

**EDITORIAL****Economic Burden and Parenting Stress Managing Special Healthcare Needs Children during COVID-19 Pandemic****Haliza Hasan\* & Siti Mariam Muda**

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Special healthcare needs refers to any physical, developmental, mental, sensory, behavioural, cognitive, or emotional impairment or limiting condition that requires medical management, health care intervention, and/or use of specialized services or programs due to limitations in performing daily self-maintenance activities or substantial limitations in a major life activity(1). The definition of special healthcare and people with disability is interchangeable for the similarity of the needs and burden for the individual and their parents. During COVID-19 pandemic, there were two main impacts currently highlighted to the parents of special healthcare needs children. The higher cost of caring special healthcare needs children poses significant economic burden because the total costs often exceed family's expectation due to the complex care. As noted by studies, having a special healthcare needs child refers to a long-term challenge for parents, no matter what type and degree of disability the special needs children have(2). Further, this issue may contribute to mental health problems among parents with special healthcare needs children.

The prevalence of people with disability have increased since the last two decades, from about 10% in 1970s to 15% in 2011(3). Malaysia as a developing country is also concerned with this increasing number of disabled persons. The records in 2012 showed that 445,006 people with various forms of disabilities have registered with the Department of Social Welfare Malaysia (DSWM), which represents 1.5% out of the 29.51 million of the country's population then. The increasing number of children with disability worldwide also contributes to the statistic of persons with disability, albeit a relatively small proportion of the statistic. Malaysia also reported that 0.1% out of 1.5% of country's population were contributed by 29,289 children (4). This proportion of the population would require long-term care that exerts an economic burden to families and nations.

Managing special healthcare needs children during the COVID-19 pandemic was a big challenge for parents, especially from the economic, emotional, mental and well-being standpoints (5) Economic burden can be defined as the costs incurred from monetary or non-monetary resources to deal with specific condition or diseases (6). Economic evaluation can be estimated using proper approach where it is differ from accounting or financial definition is called cost analysis approach (7). This analysis of costs for alternative treatments or health programs is relevant for all types of economic analysis. The cost analysis was done to explore economic burden associated with specific condition or health problems, where all the expenditures incurred relatives to the treatments in managing special healthcare needs children were calculated. The goods to be taken into consideration are e.g. money, time spent and resources. Costs were calculated from societal and/or parents perspectives where, divided into direct and indirect costs. Direct costs are the costs involved in relation to the care directly and in term of monetary such as hiring personal physiotherapist for home physical therapy. While indirect costs are the costs incurred by loss of productivity due to time spent in managing special healthcare needs children. For example, a mother spent 4 hours in managing their special healthcare needs child, which the indirect cost was estimated from salary of RM1,200 per months and calculated for 0.08 cent salary per minute. Thus, 240 minutes spent multiple with 0.08 cents to obtain indirect cost.

Several studies highlighted that high cost was incurred from the direct and indirect expenses of families to provide the best health care treatment for their child with disabilities (2,7,8,) which is not surprising. Long-term rehabilitation costs associated with the disability affects the family's future economic performance and well-being, more significantly so when compared to a family with a typical child.

As noted by studies, having a child with disability refers to a long-term challenge for parents, no matter what type and degree of disability the special needs children have<sup>7</sup>. During the COVID-19 pandemic, the nationwide home quarantine that mandated schools' and rehabilitation training institutions' closure required hundreds of children with disabilities to stay at home for months<sup>8</sup>. Some children with disabilities might experience behavioural regression and extensive problems because of their inability to access daily school education, rehabilitation training, personalized intervention, and treatments. Instead, parents had to undertake multiple tasks including parenting, educating, rehabilitating, and training, which could have increased their parenting stress level. This situation has posed a novel dimension to be studied as there is scarcity of data to explore the costs incurred by parents' children with disability during the COVID-19 pandemic.

The COVID-19 pandemic triggered a major economic recession and placed huge financial pressures on many families. The sequences of economic recessions, the increasing of unemployment, income decline, and unmanageable debts are significantly associated with a decrease in mental well-being<sup>(10)</sup>. This was similar with study by Anderson et al. (2007) which found that indirect costs in productivity led to reduced labor force participation, leisure time, and home production, damaging the economic effects of caring for child with special needs<sup>(11)</sup>.

The increasing out-of-pocket cost may have escalated the economic burden of the families seeking for rehabilitation services since all community-based rehabilitation centres (CBR) were closed during Movement Control Order (MCO) started from March 2020<sup>(12)</sup>. This situation may influence parents' decision making for seeking other rehabilitations services that can reached to their special healthcare needs children during closure of CBR centre. Care demands faced by parents of special needs children may incurred costs which can cause significant economic burden to the family. This also supported by previous study among selected rural communities in Malaysia found that the out-of-pocket costs was significantly higher in respondents of Malay ethnicity, unemployed occupants, single source of income, and having household income less than MYR 2,500<sup>(13)</sup>.

Although the COVID-19 is a very new viral strain, the resulting pandemic has affected many aspects of our life, from health to economy and education. These factors may have contributed to the

increasing mental health issues among people, especially parents with special needs, due to the increasing economic burden and psychological stress in managing their children during this critical period. Thus, further study in this regard should be explored to identify costs incurred in managing children with special needs during the COVID-19 pandemic that poses economic burden and increase parenting stress.

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