

Pandemic effects on the care of patients with inborn errors of immunity

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It is evident that the COVID-19 pandemic has challenged the healthcare systems worldwide and exposed many deficiencies in these systems and required restructuring to mitigate these deficiencies in a modern-day pandemic [1]. A myriad of effects resulting from this pandemic not only have an impact physiologically, but also psychologically and thus, has had a huge impact on the mental health of the global community [2]. Enormous resources were required to provide continuous high-level care for those infected and this led to the neglect of uninfected patients with chronic diseases. These chronic diseases include inborn errors of immunity (IEI) for which nearly 500 gene defects have been described [3]. IEI present typically with recurring infections, but also as autoimmune, autoinflammatory, and allergic conditions.

Even in the nonpandemic circumstances, patients with IEI and their caregivers would report significant care inadequacies, both in diagnostic and therapeutic care. In general, IEI are usually underdiagnosed and this could have worsened during the pandemic leading to further morbidity and mortality. On the other hand, several groups have also assessed the possibility of novel IEI presenting as severe COVID-19 infection and has led to the discovery of new IEI gene defects [4, 5]. This highlights and strengthens the observation that IEI as an experiment of nature, aids in progressive understanding of the human immune system, and thereby provides opportunities in developing targeted therapies for immune-mediated diseases. It also illustrates the importance of the field of clinical immunology during any pandemic and that immunologists, both clinical and scientists alike, play a central role in managing any pandemic.

The need for a lockdown to mitigate the spread of the recent COVID-19 pandemic had detrimental effects on an effective delivery of treatment to IEI patients. Depending on the type of IEI, therapeutic options include antibiotics prophylaxis, immunoglobulin replacement therapy (IRT), hemopoietic stem cell transplant, and gene therapy. The mainstay of treatments for

most patients with IEI, that is, predominantly antibody deficiencies is IRT, which is commonly delivered intravenously, and possibly subcutaneously. Immunoglobulin therapy contains antibodies to compensate for the defective immune system's inability to produce them. Individuals with IEI need IRT regularly throughout their lives to help combat infections and prevent organ damage. Without IRT, they are in danger of suffering from morbidity, poor quality of life, and reduced life expectancy. As immunoglobulin is derived from human plasma, there are concerns about the availability of supply, particularly to treat life-threatening conditions that cannot be improved with other medications. It is estimated that 75% to 80% of IEI patients do not have access to adequate immunoglobulin therapy throughout the world [6].

Certainly, delivery of IRT was affected during the pandemic due to reduced blood donations from the lockdown and social distancing [7]. The uncertainty of regular treatment leads to a lack of confidence in the healthcare system strained during a pandemic, resulting in heightened morbidities and mortalities. To overcome these challenges, there is a need for increased awareness and education, advocacy for increased funding and resources to support immunoglobulin therapy programs. The establishment of local plasma collection and manufacturing facilities at national and regional levels within every Asia Pacific country is desirable, if not essential. The collaboration between healthcare providers, patient groups, policymakers, and industry partners to improve the supply and quality of immunoglobulin products is crucial. These efforts can help ensure that patients who require IRT have access to this life-saving treatment, and their rights are protected.

It is envisaged patients with IEI and their caregivers will endure much mental strain affecting their quality of life [8, 9]. Studies exploring challenges in caring for children using qualitative thematic analysis may be extended to patients with IEI. Themes identified in one study included living with fear and anxiety, IEI healthcare support struggles, knowledge, social constraint, and coping [9]. From these themes, 2 main psychosocial themes were identified, namely living with fear and anxiety, and IEI healthcare support and struggles. Further subthemes were identified and amongst those for the theme of living with fear and anxiety were sickness, psychological issues, fear of infection, and hereditary issues. Prolonged hospitalization for months due to the long history of recurrent infections was an unpleasant experience for the patients and their families. Parents expressed a sense of sadness, confusion, and ensuing denial with concerns about the future for their children's development and learning abilities.

The other psychosocial theme involved the IEI healthcare support struggles, caregivers had amongst several factors, the issue of financial burden which may be attributed to the delayed diagnosis of IEI. Patients with delayed diagnosis not only had high rates of infections, but also anxiety/stress and depression [8].

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Post-traumatic stress disorder may be deemed a public mental health problem in existence during the pandemic. This disorder would incur a heavy burden on the care of the IEI community with high levels of medical utilization and high economic costs from the substantial morbidity. Hence, the psychological impact presents an overarching challenge during the pandemic for patients with IEI as well as their families. Maintaining the mental health status of these individuals is paramount as they must cope with lifestyle changes to adapt to the pandemic. Providing psychological therapy for families can improve their mental health and improve the overall health status of the family. Future studies are needed to evaluate their physical and mental health postpandemic and in preparation for future pandemics.

It is obvious that connectivity and communication are crucial postpandemic to ensure that the information circulated is genuine and accurate. This needs to be mirrored on a more patient and/or consumer-centered delivery of healthcare and medical services, and not in silos differentiating public and private sectors. Teleconsultation and m-Health would play a major role in the background that artificial intelligence being utilized to this end. This will be intertwined with the time-tested physical healthcare system but needs continued improvement to ensure that a high-quality service is always disseminated to the community. Coupling of natural and artificial intelligence would provide a platform for healthcare services to be precise and personalized, besides being wholesome. Over and above this, there must be a realization that any healthcare planning must also protect the environment and thus ensuring a healthy planet for humankind to live in harmony with nature.

Conflicts of interest

The author has no financial conflicts of interest.

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