# The impact of COVID-19 pandemic on dermatology patients with rare skin diseases

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## Abstract

The COVID-19 pandemic has caused a global health crisis, presenting novel challenges while worsening preexisting difficulties for individuals with rare diseases. Internationally, they have experienced disruptions in their medical care, with a lack of access to essential treatments and diagnostics. We focused on the specific challenges faced by individuals living with rare skin diseases in Albania, a country with limited healthcare infrastructure. The pandemic led to a significant decrease in our service, resulting in an 87.1% reduction in patients hospitalized in 2020 compared to 2019. Notable gender and age disparities were observed in hospitalizations, with a shift towards more male patients and a decline in younger age groups seeking medical attention. Innovative approaches such as telemedicine helped maintain care for this vulnerable patient population. Further research is required to understand the long-term impacts of the pandemic on individuals with rare skin diseases and develop strategies for their care in future emergencies.

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## Introduction

Since the COVID-19 outbreak in Wuhan, China, in December 2019, the pandemic has evolved into a global health crisis.[1] Healthcare utilization has experienced a significant decline during the pandemic due to a combination of patient apprehension and the implementation of public health measures aimed at mitigating the spread of the virus. Conversely, individuals living with rare diseases, who constitute a marginalized segment of the population even under ordinary circumstances, have confronted a multitude of challenges during these unprecedented times.[2-5] The periods of lockdown and restrictions have been associated with substantial delays in diagnosing and managing rare diseases. Notably, international organizations for rare diseases, spanning across the United States, Europe, and Asia, have undertaken comprehensive studies to assess the impact of the pandemic on the lives of this particular patient cohort.[6-10] These investigations have revealed a myriad of adverse consequences, including mental health deterioration, financial hardships, which may or may not be compounded by job losses, cancellation of essential medical appointments, incomplete treatment regimens, and the necessity to adapt to alternative modalities of healthcare delivery, such as telemedicine.[11]

This present study delves into the repercussions of the pandemic on individuals affected by rare skin diseases within the confines of the sole tertiary hospital center in Albania. It is important to note that Albania, a middle-income country, continues to grapple with substantial gaps in its healthcare infrastructure and lacks a comprehensive national program dedicated to the management of rare diseases. Consequently, the investigation aims to shed light on the specific characteristics of this vulnerable patient population in a unique healthcare context defined by these overarching constraints.

## Materials and Methods

This is a cross-sectional study based on data from the registry of patients hospitalized for rare dermatological diseases from January 1, 2019, to December 31, 2020, at the Dermatology Service, University Hospital Center "Mother Teresa", Tirana, Albania. The diseases were selected based on the current Orphanet classification, the European reference system for rare diseases. A total of 140 patients with rare skin diseases were included in the

study during the years 2019-2020. Demographic characteristics of patients, including age and sex, were extracted from the hospital data. The number of hospitalizations and the length of stay are estimated. All diagnoses were made by the medical staff in the dermatology department. Continuous variables are presented through mean values ± standard deviation and categorical variables through frequency and percentages. Differences between dichotomous variables are presented using Fisher's exact test. Differences between categorical variables with more than two categories are presented through the Chi-Square test. Differences between categorical variables with more than two categories and continuous variables are presented through the Anova test. Data were analyzed using SPSS version 16 software. A significance level of $\alpha \leq 5\%$ ($p \leq 0.05$) was considered for all tests.

## Results

The impact of pandemic caused a decrease in the number of outpatient consultations in Dermatology, which was also reflected in the number of patients with rare diseases hospitalized in our clinic.

The Table 1 shows the distribution of cases by gender for the years 2019-2020. The number of patients and hospitalizations in 2020 is significantly lower compared to 2019. In 2020, the number of patients decreased by 87.1%. From the data above, we see that the frequency of female patients is higher for both years, but the difference between the sexes is smaller in 2020. The Chi-Square test was applied to verify whether these changes were statistically significant. The applied test shows a statistically significant difference between these two variables (p=0.048). It is noted that in 2019, more hospitalized were women, while in 2020, more were men. Fisher's exact test was applied to verify if these changes were statistically significant. The applied test shows that these differences in hospitalization between genders are statistically significant (p=0.041). Referring to the distribution of patients according to age groups in these two years (2019-2020), for all age groups, it can be observed that there were more cases in 2019 than in 2020. It is noticeable that there are no cases in the age group of 10-30 years in 2020, and the difference in cases for the age group over 70 years narrows in these two years. The Chi-Square test was applied to verify whether these changes are statistically significant. The applied test shows a statistically significant difference between these two variables (p= 0.040). The average length of stay in hospitalization between women and men in these two years is different. To prove whether these changes are statistically significant, the Anova test was applied. The applied test shows that these changes are not statistically significant (p= 0.506). During 2020, 10 hospitalized patients (55.6%) suffered from pemphigus vulgaris, and with one patient the diagnoses were as follows: discoid lupus, bullous pemphigoid, mycosis fungoides, epidermolysis bullosa, albinism, Behcet's disease, mastocytosis, neurofibromatosis.

