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Overview of Challenges and Government Position on Rare Diseases in Hong Kong

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ABSTRACT

Public awareness for rare diseases has increased in recent years in Hong Kong as patients suffer from long diagnosis process, misdiagnosis and limited financial subsidy for expensive medications. These challenges negatively affect patients' and caregivers' quality of life as they continuously suffer from a prolonged period of clinical investigations by different specialists before a diagnosis can be made. The costly and time-consuming process, as well as the lack of experienced clinical genetics professionals are major challenges of rare disease management in Hong Kong. The Hong Kong government adopts an approach of "case by case" instead of formulating a definition of rare disease. New regulations have been performed by the Hospital Authority such as increasing funding for Hong Kong Children's Hospital for early detection and diagnosis, and review on drug formulary. International collaborations like research and sharing of information is believed to bring optimal benefits for rare disease patients and caregivers, as well as to promote best practices in policy field.

KEYWORDS: Rare disease, diagnosis, clinical genetics, drug formulary

1 INTRODUCTION

The development of healthcare services is onward to the bright side as the advanced technology level and policy design for healthcare provide outstanding treatment for those in need. However, some sicknesses are difficult to treat and the sufferers need expensive medical expenses (Katelaris, 2014; Buckland, 2019). Rare diseases, also known as orphan diseases, are diseases that affect only a small number of people. A rare disease can be defined as any unusual or uncommon disease with only a prevalence in the general population. There have been more than 6,000 to 8,000 rare diseases documented worldwide and around 250-280 new rare diseases were found annually (Czech et al., 2020; Dawkins et al., 2018). Boxleitner (2005) contended that some rare diseases are serious and life-threatening while it might be chronic and progressive. While most of the rare diseases can be identified at the young age, there are still some rare diseases among adults (Mazzucato et al., 2018; Pearson, 2016). The rarity of these diseases creates significant challenges for healthcare management, leading to misdiagnosis, delay of treatment, and substantial burden on expensive healthcare expenditure in patients (Dawkins et al., 2018; Shafie et al., 2016).

One in every 67 Hong Kong citizens suffers from a rare disease (Chiu et al., 2018). Rare diseases have gained more public attention and awareness in Hong Kong since 2014, evidenced by the establishment of Rare Disease Hong Kong (RDHK) (formerly known as Hong Kong Alliance of Rare Disease, HKARD) and discussion on policy on provision of support measures during Legislative Council meetings in 2016. The healthcare service on rare diseases has higher public expectation since these patients are more difficult to receive appropriate medical treatment (Richter et al., 2015; McCormack et al., 2016). However, the healthcare services in Hong Kong do not have specialist services for rare disease patients, resulting in delay in diagnosis, lack of a comprehensive patient registry for treatment, and limited subsidies available for medication costs (Legislative Council, 2019). Most of the patients with a rare disease in Hong Kong might have a tortured life to recover their sickness (Chiu, 2018).

Compared to the general population, patients with rare diseases are found to have poorer health-related management and quality of life as most of them suffer from more than one chronic disease (Bogart & Irvin, 2017). The experiences and challenges faced by the patients and caregivers are also frustrating as many cases have to wait more than five years for a diagnosis, and some of them may receive misdiagnosis (Molster et al., 2016). Patients with rare diseases easily suffer from negative mental health condition as some of them are socially excluded by friends and relatives, and denied employment (Zhu et al., 2017). At the same time, the financial impact of rare diseases is also significant as frequent health care utilisation increases the financial burden of patients and caregivers (Nalysnyk et al., 2014). Therefore, government regulation and policy need to ensure effective healthcare services for rare diseases including screening, treatment and financial subsidy are available for patients with equal access.

This paper presents an overview of the challenges that Hong Kong is facing in managing rare diseases, and the government's position and effort in helping rare disease patients. Policy enhancement and new regulations have been conducted by the government, but close attention and referencing to international healthcare services and policies on rare diseases is needed in order provide appropriate treatment and support for patients.

2 CHALLENGES ON RARE DISEASES IN HONG KONG

2.1 No definition of rare disease

At present, there is no universal definition of rare diseases and it varies with countries or regions. Most definitions consider a disease is rare based on the prevalence, severity,

whether it is life-threatening, and whether there are alternative treatments available (Ritcher et al., 2018). According to the standard of the World Health Organization, 6.5 to 10 cases in 10 thousand people can be treated as a rare disease. The European Union, including France, Poland, and Germany define a disease as rare when it affects fewer than 1 in 2000 (Czech et al., 2020). The United States of America defines a rare disease when less than 200,000 people are affected (Derayeh et al., 2018). In Asia Pacific countries, less than 50,000 and 2,000 people are defined for rare diseases in Japan and Australia respectively (Derayeh et al., 2018).

