

## **Reflection on the Psychosocial Interventions for Progressive Neurological Conditions during the Pandemic COVID-19**

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### **Abstract**

Life during COVID-19 witnessed major changes; the health sector demonstrated these changes the most. Chronic neurological conditions, which have minimal specialized treatment options and infrastructure facilities in India, faced a significant challenge during this period. Tele consultations became an alternative strategy for almost all health conditions to ensure that the patients are reached and cared for. The current paper is a reflection on the experiences of psychiatric social work professionals working with various neurological conditions at a national quaternary referral care center for Neurological disorders in Southern India. Reflection on the care provided for four major progressive neurological conditions, Duchenne Muscular Dystrophy (DMD), Motor Neuron Disease (MND), Dementia, and Multiple Sclerosis (MS) found that most of the persons with these conditions and their families were happy and thankful about the initiative from the health care professionals. They communicated their concerns to the health care professionals, and appropriate interventions and referrals for the same were done through telephonic consultations. Telephonic consultations can be an effective strategy to ensure

continuous care for various chronic conditions along with the general hospital-based follow-up and consultations even after the pandemic.

**Keywords:** Covid-19, Tele Consultation, Neurology, Psychosocial-intervention

## **Introduction**

COVID 19 posed a significant challenge to all facets of human life. Chronically ill who need regular medication and follow-up are a group who faced considerable difficulty during this time. Similar to various aspects of life which underwent innovative changes to face the crisis, chronically ill persons and their caregivers made many changes to ensure the wellness of the person with chronic illness.

Among chronic health conditions, chronic neurological diseases account for morbidity and mortality worldwide. Neurological disorders contribute to 6.3% of the global disease burden. In 2005, cases with neurological disorders contributed to 92 million disability-adjusted life years (DALYs), whereas in 2030, it is projected to be 103 million, which is approximately a 12% increase (World Health Organization, 2006). Neurological disorders contribute to 12% of total deaths globally (WHO, 2018). In India, there is an epidemiological transition in the prevalence rates of the spectrum of neurological disorders. It ranged from 967- 4070 per 100000 population, with an estimation of over 30 million people with neurological disorders across the country (Gourie-Devi, 2014). However, there is a mismatch between the needs and the available treatment options and infrastructure for neurological care in India (Gourie-Devi, 2008). With the current scenario of COVID-19 lockdown and the restrictions on travel (WHO Situation Report, 2020) the treatment and care of chronic neurological conditions were even more challenging.

As an answer to this crisis, telemedicine emerged and became prominent throughout the country. Tele consultations became an alternative strategy for almost all health conditions to ensure that the patients are reached and cared for. Telephonic follow-ups either initiated by the health care professionals or sought by the health care recipients, formed a major illness management strategy for months following the pandemic. The current paper reflects on the psychosocial interventions carried out through teleconsultations for major progressive neurological conditions including Duchenne Muscular Dystrophy (DMD), Motor

Neuron Disease (MND), Dementia, and Multiple Sclerosis (MS) at a national quaternary referral care center for Neurological disorders in Southern India.

### **A Brief Overview of the Neurological Diseases Covered**

Neuromuscular disorders are a major group of chronic progressive neurological conditions that are characterized by the involvement of nerves and muscles. Within the neuromuscular conditions, Duchenne Muscular Dystrophy is a genetically mediated disorder, which affects young male children between three to five years. The common symptoms include delayed motor development, enlarged calf muscles, muscle weakness, toe walking or waddling gait, Gower's maneuver, and cardiomyopathy. There will be a progressive worsening of symptoms and the child usually gets wheelchair-bound by their teens and death generally occurs in late teens or early adulthood (MDA, 2017; Birnkrant. et al., 2018).

Motor Neurone Disease (MND) /Amylotrophic Lateral Sclerosis (ALS) is a progressive neurodegenerative condition affecting nerve cells connected to the brain and spinal cord. It is mostly diagnosed among men between the 50s- 70s rarely occurs among women as well. The gradual degeneration and death of motor neurons affect the essential voluntary muscle activities such as upper and lower limb activities, speaking, breathing, swallowing, and general movement of the body (Shaw, Quinn, & Daniel, 2013; Oliver 2016). The mean survival from the symptomatic onset on an average is three years. 25% of the patients survive five years, and 10% for more than ten years. Occasionally survival following diagnosis is less than six months (Leigh, Abrahams, Al-Chalabi, Ampong, Goldstein, Johnson, & Willey, 2003).

Dementia is a progressive, irreversible syndrome that is characterized by a loss of cognitive function, deterioration in memory, thinking, behavior, and the ability to perform everyday activities that impacts social or occupational functioning. Dementia mainly affects older people, and the symptoms vary according to the stage of the illness. There are different types of dementia like Alzheimer's Dementia, Vascular Dementia, Lewy body Dementia, Fronto Temporal Dementia are some of them.

