

The impact of covid-19 on patients and families with rare and intractable diseases (NANBYO) in Japan - From the perspective of healthcare provision

Yukiko Nishimura*, Shun Emoto and ASrid JAPAN
Meiji University, Japan

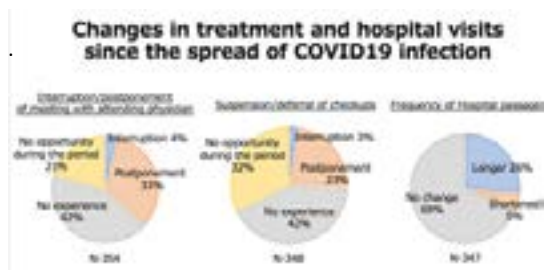
We conducted the following two surveys of patients and families living in Japan with rare/intractable diseases (NANBYO) under the covid-19 outbreak.

1. Quantitative study: To clarify the impact of covid-19 on the lives and medical situations of patients and families with NANBYO, the survey was conducted at a point in time by adding some original items to the items in the EURORDIS survey. The survey was conducted between May and October 2020, with 363 valid responses.
2. Qualitative study: To analyse narrative data related to covid-19, we asked 110 patients/families to complete an open-ended questionnaire once a month for nine months, from May 2020 to January 2021.

Results of study (1) showed that 90% of NANBYO patients recognized covid-19 as a threat to their own lives. It was "very threatening," especially for patients with renal/urologic, immunologic, and cardiovascular diseases. In addition, 37% of all patients had experienced treatment interruption or postponement. 29% of all respondents had experienced telemedicine (including telephone medical care). Of those,

98% rated the online consultation as helpful. Patients also commented that the ability to provide telemedicine and drug delivery has improved convenience for patients living in remote areas.

This presentation will include a report on the disruption of drug distribution and medical care in Japan because of this outcome and individual cases of patients who were forced to discontinue treatment.



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