and solutions to the everyday problems of chronic neurological patients. After my FCPS II in neurology, I joined the department of palliative medicine at a tertiary care hospital in Karachi, and definitely in my almost year long journey, I feel quite empowered. I have had the exposure to a multidisciplinary team, working as a unit, catering to multiple problems of a patient holistically. While the medical problems are taken care of by palliative physicians, the wound care and prevention, nutrition, excess secretions, dyspnea, pain and spasticity, oral health, mental health and other symptoms, never go un-regarded. Trained rehabilitation professionals, make physiotherapy work very effectively, and ensure some teaching of patients and families too so it's practically continued. Dental hygienists, utilize their expertise fully and offer

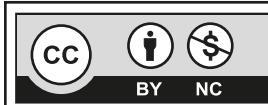
oral hygiene solutions tailored to patients' physical and financial needs. Specialized nurses ensure wound care, care of –ostomies and indwelling drains, feeding tubes so that the patients and attendants are comfortable handling them on their own. Nutritionists provide customized meal plans for every patient according to their individual requirements, also offer substitutes so as to work in resource limited settings. The psychotherapists on the team provide care for mental health of patient as well as the care-givers.

The management of these aspects maybe looked down upon as unexciting, not challenging enough, but having witnessed how tremendously relieving it is for the patients and their care-givers, I can vouch for the field of palliative medicine, and the absolute dearth of its practice in Pakistan. It is the need of time to incorporate palliative medicine in fields like neurology and neurosurgery, as with advancing medical knowledge, life expectancies of patients are increasing, and the bridge between patient diagnosis and management is getting wider each passing day. I strongly suggest adding a mandatory neuro-palliative module for neurology residents, so that at the end of their training they are fully equipped to offer support to their chronic patients with empathy and knowledge.

REFERENCES

- (1) Abbas A, Sharif Z. The effects of sensorimotor retraining in addition to conventional physical therapy on pain, involuntary contractions and cramps in focal hand dystonia patients: a randomized controlled trial. *PJPT*. 2022;05(3).
- (2) Liaqat A, Mubeen I, Murtaza F, Asif T, Anjum A, Subhani R. Effects of motor imagery training among Parkinson's patients on gait, balance and mobility dysfunctions. *PJPT*. 2022;05(4).
- (3) Sadiq M, Sharif F. Prevalence prevalence of turning difficulty in stroke survivors. *PJPT*. 2023;6(1).
- (4) Rathore FA, Mansoor SN. Disability Rights and Management in Pakistan: Time to Face the Bitter Truth. *J Coll Physicians Surg Pak*. 2019;29(12):1131-2.

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