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Roles of Digital Technology in Sustaining Mental Health among Parent of Children with Autism Spectrum Disorders during Pandemic Covid-19: A Concept Paper

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Abstract

This conceptual paper illustrates the issues, aims and significance of the ongoing study on the mental health of parents of children with Autism Spectrum Disorders (ASD) during the COVID-19 Pandemic and the role of digital technology that helps sustain well-being among parents of children with ASD. The recent COVID-19 situation lockdown and social distancing were reported to have intensified the behavioural effects on ASD children and further deteriorated the parents' mental health. Therefore, seeking related information and sharing experiences amongst parents of ASD children is crucial to sustaining the parent's mental health.

Keywords: digital technology, mental health, the parent with Autism Spectrum Disorders (ASD) children, Pandemic Covid-19

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1.0 Introduction

COVID-19 creates challenges for both children and parents with ASD in Malaysia. Parents have always been the primary support of the development of children. However, they faced many challenges, possibly due to the emergency measures involving suspension of essential services, closure of schools, work-home policy, and lack of professional support. Over time, the persistent stress of raising and caring for a child with ASD with various levels of disability has adverse effects on their mental health and well-being. Parents experienced higher parental stress and poorer physical and mental health than parents of typically developing children. The impact happened such as quarantined, lost or lesser income and changes in their lifestyle (Fong et al., 2021).

Parents have additional stress or encounter even before the Pandemic Covid-19. Therefore, they would probably lack knowledge about treatment efficacy, standards of treatment setting, and the process to seek help further contributes to their mental health status (Bhavnani, S et al., 2021). Therefore, it is essential to ensure parents know their mental health status and well-being in the current pandemic situation. This relates to the development of children in getting successful intervention.

In line with the digitalization era, many prefer digital technology platforms (e.g., Health websites, Facebook, Instagram) to conventional communication channels as they feel more secure using that. Digital technology is a platform where people seek information through their

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fingertips. It infuses our lives, and digitization is considered the most important strength in the current revolution of economic and social activities (E. Fauchart et al., 2021). It has become a vital resource for the parent, especially since the Pandemic Covid-19. Moreover, digital technology helps ASD improve communication, emotional, academic, and social skills (Laurie, M. H et al., 2019).

Digital technology creates an option in helping them find and maintain resources for their intervention of children either through mobile apps or web-based settings. Nowadays, intervention for ASD children develops through digital innovation. It includes medicine, communication apps, education in daily living skills. The study of more direct ways to capture the quality of digital technology use is needed. In particular, the lack of attempts to measure the self-reported quality of technology includes how the technological devices use themselves and their experience when used. It helps to reduce the barriers to seeking help and improve mental health and well-being (Johnson et al., 2021). Therefore, this exploratory qualitative will explore in-depth the parents' experiences in using digital technology during Covid-19 as initiatives for them to seek help regarding their mental health and well-being.

1.1 Problem Statement

In Malaysia, epidemiological data on the prevalence of ASD is still unavailable. However, by referring to the World Health Organization (WHO), the number is projected to increase from time to time. A global prevalence stated that the identification of ASD has a ratio of 1:44 ratio (Centre for Disease Control and Prevention, CDC, 2021). Children with ASD appear to have limitations performing daily living activities and may require lifelong support to facilitate their disability. Meanwhile, parents of children with ASD also faced difficulties accessing information, diagnosis, support, and intervention. The struggles have impacted the parents and caregivers, including financial burden, marital affairs, quality of life, and mental health deterioration. These may potentially affect the progress of ASD children, such as the commitment to therapy sessions, hence delaying the children's responses to intervention. The national data disclosed that one out of three Malaysians suffered from mental health (Ministry of Health Malaysia, 2015), which is becoming common nowadays.

The third goal of sustainable development (SDG 3) emphasized the need to ensure the health and well-being of the population, including mental health, through preventive and treatment by 2030. In Malaysia, the Pandemic restricted parents from seeking help and resources, adopting isolation and social distancing (Anuar M.A et al., 2021). These can be translated into efforts to help the parents explore the roles of digital technology via web-based technology and mobile-based technology in maintaining good mental health. Later, they were able to encourage their engagement and participation in the children with ASD intervention program. Unfortunately, studies exploring digital technology's roles in maintaining parents' mental health with ASD children in Malaysia are still lacking. However, the knowledge gaps are filling, as this research looks forward to determining the impact of COVID-19 on the mental health of parents with ASD children, further exploring the roles of digital technology to sustain their mental health.