Multiple Sclerosis (MS) is a chronic autoimmune-inflammatory disease that affects the central nervous system (CNS) – the brain, spinal cord, and optic nerves. The disease destroys the myelin sheath to varying

degrees by causing scars or plagues or lesions (Weinshenker, 1996). It is a progressive condition, and the symptoms vary according to the stage of the illness. Common symptoms of MS include numbness and tingling sensation, burning sensation, double vision/ loss of vision, loss of control over bodily movements, chronic pain (Goldenberg, 2012). Along with these neurological symptoms, some of the persons with MS have mood disturbances and cognitive difficulties.

The role of medication in all these conditions except MS is limited. In the absence of disease-modifying therapies, the cornerstone of management in these disorders remains symptomatic and supportive management. Psychological and social issues associated with these disorders call for a multidisciplinary team approach where the clinical social workers of the team try to address and alleviate the distress through psychosocial interventions focusing on improving the quality of life.

### **Reflection on the Reaction to the Telephonic Consultation**

Most of the people with neurological conditions and their family members reported it to be the first experience for them to receive a call from the treating team, and they were happy and excited about it. They mentioned this gesture as an indication of warmth and concern from the treating team, and many of them reported that they felt being supported by the treating team.

The initial few minutes of the call were spent on handling the excitement of the persons with neurological conditions and their family members on receiving the call. This experience for them may be like a change in the power structure, and with the consultant calling them, they do not have to wait for hours for a meeting. Talking with clients over the phone needs to be skillful because they might have many aspects to discuss, but we need to be specific in a short time. This is an opportunity for health care professionals to be aware of their communication skills with the patients. The mutual learning and the support required in a team were better understood through this experience.

### **Concerns Shared by Persons with Neurological Illnesses and Their Families**

Major concerns reported by the patients were fear and anxiety associated with the worsening of symptoms and the inability to access emergency care. They were concerned about missing follow-ups, some had difficulty in procuring medication. The changes in the

lab test dates, worries about the delaying of treatment, and possible worsening of symptoms caused considerable anxiety and fear in a few respondents (Thomas, Annam, Ravindu, Warriar, & Netravathi, 2020). Difficulty to go for regular supportive treatments like physiotherapy and further worsening of muscle symptoms due to that was a major concern for the neuromuscular disorders. Caregivers of persons with neuromuscular disorders, especially DMD, were concerned about their weak lung muscles and the possibility of them getting COVID-19. The family members of persons with dementia expressed their concerns regarding the change in the routine of the person with dementia and caregivers' difficulty to manage irritability and anger of their ill relative. The increased adjustment difficulties leading to interpersonal problems were reported by a few. Lack of social support and increased burnout with the absence of the possibility of respite in the light of financial difficulties was mentioned by many family caregivers. Some of the patients with chronic illness reported fear of getting infected with COVID 19. They were concerned about continuing their follow-ups and worsening due to a lack of inputs from healthcare professionals. They were clueless on how to contact the treating team, especially if a crisis occurs. Many of the participants were worried if they were more vulnerable to this pandemic.

### **Interventions for Persons with a Chronic Neurological Condition and Their Families**

One of the major interventions was clarifying their myths and misconceptions regarding COVID -19 pandemic. Detailed psycho-education about their illness and prognosis, focusing on the people with neurological illness's health status and symptoms was carried out. The team reviewed the medications and gave appropriate suggestions and were linked to local resources. Through the consultant neurologist's contact, people who had difficulty in procuring medications were facilitated for the same. The anxiety of the person and the family associated with COVID-19 were addressed through appropriate psychosocial interventions.

The family of people with neurological illnesses was given special importance. They were given a chance to express their concerns and insecurities regarding the progression of symptoms and interpersonal issues, especially with their ill relative. Psychosocial support to address burnout among the caregivers, the interventions to address psychosocial problems such as anticipated grief, anxiety, sadness, anger, and

resistance were carried out (Nair, Warriar, Sadasivan, & Thomas, 2020). They were educated and prepared about the transitional symptoms. The precautions to be taken to avoid respiratory difficulties, especially for the neuromuscular disorders were discussed. The family was given the contact details in case of medical emergencies. Emergency care was advised and the family was prepared to handle crises during this pandemic period. They were asked to follow the general guidelines during the pandemic period and precautions to be followed to remain safe at home.

## Conclusion

Interventions through telephonic consultation are an excellent initiative, and it can be a new model of care and replicated to all case scenarios. It was a time to think if we have to take a step back and wait for the pandemic to subside to help the needy or take that extra effort and extend our service without stringent hierarchies and help the needy. For the health care professionals who are interacting with hundreds of patients in a day, those patients whom they contacted through telephone are only one among them. But for patients, we are that ‘one doctor’ whom they trust, and hence our care and concern make much difference in their lives.

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