

Oral Feeding Difficulties Among Children with Cerebral Palsy, Aged Between Birth to 5 Years: Special Challenges Faced by Primary Caregivers During The COVID-19 Pandemic.

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The world has been confronted with the novel pandemic called COVID-19, which has been quickly spreading throughout the world from its first detection in December 2019. Cerebral Palsy (CP) can be defined as a group of disorders affecting movements of limbs, muscles, hearing, vision and posture (Das, Zaman, Hasan, Barua, & Chowdhury, 2016). It is due to damage to the developing brain. Signs and symptoms vary among children and over time. It can be caused by premature birth, not getting enough blood supply, oxygen (hypoxia), or other nutrients before or during birth. Caregivers play an important and special role in supporting children with CP who experience feeding difficulties. During this pandemic situation, introducing “telehealth” may be more beneficial for children who are getting support from health professionals. Many health professionals have been facing challenges in providing services to patients using traditional in person care. The organizations have begun advocating telehealth or tele practice for reducing person to person contact and implementing social distancing. Telehealth or the use of telecommunication technologies are able to support long distance clinical health care. It is a model that can be used in prior public health emergencies. (Miles et al. 2020). However, it is not clear if such a service may be accessible or of benefit to parents in the Sri Lankan context. Therefore, the study was undertaken to explore the special challenges which are faced by the primary care - givers who have children with CP and oral feeding during this pandemic period.

A qualitative study using a phenomenological approach was implemented to determine the special challenges faced by primary caregivers in managing oral feeding difficulties in children with cerebral palsy aged between birth to 5 years during the COVID- 19 pandemic in one clinical setting in the Western Province of Sri Lanka. Using a purposive sampling method, the study was completed by interviewing 12 participants who were at the mentioned clinical setting and who have children with CP with oral feeding difficulties. Data was collected through semi structured interviews conducted as tele- interview session with the primary caregivers. The interview guide was sent to an expert panel for the verification of face and content validity. A pilot study was done before data collection with 2 participants. The qualitative data were analysed using thematic analysis (Braun & Clarke, 2006).

The purpose of the study was to determine the special challenges faced by primary caregivers for managing oral feeding difficulties in children with cerebral palsy aged between birth to 5 years in one clinical setting in the Western Province of Sri Lanka during the COVID- 19 pandemic. In this study there were no known risk to health and safety in participation. All the participants were able to be interviewed via telephone. This was a qualitative study using in-depth discussion were included and limited current access to clients-remote data collection during this COVID-19 pandemic situation. Several themes emerged from the data as a result of qualitative analysis: challenges in accessing food, challenges in accessing medication, special challenges due to COVID-19 and transition of

service delivery model. When exploring the benefits, participants were very interested to discuss and get new ideas about the specific areas which were covered in the study on managing oral feeding difficulties in children with cerebral palsy during the COVID-19 pandemic. And also it was good opportunity to share their information with others about lived experiences during this new pandemic situation. Disadvantages: Children with chronic neurological conditions can be considered as at higher risk of COVID-19 infection (Bhasker et al. 2020). The novel corona virus (COVID-19) has a significant impact on medicine. The COVID-19 pandemic has already led to an increase in unemployment, poverty and food and nutrition insecurity, as well as poor health outcomes globally. It became challenging to find safe food for children with special needs during this pandemic situation. The current crisis in children in low and middle- income countries reminds in poor health outcome during the pandemic (Zar et al. 2020). Majority of the participants highlighted the negative feedback of having no shops and pharmacies near by the house, because of that, they faced many challenges of accessing meals and medication during the pandemic. In the pandemic period, some mothers reported confusion about daily schedule of rehabilitation because of the transition of the service delivery model, lack of awareness about the appointment, and the technology and also poor connectivity. Some participants were confused about how to manage the children with home based therapy sessions during the pandemic.

The study suggests the importance of telehealth sessions online during the pandemic. It will be more beneficial for the child and the family to have online sessions (video call sessions) to participate actively and for the professionals to engage directly with the session. The professionals can also see the family's participation in the session. Furthermore, it will be more beneficial to encourage the child and the family to access online clinics, which maintain social distancing during the pandemic than face to face clinical sessions. However, the study also found the hardships faced by parents who have children with CP when accessing food, medication and health services during this pandemic period.

It will be beneficial to investigate parental awareness about rehabilitation service programs in a follow- up study. When having online sessions during the pandemic, it will be more beneficial for the children to participate actively and the professionals to engage directly with the session as well as the professionals will be able to see the mother's participation to the session.