1.2 Research Objectives and Research Questions

This concept paper aims to present a proposal for future research exploring the impact of parents' mental health with ASD children during Pandemic COVID-19 and digital technology initiatives for help-seeking regarding parents' mental health and well-being.

This future ongoing study aims to explore the links between digital technology mental health of parents of children with ASD during the Pandemic Covid-19 in Malaysia by focusing on the following specific objectives:

1. To investigate the impacts on parents' mental health of children with ASD during the Covid-19 Pandemic.
2. To examine the roles of digital technologies in sustaining parents' mental health during the COVID-19 Pandemic.

As such, the research questions are:

1. What impacts parents' mental health of children with ASD during the Covid-19 Pandemic?
2. How does digital technology play a role in sustaining parents' mental health during the Covid-19 Pandemic?

1.3 Significance of the Research

This research may serve as a research template for parents with other special needs children or diseased children. Over the past two decades, mental health has become a national and global agenda due to high prevalence rates worldwide. The United Nations, through the third Sustainable Development Goal (SDG 3), focuses on promotional strategies in ensuring good health and well-being for all of all ages. The impacts of this research will support government directions as embraced in the Shared Prosperity Vision (SPV) 2030 with a primary aim to provide Malaysians with a decent living with the ability to lead a meaningful and dignified life.

As for the parents or caregivers of children with ASD, good mental health is vital to ensure the success and sustainability of their children's interventions. Digital technologies will become an essential part of our healthcare system. Facebook, Instagram, and Twitter have become the new platform to access health-related information, including ASD. Digital technology may benefit the parents by providing knowledge, establishing a connection, and emotional sharing related to concerns of ASD children. Hence, parents are facilitated to maintain their mental health by reaching reliable information.

2.0 Literature Review

2.1 Challenges as parents of children with Autism Spectrum Disorder (ASD) children

In Malaysia, the epidemiological study on the prevalence of ASD is yet to be reported. Nonetheless, there has been a rise in ASD cases intakes in special needs schools that have doubled from 2003 to 2016 (Fong et al., 2021).

Parenting children with ASD may expose the parents to significant challenges. The variety of difficulties ranging from the affected child's challenging behaviours to the various needs related to childcare; accepting diagnosis; accessibility to therapy and treatment; health issues, financial strain and many more may pose a greater risk to parents' psychological and health-related quality of life including their state of mental health (Costa, Steffgen, & Ferring, 2017).

2.2 Impact of Mental Health on Parents with ASD children

Mental health is known as the leading non-communicable disease worldwide. The nationally representative study of The National Health Morbidity Survey (NHMS) discovered a three-fold increase in mental health illness among adults within a decade from 10.70% in 1996 to 29.2% in 2015, which 29.3% aged 16 years and above facing it (Ministry of Health Malaysia, 2015). The numbers are expected to increase throughout the years.

The third goal of sustainable development (SDG 3) emphasized ensuring health and well-being through preventive and treatment of non-communicable diseases, including mental health-related illnesses, by 2030. By the Ministry of Health (MOH), Malaysia has also prioritized mental health as an essential element in health care delivery. MOH has spent approximately RM3 million on surveillance systems on mental health-related illness in preventive and curable approaches (e.g., psychiatric services, community centres, increasing numbers of mental healthcare professionals) to meet current and future demand (National Institute of Health Malaysia, 2017).

Undeniably, situations such as losing jobs, death, financial hardship, poor quality of life, illness, life conflicts, and the latest COVID-19 Pandemic have worsened the risk of mental health. Since a year ago, the unprecedented situation of the COVID-19 Pandemic has affected individuals in many ways, including emotional well-being. For instance, The Women Aid Organization and Talian Kasih under the Ministry of Women, Family and Community Development reported an increment of 44% and 57%, respectively, in contacts after the Malaysian government-issued Movement Control Order (MCO). Although social distancing was seen as a reliable preventive method, Canady (2020) reported that more than half of Americans in the study claimed they were afraid and anxious about getting COVID-19. Meanwhile, the literature also associated poor mental health among parents with special disability children, including Autism Spectrum Disorders (ASD), with the Pandemic COVID-19.

