



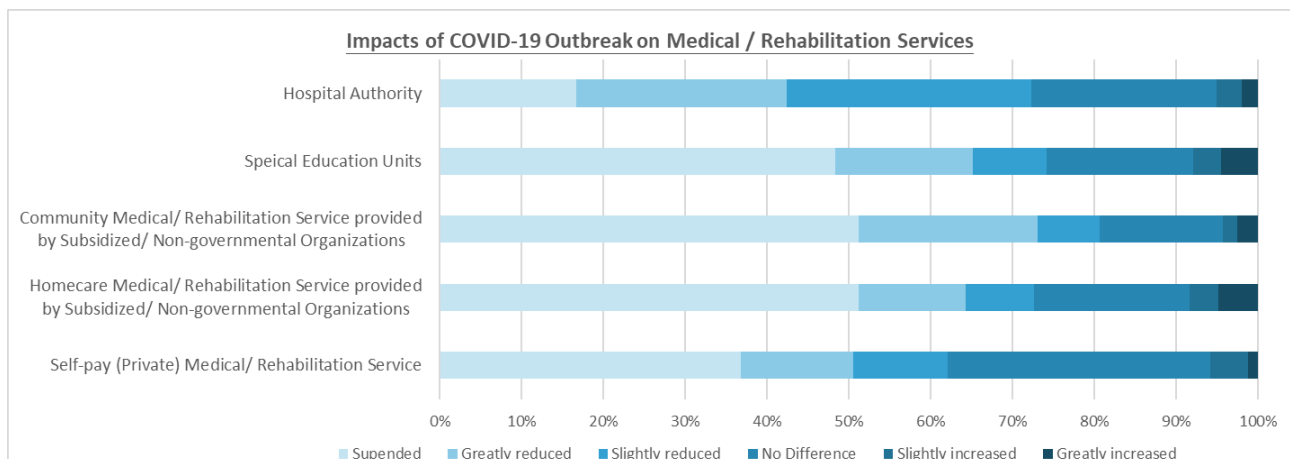
**COVID-19 Worsens Health Condition and Financial Status of Rare Disease Patients in Hong Kong
Group Calls on Government to Respond Efficiently and Effectively**

(July, 2020.)

Research has shown that the COVID-19 epidemic has continuously reduced medical and rehabilitation services. At the same time, rare disease patients are worried about being infected in medical institutions and public transport, which generally worsens their physical and mental health condition. Salary reductions due to unemployment and underemployment, as well as the sudden increase in expenses on personal protection equipment have worsened the household financial situation of rare disease patients.

Rare Disease Hong Kong (RDHK) conducted the survey entitled “Research on Impacts of COVID-19 on Medical and Rehabilitation Services and Living Conditions on Rare Disease Patients and People with Disabilities” in April 2020. A total of 305 responses were collected from rare disease patients, people with disabilities and their caregivers. Data were analyzed with the assistance of Clinical Associate Professor Dr CHUNG Hon-Yin Brian, Department of Paediatrics and Adolescent Medicine, HKU Li Ka Shing Faculty of Medicine, and PhD student Claudia Chung. More than 72% of the respondents said that during the COVID-19 outbreak, the services provided by the Hospital Authority have shown signs of reduction and even suspension. The same appeared in subsidized social welfare organizations and private healthcare facilities.

