

## **Telephonic follow ups during COVID 19 pandemic in Chronic Illness: Lessons learnt**

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COVID-19 as a pandemic has brought an unprecedented feeling of fear across the world with WHO declaring it as a global pandemic. Borders are closed, travels have been restricted, the crisis in the economy, migrants are deserted (WHO Situation Report, 2020). Visits to hospitals have been put to terms and conditions, hence it could be stated that pandemic has extended beyond the traditional pill provision. With all the big giants focusing on finding the vaccine for the condition, the underlying psychosocial issues could be often neglected (Singhal, 2020). Social Work as a profession works across many settings, one of the major settings being Hospital Social Work. Clinical social workers in hospitals work with the patients and families helping them to understand the illness, working with the reactive emotions occurring about the diagnosis and disease process, and providing intervention about the care and management. Hospital social workers predominantly work in multidisciplinary teams, and contribute, through their training and skills of working with individuals and families, an understanding of the social and emotional aspects of the condition. A major approach adopted by Hospital Social workers is Case Management to resolve educational, social, financial and psychological problems of both the patients and their family members (National Association of Social Workers, 2011).

Neuromuscular disorders are a major group of disorders of the nervous system characterized by the involvement of nerves and muscles. Some of the neuromuscular disorders (eg: Muscular Dystrophies) are genetically mediated, often with multiple family members affected. Many of these conditions are irreversible with a shortened life span( Eg: ALS/MND). In the absence of disease-modifying therapies, the cornerstone of management in these disorders remain 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.

Motor Neuron Disease/Amyotrophic Lateral Sclerosis is a progressive neurodegenerative condition affecting nerve cells connected to the brain and spinal cord usually seen among men in their fifth to seventh decade. Depending on the area where the degeneration of the nerve cells occurred, the symptoms differ like muscle twitches, cramps, tightness and stiffness and weakness, slurred and nasal speech, and difficulty in chewing or swallowing (Shaw, Quinn and Daniel, 2013). The progression of this fatal condition is such that death usually occurs within 3- 5 years. (Simmons, 2005) Exceptions in the age, gender, and prognosis are rarely seen.

Duchenne Muscular Dystrophy (DMD), a genetic condition affecting the muscles which lead to muscle wasting, affects young male children as early as 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. The symptoms worsen over some time, the child usually gets wheelchair-bound by their teens and death occurs generally in late teens or early adulthood (Birnkrant, Bushby, Bann, Alman, & Apkon, 2018).

As evident from the description, both these conditions occur more commonly among males, but in different age groups, and hence having marked differences in the symptom distress, caregiving patterns, and family involvement. Nevertheless, the pattern of progression is well established and the relentless deterioration of symptoms leads to total dependence in the caregivers, often the family members. The nature and pattern of the illness warrants interventions focusing on the rehabilitative and palliative approaches giving more emphasis on caregiving issues.

Given the role played by the periodic specialist clinic visits in helping the patients and families to manage the biopsychosocial needs associated with the disease progression, the current COVID 19 situation has resulted in a near-crisis for them. In this context, clinical social work interventions with the two different neuromuscular conditions through telephonic interviews were carried out as an adjunct till the time the regular follow up could be reinstated. Some of the lessons learned from this has been as follows:

### **Concerns and Intervention addressed during telephonic follow up**

Concerns	Interventions
Missing follow-ups	<ul style="list-style-type: none"> <li>• All client families were concerned about missing follow up and a further hospital visit.</li> <li>• Discussion on the patient's present health and illness status and list out their concerns.</li> </ul>
Medication	<ul style="list-style-type: none"> <li>• Medication was reviewed and in discussion with other team members, appropriate suggestions, and referrals were given.</li> <li>• Availability and accessibility all so checked and ensure adherence to medication..</li> </ul>
Helplessness	<ul style="list-style-type: none"> <li>• Helplessness was a common feeling among all clients and families. Try to understand the source of the helplessness. The primary concern was COVID, a chance to get this illness and impact. Addressed their concern by giving adequate information.</li> </ul>
Transition	<ul style="list-style-type: none"> <li>• In both ALS and DMD, transitions are inevitable and through the telephonic interviews the family was helped to prepare for the stages and the care required..</li> </ul>
Other Psychosocial Problems	<ul style="list-style-type: none"> <li>• There various psychosocial problems discussed such as anticipated grief, anxiety, sadness, anger, and resistance. All the patients provided with psychosocial intervention based on the needs.</li> </ul>
Crisis Management	<ul style="list-style-type: none"> <li>• Both in ALS and DMD, respiratory involvement was a concern. In light of COVID 19 being primarily a respiratory illness, precautions to be taken were discussed. Emergency care wherever required was advised and the family was prepared to handle crisis during this pandemic period.</li> </ul>

**Conclusion:**

The COVID-19 situation has made us realize that this is the time for a "New Normalcy". In the post-COVID-19 era, clinical social workers need to be able to put the client wellbeing before any other concern and institute innovative ways of meeting these needs. While the methods and approaches remain essentially the same, the method of provision of the care is modified and is used as adjunct to routine modes of intervention. It is important to remain cognizant of the ethical principles of clinical social work and remember that the client wellbeing is the priority in all cases.

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