Parents, either father or mother, do affect their mental health. Findings from the interview via phone or face-to-face among 4024 parents of children with a developmental disability (D.D.) showed that mothers of children ages 13-17 had 84% higher odds of developing anxiety/depression. Mothers who established their households had 189% higher odds of developing anxiety/depression. Fathers whose children had a developmental disability and challenging behaviours had more than five times more developed psychological distress than fathers of independent children. It means that the outcomes of parents' mental health are linked with the child's specific developmental disorder, the duration and intensity of care, anticipated future care, caregiving relationships, support, and attitudes and for adult children, whether the child lives with the parent (Jessica N.Hoyle, 2021). It is supported by the National Survey of Children (2005/2006 and 2009/2010) data by the survey on caregivers of children with special health care needs (CSHCNs). It found out that parents with special needs children impact the cost of the intervention, lack of insurance, inconvenient times and locations, the area of a resident where the urban area has a lesser impact than the rural area. The parent's education level also contributes to the mental health of the parent (Graaf, G.et.al,2022).

The current Pandemic COVID-19 has caused pervasive impacts, including mental health implications such as fear, anxiety, grief, and depression to the members of society. Alhuzimi (2021), in a study among Saudi parents with ASD children, highlighted that the majority of them experienced poor emotional well-being and stress during COVID-19 lockdown, which has caused changes in the children's routine. At times, parents may feel overwhelmed by the challenges associated with the disability and the struggle to find resources and cope with the misunderstandings and stigmas present in society. Access to information, education, and support are crucial to maintaining a stable and healthy family life. While in Malaysia, a study by Fong et al. (2021) conducted an online survey among 134 parents with ASD children and typically developing children found out that lockdown contributed to the increasing stress level among both groups during Malaysia. Even though the characteristics of ASD children remain the same, the level of depression, anxiety and well-being is much affected.

2.3 Help-Seeking Behavior on Parents of children with Autism Spectrum Disorders

Help-seeking behaviour is when a person is aware and accepts the problem, seeks help from others, and is part of the mental health issue. Generally speaking, people go through three stages to seek mental health services, including identifying the problem, making decisions for help-seeking, and choosing the appropriate service. However, stigma about mental health issues has caused delays in help-seeking behaviour. In addition, some barriers contribute to poor help-seeking such as parents' refusal, stigma about mental health issues and cultural settings (Wong et al., 2020).

In addition, a cross-sectional study among parents whose children attend specialist child and adolescent mental health services (CAMHS), Denmark stated that they had difficulty in terms of the lack of information on where to seek help, lack of knowledge about treatment efficacy, standards of treatment setting and the proper process to seek help further contribute to lower help-seeking behaviour (Hansen, A.S, 2021). Various interventions are stated when it comes to a medium of seeking help. A study by Sahu et al. (2016) mentioned that 35% of adults preferred the first point to seek help was general physicians in private practice, and 34% chose the first place to seek help was tertiary care. This means that there are a variety of help-seeking pathways, which comprises contact with the health system, getting a different method of diagnosis from doctors and consulting another health professional first when problems arise.

Seeking a professional is the most help-seeking pattern that parents search for. A systematic review stated that 18/21 (85%) selected studies used Internet-based programs or apps as a medium to seek help for mental health concerns (Johnson JA et al., 2021). This is supported by the study by Bhavnani S et al. (2021), where parents of children with autism mentioned they seek to get a different method

of diagnosis from doctors and consult other health care professionals and have contact with the health system. Therefore, efficient and well-informed help-seeking helps improve the mental health and well-being of the parent.

2.4 Digital Technology

Malaysia has started integrating digital technologies with people's daily activities, including health. The digital landscape in Malaysia is growing tremendously, with the number of smartphone possession is expected to reach 90% of Malaysians by 2024 (thestar.com.my). The transformation from conventional to digitalization in healthcare offers benefits to many people. Mental health has emerged as the most concern non-communicable diseases (NCDs) across the continent, including Malaysia. Malaysia reported an alarming statistic with approximately 30% of mental health illnesses (Ministry of Health Malaysia, 2015). The unprecedented COVID-19 situations have impacted people's psychological well-being and mental health worldwide (Gao et al., 2020) due to lack of knowledge, false information, and uncertainties. For children with neurodevelopmental disabilities such as Autism Spectrum Disorders (ASD), COVID-19 has disrupted the children's routine, hence intensifying stress perceived by parents (Alhuzimi, 2021).

