Systematic review: family efforts in preventing covid-19 on special needs children

Amin Samiasih1*, Dera Alfiyanti2, Mariyam1

ABSTRACT

Introduction: Indonesia has experienced a crisis due to the COVID-19 pandemic. Both adults and children are affected by the crisis. The incidence of COVID-19 in children is not as many as in adults, but prevention efforts need to be done by families. Likewise for children with special needs. The article aims to explain family effort in preventing COVID-19 on children with special needs.

Method: A systematic literature review was conducted to identify papers on family efforts to prevent COVID-19 in children with special needs using the PubMed databases between 1st of January and 31st of December 2020. The search identified 15 relevant scientific papers.

Results: Indonesia has 80 million children (about 30 percent of the population), and although the health risk from COVID-19 infection is lower in children compared to the older age group, children are most likely to be severely affected by COVID-19 in both the short and long term. Family efforts during the pandemic COVID-19 aim to provide necessities and care, provide nutritional needs, maintain children learning process, protect children from violence, exploitation, and abuse.

Conclusion: Family efforts in preventing COVID-19 include providing knowledge, regional authority, mental health services, finance, nutrition and health, education, and child protection. Studies regarding the impact of COVID-19 on children with special needs have been undertaken, although not many.

Keywords: COVID-19, effort, needs, prevent.

INTRODUCTION

December 2019 saw an outbreak of a new infectious disease in Wuhan in the Hubei province of China. Coronavirus disease 2019 (COVID-19) is caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), previously also known as 2019nCoV.1 The 2019 coronavirus disease (COVID-19) pandemic has affected hundreds of thousands of people. People all over the world, but data on how it affects children is scarce. Children so far account for 1-5% of diagnosed cases. COVID-19 has occurred in children, but they appear to have a milder disease with a better prognosis than adults. Death is very rare.2 The Covid-19 death rate or case fatality rate (CSR) in the child age group in Indonesia is 0.2 percent. The data is the result of an analysis by the Ministry of Health’s Center for Data and Information (2021).

However, it is possible for parents to worry about children with special needs during the COVID-19 pandemic. During the COVID-19 outbreak, parents of children with special needs experienced mental and behavioral problems. Caregivers also experience stress. They face a greater risk of psychological burden and experience various mental health problems such as anxiety, depression, marital discord, and sleep problems. This problem causes children with disabilities might experience behavioral regression and extensive problems because of their inability to access daily school education, rehabilitation training, personalized intervention, and treatments. These findings can be used to develop relevant psychological interventions to improve the mental health of vulnerable groups during pandemics such as COVID-19.

Family efforts during the pandemic COVID-19 aim to provide necessities and care, provide nutritional needs, keep children learning, protect children from violence, exploitation, and abuse. Family efforts in preventing COVID-19 include providing knowledge, regional authority, mental health services, finance, nutrition and health, education, and child protection. Factors that influence the occurrence of parental anxiety include educational background, family monthly income, and the type of disability of their children, and stress on caregivers also affects the degree of parental stress.3 Research on children with COVID-19 is rare. This paper summarizes the findings from systematic reviews on family efforts to prevent COVID-19 in children with special needs.

METHODS

The literature review search process obtained from articles received by PubMed was searched for relevant terms related to family efforts in preventing COVID-19 in children with special needs. There were 73 papers published on Medline between January 1 and December 31, 2020. Of these, 15 were deemed relevant to this review. Most of the studies came from China, and it should be noted that there were very few reports of children from

1Departemen of Nursing, Faculty of Nursing and Health Sciences, Universitas Muhammadiyah Semarang, Indonesia;

2Corresponding author: Amin Samiasih;
Departemen of Nursing, Faculty of Nursing and Health Sciences, Universitas Muhammadiyah Semarang, Indonesia; aminsamiasih@unimus.ac.id

Received: 2021-10-31
Accepted: 2021-12-18
Published: 2021-12-30
Canada, Italy, Germany, or South Korea. This systematic review was conducted following the reporting guidelines for systematic review and meta-analysis (PRISMA).4

RESULTS
According to the Cochrane handbook, this systematic review was conducted for systematic reviews and reported following the guideline of preferred reporting items for systematic review and meta-analysis (PRISMA).5 The literature was systematically searched from various electronic databases. The databases include PubMed. Ratings were assigned (very poor, poor, fair, good) across nine different categories: abstract and title, introduction and aim, method and data, sampling, data analysis, ethic and bias, result, generalizability, and implication and usefulness.

DISCUSSION
Family efforts to prevent COVID-19 in children with special needs include the provision of knowledge, local area authorities services, mental health finance, nutrition and health, education, and child protection.

Provision Of Knowledge
Family efforts to prevent the transmission of COVID-19 are providing knowledge. The majority of respondents know basic information about COVID-19, including transmission, preventive or protective measures, and symptoms. However, families often did not realize that immediate action was needed if they experienced any symptoms and how to deal with stigmatization. Some families had different interpretations or adherence to COVID-19 prevention guidelines. Knowledge of self-isolation was also essential. If families with children with special needs must self-isolate, this was not possible. The local government provides self-isolation services. It was not a hospital, but health workers would check on the patient while the patient is there. The patient would also have access to general practitioner (GP) services.6

Local Area Authorities
Authorization local government authority was needed. Systematic communication about risks and the extent of community involvement. What were strategies that provide reasoning and practical steps about certain behaviors and actions to resolve misunderstandings and uncover positive stories that can reduce fear and stigma. Local authorities work with other organizations to help vulnerable people in the community, including children with special needs. Children with special needs include people who are at very high risk of COVID-19. Efforts were provided in collecting and delivering food, essential household items, fuel and medicine, social isolation, medical needs, or other health care. What if the child has to self-isolate? Claim for COVID-19 treatment financing on Health insurance.6-11

