Short Communication

Ageing parents of children with intellectual disabilities during the COVID-19 epidemic in Hong Kong

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ABSTRACT

During the outbreak of COVID-19, the situation of aging parents of adolescents with intellectual disabilities (ID) in Hong Kong have encountered great difficulties in their daily lives. Due to the rapid changing conditions of the new virus COVID-19, it posed a lot of uncertainties and risks to the health of the public at large. In this regard, this group of parents and their children with ID are vulnerable to even greater risks and challenges in combating against the new virus. This paper has looked into the difficulties these parents and their children with ID have experienced and how they adjusted to carrying on with their living.

Ageing is an inevitable stage of life and the population of Hong Kong is growing old. According to statistics from the Census and Statistics Department (CSD) of the Hong Kong government, individuals in the age group ‘>65 years’ will comprise approximately 19–23% of the population by the year 2021 [1]. An additional study by the CSD estimates that there are appropriately 154,000 people classified as having an intellectual disability (ID) in 2020 [2]. Among this group of individuals with ID, approximately 26,600 are living in the same household as their families.

The novel coronavirus disease 2019 (COVID-19) has caused massive infection worldwide since the end of 2019 and Hong Kong is no exception [3]. Everyone has been advised to take precautionary sanitary measures against COVID-19. Individuals with ID are often unable to take care of themselves or to follow the advised precautionary measures. So, how can family members help care for individuals with ID during the COVID-19 pandemic?

Since January 2020, there has been an increasing number of confirmed COVID-19-positive cases in Hong Kong. During the outbreak of COVID-19, which evolved quickly and lead to the rapid growth of infected cases, people in Hong Kong used several strategies to protect themselves. These included sourcing and securing the supply of face masks, keeping a social distance from friends and people passing by, and working from home to avoid being in an office with groups of colleagues. The COVID-19 pandemic has posed an especially difficult situation for vulnerable groups taking care other individuals, such as ageing parents who have children with ID. This at-risk older population group are struggling to provide a balance between adequate protection against the virus and maintaining a healthy daily lifestyle for their children. This sudden and huge impact has disrupted their lives, their daily routines and caused many emotional problems. Children with ID often have underlying mental health problems, which may be exacerbated by confining them to the home for long periods of time. When activities are restricted to the home, friction and conflict between children with ID and their parents may also increase, in addition to the possibility of injuries caused by their involuntary body movements as a result of their emotional behaviours towards the new rules imposed upon them. Many parents are worried and helpless about the self-care abilities of their children with ID. Some individuals with ID do not have the ability to express their feelings through speech or body language in order to make others understand their needs. They may also lack the cognitive ability to understand the importance of various interventions to interrupt or reduce the spread of infectious diseases, such as COVID-19. For some individuals with ID, their compulsive behaviour and lack of understanding of the rules may have a significant adverse impact in protecting themselves against COVID-19. For example, some individuals with ID may not understand the need and benefit of protecting themselves, and therefore resist the proper hand washing protocol or wearing of face masks. Due to their inability to care for themselves, children with ID might easily be infected with the COVID-19 virus [4,5].

Most of the ageing parents emphasise that they do not know how to look after their children with ID during the COVID-19 pandemic due to the deterioration of their own physical health and the fear of not knowing how to avoid contamination. Ageing parents of children with ID have

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shown significant emotional problems during the pandemic; they are irritable, tense with anxiety, fatigued and struggle to sleep as they are worrying about the lack of awareness of self-protection that their adolescent children have during the pandemic. These parents face great pressure of not knowing how best to take care of their children with special health needs. With the high prevalence of COVID-19, they do not know how to plan or engage future care planning for their children with ID if they themselves become infected or pass away, leaving behind their children. Parents shoulder the burden of caring for children with ID every day and often have restrictive lifestyles to protect their children. The COVID-19 epidemic has further added to their uncertainties around the proper way to protect their children and this may ultimately result in complete isolation at home.

In Hong Kong, there are a number of care facilities, such as sheltered workshops (for disabled adults), long-stay care homes (for individuals with previous mental health problems), care homes (for severely disabled persons) or hostels for rehabilitation services (for people with disabilities), organised by the government or non-governmental organisations. These organisations provide work training and residential care for those with ID in need [2]. Ageing parents may choose the option of waiting for allocation of residential care places for their children. As the places are limited, there is a lengthy waiting time from a few years to over 15 years to get a residing place for their children with ID in to these facilities [6,7]. Until they are allocated a place, the underprivileged children with ID will have to stay with their parents at home.

It is also important to note that the management of these residential care facilities and hostels are facing a huge challenge to follow organisational policy to prevent the spread of COVID-19. Limiting the number of visitors to the facilities to avoid contact with the residents or requiring residents who have returned from visiting outside places to take preventive measures, such as self-quarantine for 14 days, are no easy tasks. As a result, residents are not allowed to leave these facilities during the COVID-19 pandemic. Children with ID staying in residential care facilities are likely to feel lonely and forgotten despite their parents being eager to, but refrained from, visiting them during the pandemic. At the same time, many parents may feel sorry for their children and blame themselves for the need to keep their children in the residential care facilities during this time, resulting in the children being socially isolated from their parents.

Life in residential care facilities and hostels has also been greatly impacted by the COVID-19 pandemic. The usual daily activities and work routines of adolescent children with ID have been suspended. All their daily training services and outside communication have been withheld [8]. Without daily training, other routine work and support, children with ID will not have the opportunity to properly exercise and stretch their arms and legs; thus, their physical and emotional health are likely to deteriorate. However, it is a relief that, with the advancement of telecommunication technology, some care takers in these facilities help children with ID stay connected to their families via social media, video communications, emails, WhatsApp or text messages.

In the long term, a recommended strategy to overcome this difficulty would be to have additional centre-based care training and therapy services to the healthcare providers and extend the collaboration to the social welfare sectors to provide person-based support to individual parents after the pandemic. Local non-governmental organisations could also coordinate with social support networks to help tackle the stress experienced by ageing parents of children with ID and help them connect with appropriate services. In addition, parents of children with ID, especially those in the older age groups, can make use of peer-support groups via different online communication channels to share their grievances, worries, advice and comfort. It is hoped that, following the extreme situations brought about by the COVID-19 crisis, policymakers will invest and improve current caring and rehabilitative services; for example, by increasing the allocation numbers of residential care places for people with ID in order to shorten the waiting time. For further planning after the COVID-19 pandemic, policymakers could consider providing and maintaining adequate and continuous healthcare support and care services for current and future needs of this unique group of ageing parents and their children with ID.

To enhance the social relations and health care assistance for children with ID and their parents, a person-centred approach with guidance from professionals working in social services and health care sectors, is necessary. It is hoped that with proper planning and resource allocation, ageing parents who are taking care of their children with ID can receive the attention and support from the community that they need in order to allow them to have peace of mind, especially during a pandemic crisis.

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Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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