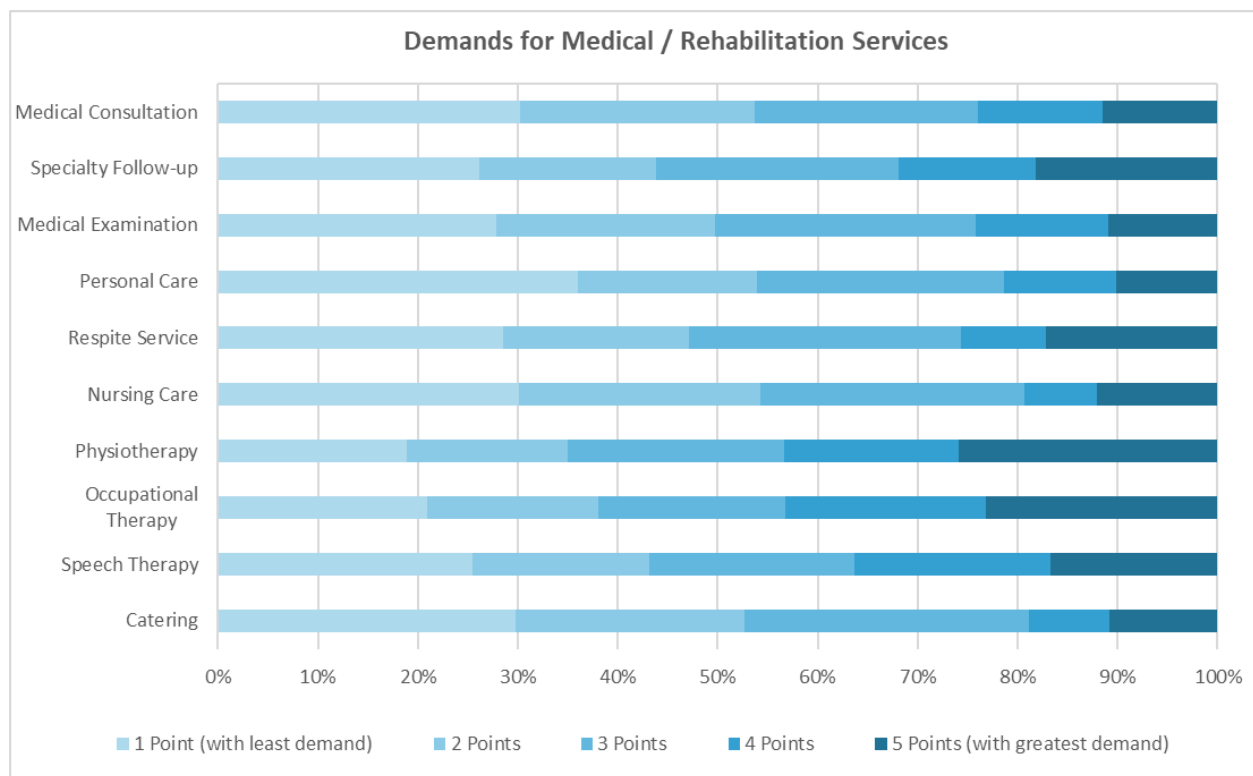
Graph 1 – Impacts of COVID-19 Outbreak on Medical / Rehabilitation Services