## Discussion

Approximately 470 million people worldwide are affected by at least one of the over 6000 rare diseases[12,13] and 6.8 million people suffer from 800 known rare skin diseases.[14] People affected by a rare disease experience challenges in healthcare due to long periods until assured diagnosis, centralized expertise of medical care or lack of effective treatment.[15] Many rare diseases are progressive, and clinical conditions worsen over time.[11] At the same time, people with rare diseases do not feel well supported, especially apart from the medical aspects of their disease.[14, 16] The National Institutes of Health (NIH) estimates that only 5% of rare diseases have approved treatments, while many therapies work only in young ages and early stages of the diseases.[17]

Rare disease community is a vulnerable patient group suffering during the COVID-19 pandemic due to pandemic stress, disruption in health care and daily life. During the pandemic, participation was impaired for adults and children with rare diseases as well as caregivers.[15] According to a European study organized by Rare Barometer, an initiative of the European Organization for Rare Diseases (EURORDIS), 83% of rare disease patients interrupted their medical care, including diagnostic procedures, medical appointments, therapies, rehabilitation, or surgical interven-

**Table 1.** Distribution of cases by gender for the years 2019-2020.

| | 2019 year | 2020 year | Statistical analyze |
|---|---|---|---|
| Patients N | 124 | 16 | Fisher's exact test 3.810 p=0.048 |
| Females N (%) | 78 (62.9) | 6 (37.5) | |
| Males N (%) | 46 (37.1) | 10 (62.5) | |
| Hospitalizations N | 158 | 18 | Fisher's exact test= 4.037 p= 0.041 |
| Females N (%) | 100 (63.3) | 7 (38.9) | |
| Males N (%) | 58 (36.7) | 11 (61.1) | |
| Age group | | | $\chi^2$= 16.182 p= 0.040 |
| 0-9 N | 2 | 1 | |
| 10-18 N | 3 | 0 | |
| 19-29 N | 10 | 0 | |
| 30-39 N | 10 | 3 | |
| 40-49 N | 25 | 1 | |
| 50-59 N | 29 | 3 | |
| 60-69 N | 31 | 2 | |
| 70-79 N | 6 | 4 | |
| ≥80 N | 8 | 2 | |
| Average length of stay (days) | | | F=0.444 p=0.506 |
| Females | 7.50±5.239 | 5.86±3.805 | |
| Males | 8.60±5.926 | 7.73±5.623 | |

tions.[18] Since the pandemic outbreak, they have struggled without the proper palliative care. This kind of pause in development represents a regression for patients with rare diseases. As an immediate response to the pandemic, most pharmaceutical industries and researchers focused on developing therapies for COVID-19, leading to a pause in developing therapies for other diseases, including rare diseases. [2,11,15] Participants with rare diseases in the Genomics England 100k Genomes project had increased risks of COVID-19-related mortality. This was probably because rare disease patients had significantly higher frequencies of certain comorbidities and a higher number of comorbidities, which is known to affect COVID-19-related mortality.[19] In another study by Chung et al., increased COVID-19-related mortality was observed in hospitalized patients with rare diseases compared to the general population.[20]

In the Albanian context, the pandemic period caused an 85% reduction in hospitalizations, an 89% reduction in patient length of stay, and an average length of stay that decreased from 7.91 days in 2019 to 7 days in 2020. In terms of the average length of stay during the pandemic, there was a decrease for both males and females in 2020 compared to 2019, but there was no statistically significant difference between genders ($p < 0.506$). This suggests a similar risk perception among males and females, as well as a balanced approach to each patient in managing the spread of the Sars-CoV-2 virus in the hospital setting. Interestingly, younger age groups reduced hospital visits, while those aged 70 and above continued to seek medical attention. This can be explained by the fact that older individuals, in addition to the severity of their conditions, often have other comorbidities requiring medical management. Additionally, younger individuals had easier access to telemedicine during the pandemic.

The COVID-19 pandemic fundamentally altered the functioning of the healthcare system. To reduce infection spread, especially in this vulnerable group, early preventive measures, such as requiring a negative Sars-CoV-2 test result at least 48 hours before hospital admission and limiting accompanying persons, were implemented in our clinic. Despite the decrease in hospitalized patients, our clinic continued to provide care through telemedicine. Various forms of communication, such as telephone consultations, video calls, or email, were adopted. This collaboration optimized patient self-monitoring, treatment adherence, infection prevention measures, and reduced anxiety and stress.

## Conclusions

In conclusion, the COVID-19 pandemic significantly impacted dermatology patients, particularly those with rare skin diseases in our country. The pandemic highlighted the vulnerability of patients with rare diseases and the need for adapted healthcare services during such crises. Innovative approaches such as telemedicine helped maintain patient care and improve patient monitoring and adherence to treatment. Further studies are required to understand the long-term effects of the pandemic on this patient population and to develop strategies for their care in future emergencies.

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