

## The Impact of Covid-19 Pandemic: Challenges, Family Relationship and Coping Strategies

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### Abstract

This study aims to explore in-depth about the life experiences of families caring for individuals with neurodevelopmental disorders (NDD) in Malaysia during the coronavirus disease 2019 (COVID-19). The exploration focused on the challenges, relationships and coping strategies used when taking care of people with NDD. This qualitative study used a semi-structured interview with 7 informants who are the parents and sibling of the people with NDD that lived in Negeri Sembilan, Kedah, Selangor, and Kuala Lumpur. The data were analysed using thematic analysis and the results found three major themes: care challenges, family conflict and social support. The results of the study found that most families face challenges when taking care of people with NDD due to the increased of behavioural and emotional problems during the COVID-19 pandemic. Positive family relationships and strong social support system help families to cope with stress and get through challenges.

**Keywords:** Coping Strategy, Family Relationship, Social Support, Family Conflict, Parents-Siblings Relationships

### Introduction

On 25 January 2020, Malaysia received the first COVID-19 case involving tourists from China. Since then, the number of positive cases has been increasing and worrying many. The lockdown or known as Movement Control Order (MCO) was first enforced on 18 March 2020 aimed at curbing the spread of the COVID-19 pandemic. This government initiative aims to reduce movement and social interaction among people in public places (Rashid & Hassan, 2020). Previous studies found that parents of disabled people face challenges in terms of finance and support (Ainbinder et al., 1998), experience higher stress than parents of typical developmental children (Boyd, 2002) as well as worry about their children's behavioral and emotional problems especially during the COVID-19 pandemic (Arim et al., 2020). This is in line with the study conducted by Ogundele (2018) that disabled people with cognitive, behavior and emotional problems are often associated with stress, anxiety, and other mental health problems.

The lockdown resulted individuals with NDD to experience a drastic change in life because of the closure of various social sectors such as schools and special need centres. Therefore, strong family relationship is very important for individuals with NDD to ensure that they can cope with the COVID-19 pandemic. Family members play an important role by applying effective coping strategies in caring for people with NDD because according to Dhiman et al. (2020) coping strategies helped to improve the psychological well-being of disabled people during the COVID-19 pandemic.

### **Literature Review**

Neece et al (2020) found that the effects of COVID-19 pandemic caused the parents with intellectual and developmental disability children to face significant challenges. Due to lockdown, working parents need to cope with the sudden change of daily routines by managing time between work from home while consistently look after their disabled children with the absence of many essential services. This study also emphasizes the importance of professional's support to provide guidance to parents for overseeing their children's developmental progress at home and critically support psychological well-being of the family. A study by Critchley et al (2021) had interviewed the parents and siblings of people with autism spectrum disorder (ASD). This study aimed to identify the impact of an ASD individual on the family relationships during the COVID-19 lockdown. It was found that people with ASD can produce a positive family relationship because the data suggested a stronger bonding and higher affection within the families towards the individual with ASD. Researchers also emphasized the importance of professional services to support the family with an ASD individual given that the challenges experienced during the COVID-19 pandemic were greater than usual.

A study by Prime et al (2020) have identified the risks of family well-being during the COVID-19 pandemic which are the financial issues, mental health, racism and caring for children with disabilities. Based on the family resilience framework guided by Walsh (2015), family well-being is conceptualized by three factors which are also applicable during the COVID-19 pandemic: (a) communication (clear information, emotional sharing, collaborative problem-solving), (b) organization (adaptability, connectedness, and access to social and economic resources), and (c) belief systems (meaning making, hope, and spirituality). These coping strategies not only promote a healthy relationship and strong teamwork among the family members but also help families to keep positive expectations and remain optimistic during difficult situations.