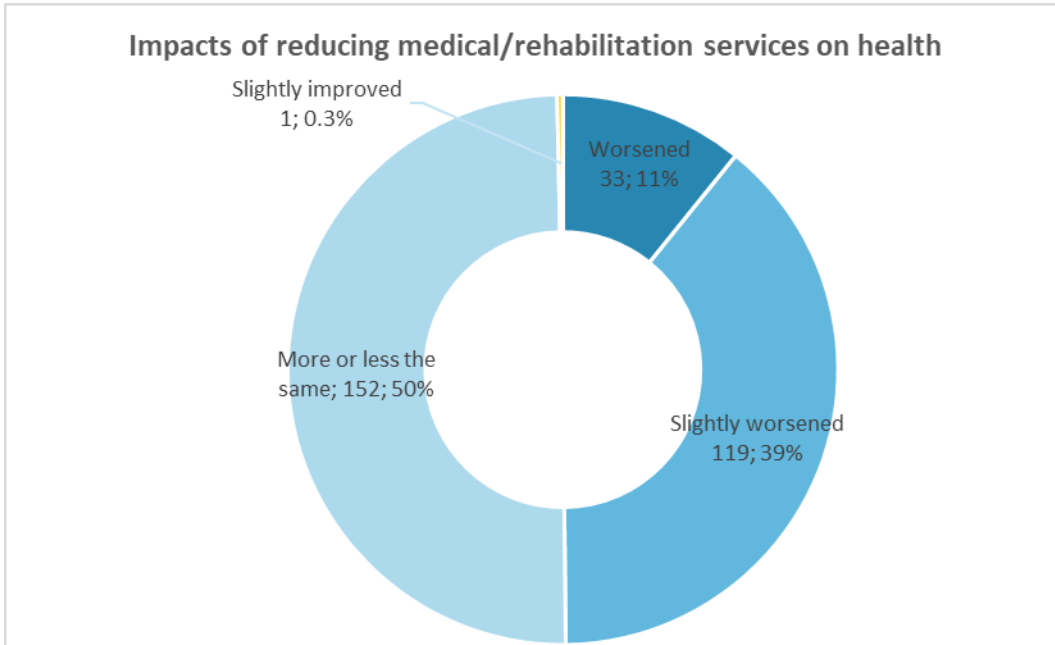


The survey found that the top three most demanded rehabilitation services were physiotherapy, occupational therapy and speech therapy. Due to the persistent lack of medical and rehabilitation services, half (50%) of the respondents claimed that their health conditions have deteriorated during the COVID-19 outbreak, of which 78% of them have their conditions slightly worsened and 22% of them have their conditions deteriorated significantly. In terms of psychological health, 81% of the respondents said that their mental health conditions were affected by the outbreak to varying degrees, including having their mental health conditions slightly affected (42%), largely affected (23%) and drastically affected (16%). The survey has shown that the more severe the disability, the greater extent of impact and more common health deterioration.

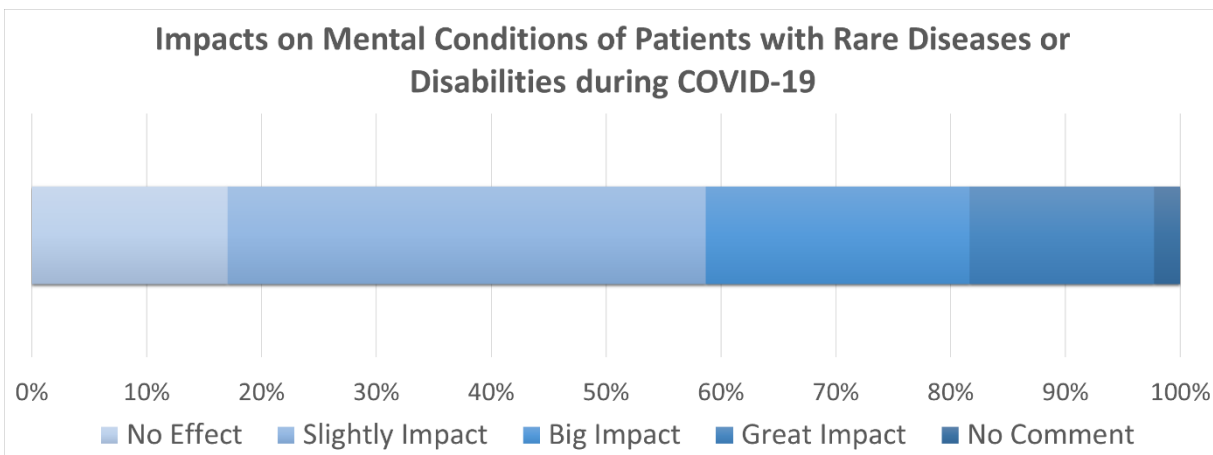
Graph 2 – Demand for Medical and Rehabilitation Services by Rare Disease Patients / People with Disabilities



Graph 3 – Impacts of Reduction of Medical / Rehabilitation Services on Health Conditions of Rare Disease Patients and People with Disabilities



