

IMPACT OF COVID-19 PANDEMIC ON RARE DISEASE PATIENTS AND ORGANISATIONS IN TEN JURISDICTIONS ACROSS THE ASIA PACIFIC REGION

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Background

The COVID-19 pandemic has had significant health, social, and economic consequences internationally. The existing difficulties that rare disease patients face might be exacerbated under the pandemic. Not only did patients and caregivers had to adapt to the new normalities, rare disease organisations also had to react swiftly as they are the pillar of support for many. This study sought to assess the impact of the pandemic on rare disease organisations and patients in the Asia Pacific Region, analyse the major challenges that each stakeholder encountered and provide future directions in case of similar incidents in the future.

Methods

A cross-sectional survey was distributed to rare disease organisations in ten jurisdictions between 27 April and 23 May 2020. Quantitative and qualitative data on the impact of COVID-19 on organisations and patients were collected from the organisation representative's perspective. Quantitative data was mainly descriptive while qualitative data was analysed using Braun & Clark's framework of thematic analysis to identify semantic themes and patterns. Subgroup analysis by jurisdictions was performed to identify similarities and discrepancies across the region. A follow-up focus group meeting was conducted on 18 August 2020 to validate the survey findings and obtain additional information from participants.

Results

A total of 80 rare disease organisations from Australia, Hong Kong Special Administrative Region of China, India, Japan, Mainland China, Malaysia, New Zealand, Philippines, Singapore and Taiwan participated in the study. 63% of the organisations functioned at a reduced capacity or was completely non-functional during the pandemic. 89% were concerned about the impact of COVID-19 on their organisations. The most frequently identified areas were organisation's operation capacity, ease of supporting their patients, and mode of communication. 95% believed their patients were impacted by the pandemic, in which 57% were very or extremely impacted. Top five most frequently identified impacts were reduced healthcare access, impact on social lives, impact on physical health, impact on mental well-being, and financial impact. Subgroup analysis by jurisdictions showed discrepancies across different regions, indicating heterogeneity in patient characteristics, healthcare systems, healthcare policies, and cultural perspectives.

Conclusion

This serves as the first study to assess the impact of the pandemic on rare disease patients and organisations across the Asia Pacific Region. It highlights the need for mental health support and sheds light on moving towards telemedicine and digitalisation of organisation operation, which constitutes a sustainable model in times with and without pandemic.