### **Methodology**

#### *Informant*

The population in this study referred to family members who cared for people with NDD and lived in the same household during the COVID-19 pandemic. People with NDD are primarily associated with the impairment of growth and development of the brain that can impact five aspects of developmental domains which consists of physical, communication and language, social-emotional, adaptive behaviour and cognitive. A qualitative study has a small sample because the aim is not to make statistical calculations but to obtain in-depth information and understanding of the research questions. In this study, purposive sampling technique and snowball sampling are used to search for the right candidate that qualified the criteria of the informant.

**Informant Profile**

Informants are parents and siblings who care for people with NDD and live in the same house during the COVID-19 pandemic. Informants must be proficient in Malay or English language. The researcher ask consent from the informants before proceeding with the interview to ensure the informants are willing to participate in this study. The inclusive criteria for people with NDD are (1) age-groups between childhood, adolescence, or adult; (2) have learning difficulties; and (3) requires full or partial care by the family. The demographic information of the informants are obtained through interviews which is as shown in Table 1. Five informants involved are biological mothers while the other two are the siblings of people with NDD.

**Instrument**

The audio of the whole interview was recorded with the informant's consent to facilitate the transcription process which aims to ease the process of thematic analysis. The informants were informed that the whole recorded conversation was only for research purposes and that every piece of information shared are confidential and preserved. The audio recording allows the researcher to give whole attention on the interview and rapport building without having to worry about taking notes. The researcher also prepared paper and pen during the interview to record any important observations and information into the field notes.

**Interview**

The data were collected based on the semi-structured interview that in accordance with the variables of the study as followed: (1) the effect of COVID-19 pandemic on the challenges and relationships of families with people with NDD; (2) coping strategies used during the COVID-19 pandemic; and (3) type of social support received when caring for people with NDD during the COVID-19 pandemic. The semi-structured interview allows researcher to be more flexible when directing a question which helps when trying to obtain the details of the conversation. The duration of the interview is between 45 minutes to 1 hour. Due to the lockdown, every interview was conducted virtually via video calls.

**Results**

Table 1 shows the demographic profile of the informants. In total, there are five parents of people with NDD (S1, S2, S3, S4 and S6) and two siblings of people with NDD (S5 and S7). There are three married informants (S1, S2 and S3), one widow (S4), one divorcee (S6), and two single informants (S5 and S7). A total of four informants were working from home (S1, S3, S4 and S5), two informants (S2 and S7) working at the workplace and one retiree (S6). Based on these findings, it was found that most informants were working from home during the COVID-19 pandemic. People with NDD involved were 9 years old (A1 and A3), 14 years old (A7), 20 years old (A2), 24 years old (A6), and 27 years old (A5 and A6). Six people with NDD are male (A1, A3, A4, A5 and A6) and only one female (A2). There are four types of neurodevelopmental disorders involved in the study which are Williams Syndrome (WS), Down Syndrome (DS), Attention Deficit and Hyperactivity Disorder (ADHD) as well as autism spectrum disorder (ASD). In total, there are four individuals with ASD (A4, A5, A6 and A7), one diagnosed with WS (A1), one diagnosed with SD (A2), and one diagnosed with comorbid ASD and ADHD (A3).

Table 1. Demographic information of informants

| Family member | Relationship | Marital status | Occupation status during COVID-19 pandemic | People with NDD | Age of people with NDD | Gender of people with NDD | Diagnosis    |
|---------------|--------------|----------------|--|-----------------|------------------------|---------------------------|--------------|
| S1            | Mother       | Married        | Work from home                             | A1              | 9                      | Boy                       | WS           |
| S2            | Mother       | Married        | Work at office                             | A2              | 20                     | Girl                      | SD           |
| S3            | Mother       | Married        | Work from home                             | A3              | 9                      | Boy                       | ASD and ADHD |
| S4            | Mother       | Widow          | Work from home                             | A4              | 27                     | Boy                       | ASD          |
| S5            | Sibling      | Single         | Work from home                             | A5              | 27                     | Boy                       | ASD          |
| S6            | Mother       | Divorcee       | Retiree                                    | A6              | 24                     | Boy                       | ASD          |
| S7            | Sibling      | Single         | Work at office                             | A7              | 14                     | Boy                       | ASD          |