In this new century, the use of digital technology has increased rapidly worldwide. The latest development of high technology globally, web-based and mobile-based technology, leads to digital technology. People prefer to use digital technology as the primary source of information and communication, including health-related concerns. Digital technology consists of web-based technology and also mobile-based technology. A review by Johnson et al. (2021) indicates an internet-based program/app is selected as the best type of digital intervention among parents. In addition, the present review highlights the use of digital interventions to improve help-seeking rates for mental health as a promising area of work.

Technology likewise helps in providing intervention among ASD children. A review by Kumm AJ et al. (2021) on the feasibility of digital technology during Pandemic Covid-19 rules out various digital technology used such as personal computers, robotics, virtual reality and sensing technologies like a smartwatch. It also specified the effect on both low- and middle-income countries (LMIC) and high-income countries (HIC) in implementation of it. Although HIC affords some high technology such as robotic and virtual reality, LMIC still gets exclusive use of other types of digital intervention to amply the gap exhibited during the Pandemic. Computers, for example, are still affordable, accessible and culturally appropriate for the interventionist, caregivers and ASD children.

Nonetheless, many studies reported the disadvantages of its use. For instance, a recent study among Chinese people discovered that mental health symptoms were common among those frequently engaged in social media (Gao et al., 2020). On the other hand, digital technologies do benefit us. The use of digital platforms has slowly taken the roles of conventional approaches such as information-seeking behaviour, experience sharing, self-monitoring, health promotion, and health intervention. Research among caregivers of ASD children agreed that they preferred to seek ASD-related information using digital technology as it has no limits across the globe (Gibson, Kaplan, & Verdell, 2017).

3.0 Methodology

This study uses the Focus Group Discussion (FGD). Thirty participants, including parents of children with autism who enrol in the Early Intervention Centre (EIC) located in Klang Valley and Selangor and key informants, are involved. The ideal number of participants for each FGD is around five to eight per session. Meanwhile, the sample size for FGD with key informants will be around six to ten key persons, as this will be enough to satisfy qualitative analysis needs. Gathering opinions of key informants or experts is vital to provide a deeper understanding and particular knowledge. If the situation permits, the FGD with the key informants will be face-to-face in this study. Careful preparation and consideration are needed before the FGD, such as identifying the meeting's main objective(s), developing key questions, developing a schedule, and planning how to record the session. Figure 1.0 illustrates the flow chart of the focus group discussion technique steps adopted from the previous literature (Morgan et al., 1998).

It is estimated to take about 45 minutes to 1 hour or until data saturation is achieved. The session will be audio recorded with the consent of the participants. The interview will be transcribed and coded. Qualitative data entry and analysis will be using computer-assisted qualitative data analysis software (e.g. NVivo software). This research will apply for ethics approval from the university research ethics board.