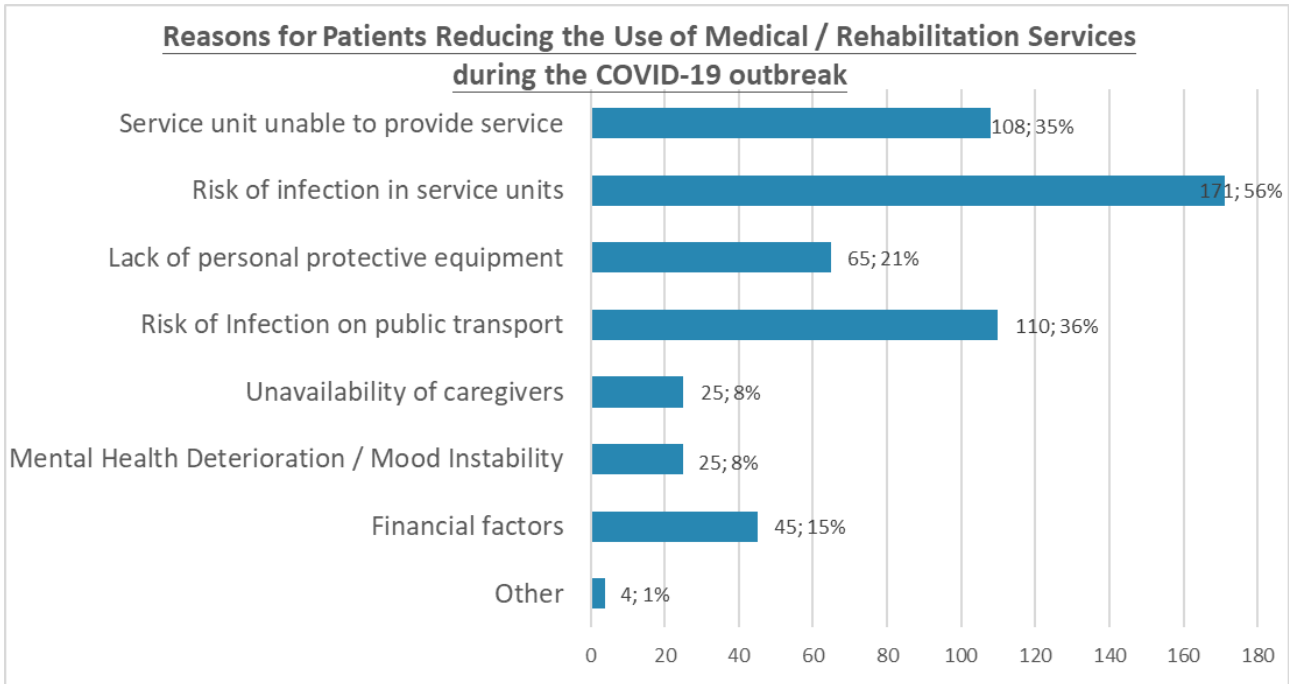
Graph 4 – Impact of COVID-19 on Mental Conditions of Rare Disease Patients and People with Disabilities



The findings highlight the concerns of respondents regarding the risk of infection. According to the survey, more than half (56%) of the respondents were afraid of being infected in medical and welfare service units, and 36% of them were concerned about the risk of infection on public transport. This illustrates the lack of confidence in terms of epidemic prevention of medical institutions and public transport.

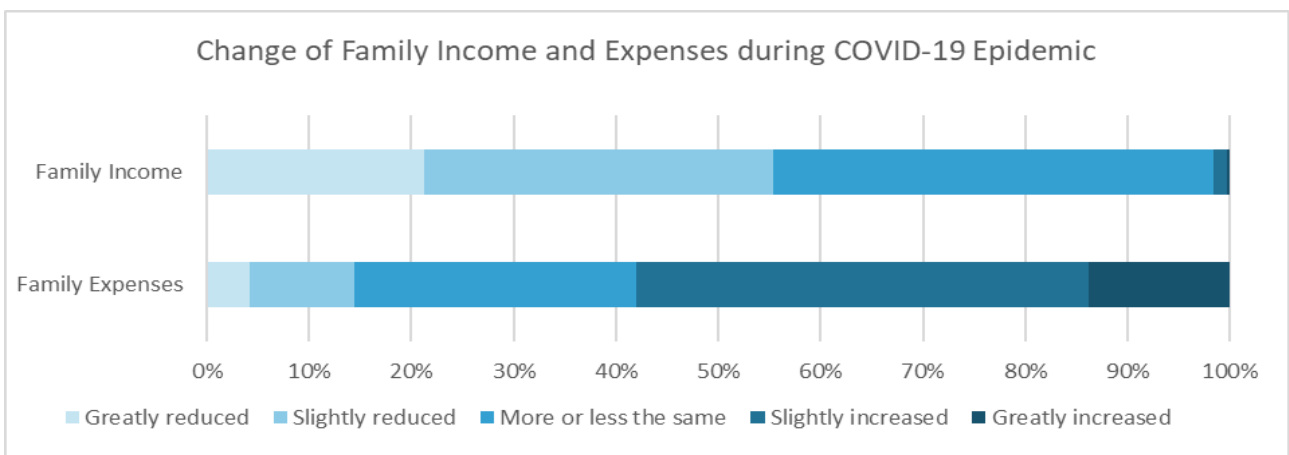


Graph 5 – Reasons for Patients Reducing the Use of Medical / Rehabilitation Services during the COVID-19 outbreak