Based on Table 2, there are some developmental problems of people with NDD that occur during the COVID-19 pandemic. The developmental problems are categorized by each developmental domains; cognitive, adaptive behavior, communication and social emotional. Some of the developmental problems are already existed before the pandemic and some emerged during the pandemic. The highest prevalence of developmental problem that occur among the people with NDD in this research is the communication. All people with NDD (A1, A2, A3, A4, A5, A6 and A7) have communication problems since before the pandemic happened. From the interview, it was reported that they have difficulty to communicate and interact well with other people. The second highest developmental problem is the adaptive behavior. It was reported that six people with NDD (A1, A3, A4, A5, A6 and A7) have poor ability to manage daily routine independently while another four NDD individuals (A3, A4, A5 and A6) have difficulty to behave according to the place and time. There are four individuals with NDD, (A3, A5, A6, A7) who have poor cognitive ability to process meaningful information and the other four, A1, A3, A5, A6 NDD individuals have learning difficulties. Lastly, five individuals with NDD, (A1, A3, A4, A5 and A6) have poor social emotional skills as they have difficulty to regulate their emotions and behaviors.

The exploration of developmental problems of people with NDD during the COVID-19 pandemic helps to enlighten the understanding of the family life experiences when caring for people with NDD. Based on the data, the developmental problems were also faced by adults with NDD, not just in children. This suggests that the developmental problems that arise during the pandemic can occur in people with NDD regardless of age. The emergence of the developmental problems during the COVID-19 pandemic are based on the level of severity of developmental problems that have already existed before the pandemic. Thus, COVID-19 may increase the developmental problems.

Table 2. Developmental problems of people with learning disabilities during pandemic

| Developmental issues during COVID-19 pandemic          | People with NDD (A)        | Number of people with NDD (N) |
|--|----------------------------|-------------------------------|
| <b>Cognitive</b>                                       |                            |                               |
| Meaningful information processing                      | A3, A5, A6, A7             | 4                             |
| Academic   | A1, A3, A5, A6             | 4                             |
| <b>Adaptive behaviour</b>                              |                            |                               |
| Daily routine management                               | A1, A3, A4, A5, A6, A7     | 6                             |
| Behave accordance with the place and time              | A3, A4, A5, A6             | 4                             |
| <b>Communication</b>                                   |                            |                               |
| Communicate and interact well                          | A1, A2, A3, A4, A5, A6, A7 | 7                             |
| <b>Social-emotional</b>                                |                            |                               |
| Emotional and behavioural regulation when under stress | A1, A3, A4, A5, A6         | 5                             |

Most informants (A1, A3, A4, A5, A6 and A7) faced challenges of caring for people with NDD. Due to the lockdown, almost all informants worked at home. Among the challenges faced by the families is the daily routine management of people with NDD because they need to be monitored and managed constantly especially in terms of hygiene. This poses a challenge to informants to focus on other matters such as work and household affairs. Some informants (A4, A5 and A6) faced the challenge of increasing behavioral and emotional problems of people with NDD such as tantrums, emotional instability, and repetitive behaviors. Informants A4 and A6 are reported to suffer from stress and easily lost their temper because of the sudden behavioral change of people with NDD during the COVID-19 pandemic. Most informants (A4, A5, A6 and A7) were found to have family conflicts while caring for people with NDD because of lack of effective communication, lack of understanding and lack of cooperation from each family member. However, some informants (A1, A2, A3) were found to have positive family relationships by having discussion and cooperation with each family member while facing challenges in caring for people with NDD especially during the COVID-19 pandemic. Informants A1 and A3 informed that the new lifestyle during COVID-19 pandemic resulted a growth of family relationship because family spend more time together compared to before.