There are some commonly known rare diseases in Hong Kong, such as Pome Disease, Mucopolysaccharidosis, Muscular Atrophy, Gaucher Disease, Achondroplasia, etc. (Rare Disease Hong Kong, 2022). It is estimated that rare disease patients in Hong Kong are up to around 2,500 cases (Wong, 2018). Furthermore, Wong's study (2018) found that one in 67 Hong Kong people was struggling with a rare disease. But Hong Kong government still has not set clear direction or definition of rare diseases, and failed to formulate related policies. Compared to other Asian countries such as Singapore, South Korea and Japan, Hong Kong is way far behind in terms of prevention and treatment of this group of patients (Kong et al., 2015; Mak, 2019; Wang, 2018). Over time, the issue of rare disease is still ambiguous for the public as well the professional in Hong Kong. Doctors and social experts fail to have accurate understanding and knowledge about how to help needy patients with rare diseases (Cheung, 2020; Sit, 2017).

2.2 Prolonged period of clinical diagnosis

There are limited knowledge about the causes or epidemiological data for most of the rare diseases. While the experts of rare diseases are competent in diagnosing and treating rare diseases, the lack of evidence-based or scientific knowledge and sound information always led to delay in healthcare services (Breining, 2017; Silver, 2018). The duration of diagnosis is often a painful struggle for patients. The lack of concern in clinical genetics may lead to prolonged and delayed medical investigations until a follow-up action is planned (Kuiper et al., 2018; Vries et al., 2018).

In Hong Kong, clinical genetics is not registered in the list of specialists by The Medical Council of Hong Kong and there is no designated department for the treatment of rare diseases in the universities or Hospital Authority (HA) (Legislative Council, 2019). Medical professions in Hong Kong pay little attention or concern to rare diseases, resulting in limited research and development, and lack of experienced medical staff in this discipline. Patients have to visit different specialists and have their specimens sent to foreign laboratories for diagnosis (Rare Disease Hong Kong, 2022). The prolonged lag time between first symptoms and diagnosis may cause delay in access to clinical interventions for the best outcome for patients.

2.3 Lack of financial support

Another challenge for rare disease patients is the lack of financial support for them and their family. Most rare diseases cannot be cured and require long-term medication, while some patients can only use medication to control the disease instead of completing the whole treatment (Picavet, 2011). Only few patients could have standardised orphan drugs for treatment (Angelis et al., 2015; Coyle et al., 2014). The high medication cost causes heavy financial burden and most families cannot afford such expensive drugs and treatments.

In Hong Kong, patients receiving subsidies for rare disease drugs are assessed and evaluated annually by the Expert Panel on Rare Metabolic Diseases, and then given additional recurrent funding from the government (Lee, 2020). However, most of the drugs for rare

diseases are not placed under the Hospital Authority Drug Formulary (HADF) system, which means many drugs are not covered in the Samaritan Fund or the Community Care Fund (CCF) (Lee, 2020). Therefore, most of the patients do not have a chance to get financial support or benefit from the current mechanism and have to pay high-prices drugs charges out-of-pocket. There are identified cases in Hong Kong in which patients suffered from rare diseases but could not afford the medication. Patient named Wong Fung Ming and her two daughters suffered from Tuberous Sclerosis Complex and the medication reached HK$30,000 per month. One of her daughters died in 2015 and the medication at that time was not listed in the HADF. Another patient suffered from Tuberous Sclerosis Complex passed away after expressing her wish about including the concerned drugs into the HADF at the Legislative Council in 2017 (Cairns, 2017). These two cases reflect insufficient medical subsidies for patients with rare diseases leading to unavailability of treatment.

3 GOVERNMENT'S CURRENT POSITION AND SUPPORT FOR RARE DISEASES

There are many limitations on the current healthcare management in terms of treatment, funding, and support for rare diseases in Hong Kong. RDHK, the first patient organisation in Hong Kong composing cross-category rare disease patients and caregivers, has continuously raising public awareness of rare diseases through collaboration with different stakeholder. The organisation conducts workshops and rare-disease-related research studies, as well as proposes various initiatives regarding rare disease management that have contributed to policy advocacy.

Drawing more public awareness and attention, the initiatives in the bill proposed by Dr Hon Fernando Cheung at the Legislative Council Panel on Health Services in 2019 had provided policy and resource implications. Somehow, the Hong Kong government stated that legislation on rare diseases would be unnecessarily as each rare disease has its own uniqueness and patients with different circumstances would require different clinical treatment and care. Instead, they held the view that adopting the strategy of "case by case" and refining clinical diagnosis, multi-disciplinary care and rehabilitation services would be more effective in providing optimal treatments for all these patients (The Government of the Hong Kong Special Administrative Region [HKSARG], 2021a).