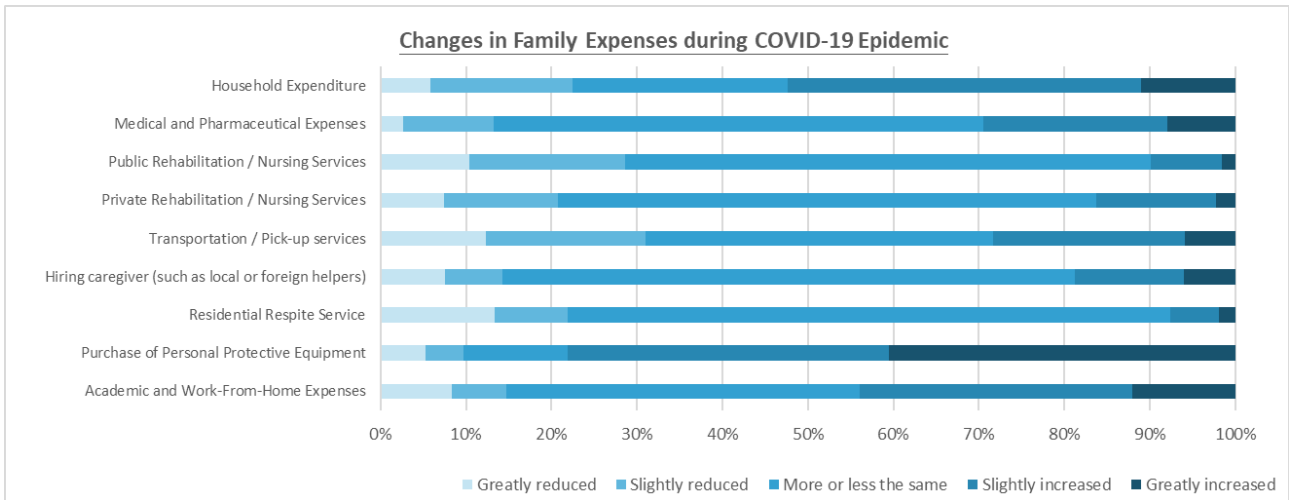
During the COVID-19 outbreak, while the expenditure of patient families increased, their household income decreased. According to the survey, more than half (55%) of the respondents claimed that their income has decreased and 58% of those surveyed said that their expenditure has increased. Among the nine expenses, the purchase of personal protective equipment, daily household expenses and the purchase of academic/ work-from-home resources are the top three expenses with the most significant increase. Although the supply of personal protective equipment has gradually stabilized now, around one-third (32%) of the respondents said that there is a shortage of surgical masks.