Coping strategy that is most common among the informants in overcoming the challenge of caring for people with NDD during the COVID-19 pandemic is the social support. Informants (A1, A2 and A3) received social support from spouses, parents, and siblings. For instance, informant (A2) utilizes communication and cooperation from each family member by assigning roles and responsibilities to all family members to jointly care for people with NDD while some informants (A1, A2 and A3) obtained support from family members such as parents, spouses, and siblings in terms of finance and energy. However, it was found that most informants (A4, A5, A6, A7) found it difficult to obtain adequate social support when faced with the challenges of caring for people with NDD due to family conflicts.

**Discussions**

During the COVID-19 pandemic, most people with NDD needed consistent help to manage themselves, so time management is a challenge for the family members. Family members are more vulnerable to stress due to having to adjust to working at home, managing the home, and caring for people with NDD especially those who show increased behavioral and emotional problems due to the COVID-19 pandemic. Most family members who are often stressed have poor family relationships such as no effective communication between family members and lack of cooperation in the division of tasks to care for people with NDD. These families often place the burden on only one family member to manage the house chores and people with NDD. According to van Steensel and Heeman (2017), individuals with ASD are common to have a higher anxiety level compared to individuals with typical development. A sudden change of life routine due to the COVID-19 pandemic increased the level of anxiety of people with NDD, further making developmental problems exacerbated. Nonweiler et al (2020) found that people with NDD are more vulnerable and prone to mental health problems due to the COVID-19 pandemic. Among the behavioral and emotional problems of people with NDD that the family members must face are the tantrums and repetitive behaviors. Oliver et al. (2011) found that individuals with ASD and hyperactivity showed repetitive behaviors which may be challenging for family members to take care of them. Repetitive behavior become more prevalent when people with NDD must deal with a sudden change of routine, especially those who have difficulty to adapt with changes and process information.

Positive family interactions help to protect the child's mental health (Dimitry 2012). Positive family relationships can improve psychological well-being of disabled people such as people with NDD as they need more attention and guidance than the typically developed children especially during the COVID-19 pandemic. The division of tasks among each family member to take care of people with NDD is found to be one of the effective and meaningful coping strategies. It helps to fill their free time consistently, give each family member the opportunity to function, improve relationships with people with NDD and train each family member to take responsibility in caring for people with NDD. Calhoun and Tedeschi (2014) reported that families who share difficult experiences together become more resilient and able to weather difficulties in life. This type of family situations is greatly influenced by the social support received from other family members. Families with strong social support systems can weather challenging situations especially during the COVID-19 pandemic while families that are always in conflict and hard to cooperate are more vulnerable to stress. Indeed, social support from family members plays a significant role in helping informants face the challenges of caring for people with NDD during the COVID-19 pandemic.

**Conclusion**

Most informants experience stress when caring for NDD individuals especially when they show behavioral and emotional problems. Due to lockdown, informants face challenges to manage time between working, manage house chores and caring for people with NDD. Informants who received less social support from family members found it more difficult to maintain positive psychological well-being while families who received strong social support were more resilient and able to weather the COVID-19 pandemic. The coping strategy that often used by informants while facing the challenges during the COVID-19 pandemic was social support from other family members.

**Limitations and Future Studies**

There some limitations found in this study. First, the accuracy of developmental problems experienced by people with NDD because this study only relies on information from the interviews without conducting any standardized psychological assessment to identify in-depth psychological and developmental issues. Second, the criteria of the targeted informants are quite broad i.e., parents and siblings. This can lead to bias in determining the level of seriousness of the challenges experienced by the informants because both play different roles in a family institution. Third, the whole interviews were conducted online, therefore there are limited observations on the nonverbal communication which may help to understand an information better. Future studies are suggested to use standardized psychological assessment to analyse in-depth of any developmental and psychological issues of the people with NDD. Next, specify the criteria of the informant to avoid any bias on the generalization of the research finding. Lastly, ensure a smooth interview session such as using a strong internet connection to facilitate the observation process.

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