The Prevalence and Healthcare utilization of Rare Neurological Diseases in Hong Kong: 2014-2018

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Background.
Rare diseases (RD) are rare and often debilitating or even life threatening diseases or conditions with prevalence of or less than 1 in 2000. Rare neurological diseases (RND) constitute a large proportion RD. A previous study in Hong Kong placed the proportion of RND amongst RD at 7% and 18% amongst children and adult population respectively. However, there has not been any study dedicated to the elucidation of prevalence and healthcare utilization pattern of RND and its subtypes. There is also a lack of understanding into the state of pharmacological research in RND.

Methods.
A list of ICD-10 codes corresponding to RNDs was compiled with adaptation from the Orphanet Classification of Rare Diseases, and classified into rare epilepsy, movement-related, neurocutaneous, neuroimmune, neurometabolic and neurodegenerative, neuromuscular and other RNDs. Using the Clinical Data Analysis and Reporting System (CDARS), which holds public hospital healthcare records of Hong Kong in an anonymous manner, we calculated the prevalence and healthcare utilization of patients RNDs between 2014 and 2018.

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Results.
The prevalence of RND in Hong Kong is 3.6 in 1000, which was similar between paediatric and adult population. Rare epilepsy has the highest subcategorical prevalence, followed by rare neuroimmune conditions (see table 1).

Different categories of RND also showed different patterns of healthcare utilization. Patients with neuromuscular conditions have the highest length of stay; whereas rare epilepsy patients have the highest A&E attendance and number of admissions per year; and neurometabolic patients had the highest number of outpatient clinic visits per year (see table 2).

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Discussion.
This is the first comprehensive review on the prevalence and healthcare utilization in RNDs. It shows high healthcare utilization rate amongst patients with RND in the Emergency Department, inpatient and outpatient settings. Each subcategory of RND may be recognized by a unique pattern in consumption of healthcare resources. Whilst rare epilepsies had the highest average number of admission per year, it was neuromuscular and neurometabolic and neurodegenerative conditions that required the most intensive care with highest number of outpatient sessions per patient. It would be important to design interventions and programs around the needs of patient within each RND subcategory.

References: