Collateral Damage of COVID-19 Pandemic on Lysosomal Storage Diseases: A Single Unit Experience

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Objective: COVID-19 epidemic caused significant problems in countries’ health systems. Direct and indirect effects of this unprecedented outbreak on patients with rare diseases are not clear. The aim of this study is to identify the pandemic related problems encountered by adults with LSDs and parents who have children with LSDs and to evaluate the socioeconomic and psychological effects of the COVID-19 outbreak in the lysosomal diseases community.

Methods: Our study included 27 adult patients receiving ERT treatment and 19 parents of child patients who were being followed up with LSD diagnosis. Sociodemographic Data Form and COVID-19 Traumatic Stress Scale were applied to patients and their parents.

Results: We found that 44.4% of adult patients and 36.84% of child patients’ treatment were disrupted due to the COVID-19 outbreak. We found that 50% of adults and 80% of parents had a fear of going to the hospital due to the COVID-19 pandemic. Economic distress was higher in the treatment-disrupted group. Also, patients who had a fear when going to the hospital for ERT had higher “fear/threat of infection” scores.

Table 1: Disease and treatment characteristics in the patient group

Table 2: Comparison of COVID-19 traumatic stress scale sub-dimensions and total scores in patient and parent groups

Table 3: Comparison of sub-dimensions in the COVID-19 traumatic stress scale regarding the treatment continuity

Conclusion: The pandemic brought wide-ranging changes in the treatment and follow-up of patients with rare diseases. The most effective way to maintain access to treatment during a pandemic appears to be home therapy; however, the personnel involved should be monitored and much attention should be paid to the proper use of personal protective equipment. It is also of great importance to provide adequate social, economical and psychological support to individuals.