Moving forward from the 2021 Policy Address, more drugs are covered by the Samaritan Fund and the CCF Medical Assistance Programmes, and the clinical criteria for existing drugs are relaxed (HKSARG, 2021b). The government has further refined the mean test mechanism of both funding sources in order to benefit more patients to receive financial support (HKSARG, 2021a). In response to the demand on purchasing ultra-expensive drugs, the implementation of Ultra-expensive Drugs Programme under the CCF since 2017 approved 77 applications, with a total amount of HK$259.5 million of subsidies granted. The HA's Drug Management Committee also regularly calls for submissions from clinics on self-finance drugs to be included into the safety net. Liaise with pharmaceutical companies, patients can access drug treatment earlier.

Helping children with rare diseases, the government has increased HK$25 million of recurrent funding for HA to support the Hong Kong Children's Hospital in providing more comprehensive services, including increasing manpower for clinical genetic service and the capacity for genetic and genomic testing services. As early detection and diagnosis are very important for newborns, HA has launched a case manager programme for managing patient's treatment and care and developing databases for uncommon disorders under exiting newborn screening programme.

The HA has an established mechanism for regular evaluation of registered new drugs and the coverage of the safety net with the support of multiple expert panels of different specialties in the HADF. The review process is based on an evidence-based approach, evaluating the safety, efficacy and cost-effectiveness of drugs. Other relevant considerations including international recommendations and practices as well as professional and patients' views are taking into account so as to ensure effective use of public resources in providing optimal support for patients.

The HA has been staying up-to-date with international developments in the medical field and new drugs in order to introduce into the pharmaceutical market (HKSARG, 2021a). Locally in Hong Kong, allocating more resources to promote scientific development and clinical research relating to rare diseases is important to benefit patients from getting precise diagnosis and effective treatment earlier. In 2020, the Hong Kong Genome Project was implemented by the Hong Kong Genome Institute to perform large scale of genome sequencing, which will cover cases of undiagnosed genetic diseases and hereditary cancers (Hong Kong Genome Institute, 2021). The project is currently carrying out a pilot phase that targets 2,000 eligible volunteers with undiagnosed disorders and hereditary cancer from Hong Kong Children's Hospital, Prince of Wales Hospital and Queen Mary Hospital. The second phase will be launched in due course and will be expanded to cover other heredity diseases and perform sequencing for additional 18,000 cases. Collaborating with the Department of Health, HA and local universities, it is hoped to enhance the development of genomic medicine and nurture talents in Hong Kong.

4 THE WAY FORWARD

Nearly 80% of rare diseases are genetic in origin and the lack of specialists in this medical field is on ongoing problem in Hong Kong. The Clinical Genetic Service under the Department of Health provides genetic diagnosis, counselling and prevention, but the current medical professional framework of Hong Kong does not include clinical genetics as a subspecialty. It is claimed that services related to clinic genetics are provided by different specialties, and multidisciplinary specialist clinics and coordinated services appear to be a key to delivering proper care for rare diseases. To solve the problem of paying multiple visits to different specialists among patients and caregivers, an enhanced sharing of expertise and genetic information system will be needed. Besides, empowering healthcare workers with the right knowledge and functional understanding of identifying suspected rare disease cases is also essential (Rahma et al., 2020). In addition, careers and diversity for genetics-related medical healthcare staff should also be promoted, including genetic counselors, metabolic dietitians, physician assistants, genetic nurses, and laboratory geneticists (Jenkins et al., 2021).

Improving diagnostic resources and innovative research are important for early diagnosis. New scientific and methodological approaches are being developed to improve evidence generation and analysis for rare diseases. For instance, new trial designs and clinical endpoints were done in the European Union 7th Framework Programme (FP7) and its subprograms, which are Integrated Design and Analysis of small population group trials, and Advances in Small Trials dEesign for Regulatory Innovation and eXcellence (ASTERIX)(Czech et al., 2020). Because of the wide variety of rare diseases, international medical and scientific collaboration to investigate in the common proposal and conclusion about different cases can pool information across different regions, provides chances to resolve the difficulties and challenges of rare diseases (Schieppati et al., 2008; Schulenburg & Frank, 2015). The establishment of the Hong Kong Genome Institute and commissioning of the Hong

Kong Genome Project are promising but continuous research and sharing of information with other countries is believed to bring actual benefits for rare disease patients, as well as to promote best practices in that rare disease policy field.

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