**THE EFFECT OF COVID-19 ON RARE DISEASE PATIENTS: A SYSTEMATIC REVIEW**

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**Abstract**

The COVID-19 has a serious epidemic affecting more than sixteen million people worldwide. The epidemic has had serious adverse effects on healthcare and social systems. Some patient groups have been affected most painfully by the pandemic. With a rare disease, 30 million people in Europe and 300 million worldwide were among the most vulnerable population group during the pandemic. Because rare diseases, which are often chronic, complex, degenerative, and seriously disabling, create special care needs. This study aims to examine how patients with rare diseases are affected by COVID-19. We started by identifying studies addressing the impact of COVID-19 on rare diseases. The databases managed for the search were: Scopus, Web of Science, Networked Digital Library of Theses and Dissertations, Proquest, and Google scholar. The keywords used were rare diseases and COVID-19; rare diseases and coronavirus; the impact of COVID-19 on rare diseases. Based on inclusion criteria, the number of articles that were aligned with the objective of the present study was reduced from 40 to 18. The findings of the study show that patients with rare diseases experience problems in areas such as access to healthcare systems, holistic care, daily life dynamics, and psychosocial. Patients feared visiting hospitals because of the risk of infection. For this reason, serious problems such as restriction of treatment options for rare patients, disruption of appointments, medication follow-ups by telemedicine or telephone, patients whose treatment is in a different city due to travel restrictions are observed. In terms of holistic care, the provision of basic care services for patients who need home care services due to the lack of personnel and personal protective equipment was interrupted. For example, institutions providing physical therapy and rehabilitation services and daycare centers were either temporarily or completely closed. This made it difficult for patients to benefit from rehabilitation services. In terms of the dynamics of daily life, the closure of private care facilities and schools has caused families of patients to be unable to work and to provide more care. This increased the crises in terms of both economic and family relations. In terms of psychosocial aspects, there are serious symptoms in patients such as fear of getting sick, being unhappy and depressed, anxiety, and loneliness. As a result, services need to be improved so that rare disease patients, a vulnerable group, are in biopsychosocial well-being in the COVID-19 pandemic.

**Key Words:** COVID-19, Rare diseases, Vulnerable groups.