Graph 6 – Change of Family Income and Expenses during COVID-19 Epidemic





Graph 7 –Changes in Family Expenses during COVID-19 Epidemic

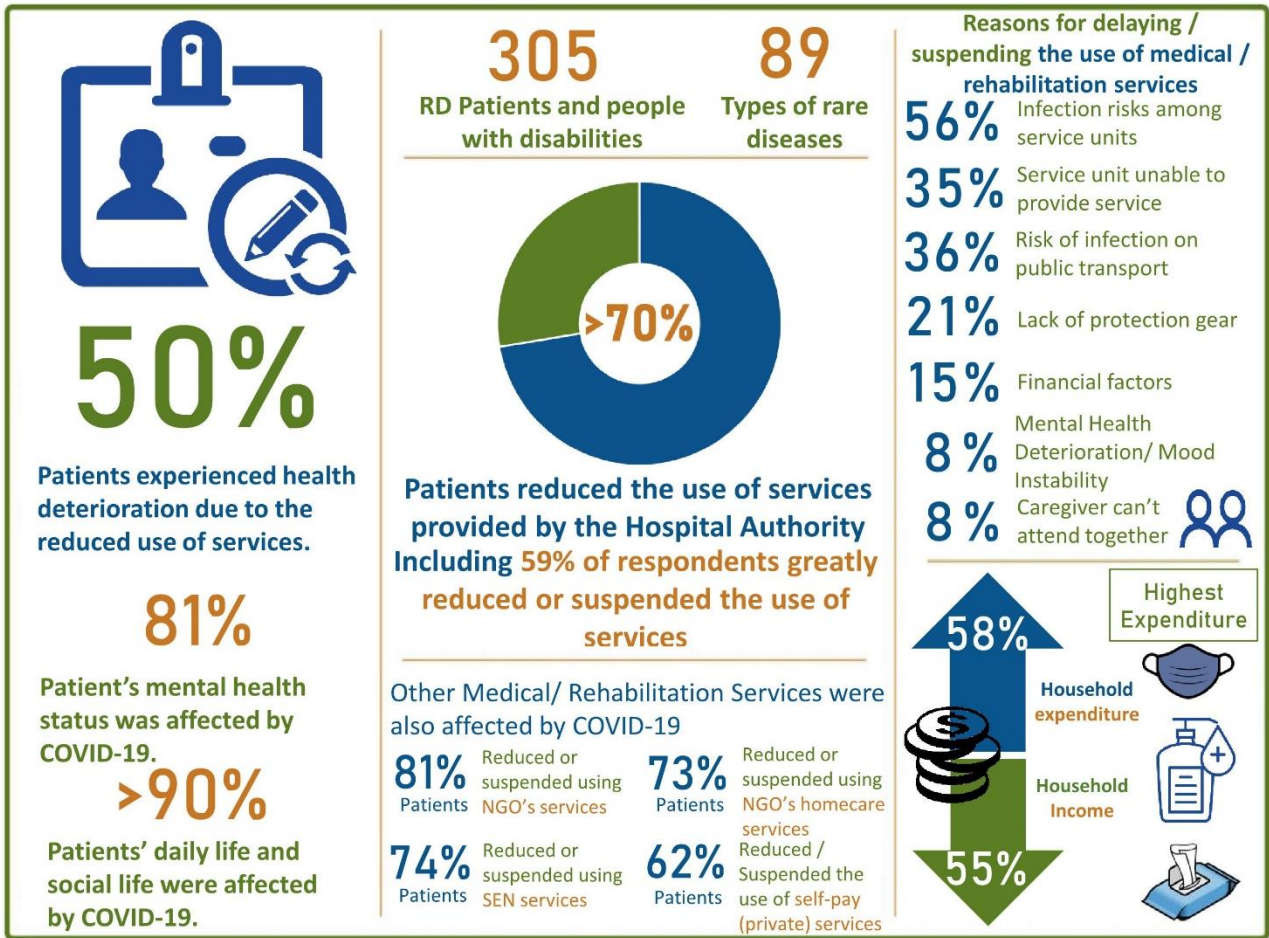


In response to the survey results, RDHK raises the following demands to government authorities:

- During the period of gradual resumption of medical and rehabilitation services, patients with rare disease and disability in more serious conditions should be given priority in terms of healthcare services, especially physiotherapy, occupational therapy and speech therapy which they needed the most. Home care services should also be provided according to patients' needs.
- Resources should be provided to RDHK and other qualified rare disease groups to explore and strengthen the use of information technology in order to respond to the needs of rare disease patients.
- Online counseling and training with diversified themes and formats should also be carried out. For instance, online activities regarding environmental hygiene, personal health, soothing exercises and prevention of epidemic could be conducted in one-on-one or group format.
- Short-term job positions addressing the needs of rare disease patients, such as in-home caregivers and residential respite workers, should be created during the COVID-19 outbreak.
- Departments and organizations such as Social Welfare Department and Hong Kong Council of Social Service should continue to distribute masks and self-protection resources to RDHK and other rare disease groups for more efficient distribution to patient families in need.



Summarized Infographic:



* HKU PhD student Claudia Chung created the above infographic.

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