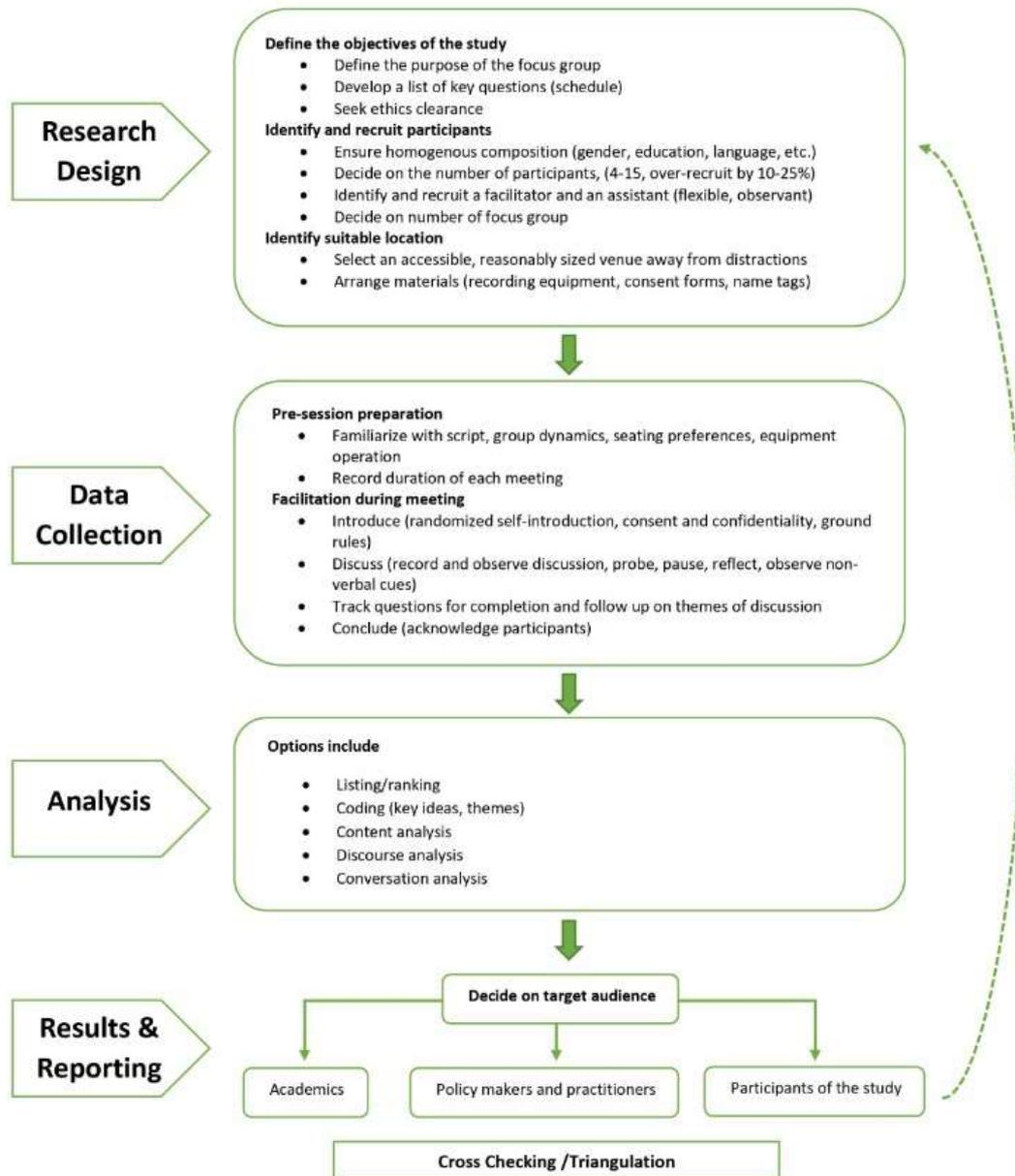


Figure 1.0 The four steps of focus group discussion techniques

4.0 Findings

Digital technology may benefit the parents of ASD children, especially with the situation of Pandemic COVID-19. Hence, the parents can maintain their mental health by reaching reliable information. The findings from the study will offer some critical insights into adding to the Malaysian data on the mental well-being of adults, especially among parents of ASD children. The importance and originality of this study is that it explores how digital technology in Malaysian settings helps sustain decent mental well-being among parents with ASD children. These findings will provide an exciting opportunity to contribute a recognized user-friendly digital tool as a virtual one-stop hub for parents with ASD children. In addition, it assists in information searching, counselling aid, support groups, and providing them with encouragement, help, sustenance, and livelihood.

5.0 Discussion

It showed that barriers to seeking help could affect the parent's mental health with ASD children, especially during the Pandemic COVID-19, as discussed above. For the parents or caregivers of ASD children, good mental health and effective help-seeking methods are vital to ensure the success and sustainability of interventions for their children.

Digital technologies will become a significant part of our healthcare system. Facebook, Instagram, and Twitter have become the new platform to access health-related information, including ASD. This paper showed implications that digital technologies might benefit the parents by providing knowledge, establishing a connection, and emotional sharing related to concerns of ASD children. Hence, the parents can maintain their mental health by reaching reliable information.

6.0 Conclusion & Recommendations

This paper has explained that seeking behaviour needs to maintain the mental health status of the parents with ASD children and the importance of applications of digital technology during this Pandemic. It has investigation limitations as it is merely a review from other journals, and the data is not yet been collected. The future study is expected to offer new knowledge and alert the stakeholders on digital technology roles to sustain the mental health of ASD parents. In addition, it is also expected that the outcomes can be translated into formulae in developing quality content of digital promotional materials targeting to assist parents with ASD children.

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Paper Contribution to Related Field of Study

This paper contributes to the body of knowledge in health professions like psychology, health promotion and other health-related fields.

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