UNICEF also carried out the activities of regional authorities. During November, UNICEF and its partners involved 7119 children (2766 girls) in mental health and psychosocial efforts activities (MHPSS). There are more than >1.5 million people who participated in mental health and psychosocial (MHP) activities. Children with disabilities also attended this activity, such as messages of understanding mental health, tips on maintaining mental health, and referral information posted on social media. The messages were published by UNICEF together with the Ministry of Women’s Empowerment and Child Protection and the Ministry of Health. In the three provinces, young people continue to be involved and lead the dissemination and discussion of MHP.8,10-12

In one province, contextual messages on MHPSS continued to be disseminated through local TV and radio, including four radio and TV talk shows. The local adaptation of “My Hero is You,” a storybook published by the Inter-agency Standing Committee on Mental Health and Psychosocial Efforts, was complemented by video storytelling in local dialects. It added to other adaptations supported directly by UNICEF, including Indonesian language books and books on 7 Papuan regional languages and audiobooks. After six waves of online gender-based violence training took place in October, UNICEF and partners started additional online training. Training deploys gender violence risk mitigation internally, reaching all of their staff, volunteers, and targeted frontlines.12-14

Figure 1. Preferred reporting items for systematic reviews and meta-analysis (PRISMA)
Mental Health Services

The impact of the COVID-19 pandemic had caused unprecedented changes in the lives of 1.6 billion children and youth. The first survey was on the negative impact of children's mental health. This study related the quality of life (HRQOL) and mental health of children and adolescents in Germany from a child's perspective. The survey was conducted on May 26 and June 10 on 1586 families with children aged 7-17 years. Instruments to measure the quality of life problems HRQOL (KIDSCREEN-10), mental health problems (SDQ), anxiety (FEAR), and depression (CESDC). The data were compared with 1556 study groups in Germany before the pandemic. Two-thirds of children and young people were reported to be heavily burdened by the COVID-19 pandemic. They got a lower quality of life problems (17.8% vs. 9.9%), and higher levels of anxiety (24.1% vs. 14.9%) from before the pandemic. Children with low socioeconomic status, migration status, and limited living space are significantly more affected by life problems, mental health, anxiety, and depression.15-17 Health promotion and prevention strategies need to be implemented to maintain the mental health of children and adolescents, improve their HRQOL quality of life, and reduce the burden caused by the COVID-19 pandemic, especially children who are most at risk, namely persons with disabilities.16

The length of the COVID-19 pandemic could cause anxiety and even depression. It could affect the mental health of children with special needs. Mental health efforts and services were urgently needed during a pandemic. Some face-to-face services were currently limited due to the COVID-19 outbreak.17

Due to the pandemic, many institutions no longer allow children to visit or leave institutions, increasing isolation, reducing family contact, and increasing the risk of psychological distress. Finally, children are at high risk of contracting COVID-19 due to overcrowding and inadequate health and sanitation conditions.8,16,18

Factors that affect the anxiety of parents of children with special needs, namely: educational background, family monthly income, and the type of disability of their children, made differences in the degree of parental anxiety. Multiple linear regression results showed that during the epidemic, social support negatively predicts parental anxiety state (B=0.15, p < 0.001), while parenting stress (B=0.07, p = 0.001) and parental mental and behavioral problems (B=0.37, p < 0.001) positively predicted parental anxiety.8

The impact of the COVID-19 pandemic was felt on all groups of society. Children with intellectual disabilities (ID) were particularly vulnerable to the pandemic's physical, mental, and social impacts. Cognitive impairment could limit understanding of information, thus relying on caregivers to be alert during quarantine.19 Restriction of usual activities tends to cause stress mental disorders, especially among those with autism leading to escalation of challenging behavior, risk of placement disorder, and increased use of psychotropic drugs. People with IDs were vulnerable to exploitation by others where the community that used to support them no longer serves to protect them. In future pandemics, it was important to learn from the impact of COVID-19 on people with ID. Gathering evidence would help empower people with IDs and their caregivers to face future outbreaks of infectious disease.20-22

Preparing to care for people at high risk of death was a challenge for caregivers and family members. Care planning helped caregivers care for families and children with ID to prepare for possible death. It required a relatively trouble conversation about their perceptions and expectations about death. The escalation treatment plan became a very important part of the initial planning in helping caregivers recognize the need for greater medical care and to consider end-of-life care. Establish flexible work arrangements for caregivers of children with disabilities, including providing pay if they were at high risk.
Improving access to shops and arrangement of special shopping hours for parents with children with disabilities. School and other educational facilities should be appropriate to ensure the continuity of education for children with disabilities. Family, friends, and neighbors should provide emotional support, communication, and regular check-ups for children with disabilities.

However, several organizations still provide online counseling. The counseling includes recognizing the symptoms of stress, how to reduce stress in children, and teaches simple ways of stress management. Follow-up counseling in the event of an emergency psychiatric condition. Psychosocial support efforts for children and parents, including fun and creative activities, are very important to maintain their motivation and encourage peer groups among students or siblings.

Finance, Nutrition, and Health

The impact of the pandemic on the household economy includes a loss of income. The impact felt by children in terms of maintaining a healthy lifestyle and ensuring adequate nutritional intake. The main finding was that 30 million children under five were at a higher risk of experiencing malnutrition or malnutrition. 30.8% of children were recorded as experiencing stunting in 2018 due to food insecurity such as a lack of income. Some 10 million children under two years have not had access to immunizations for weeks due to social restrictions. This child is at risk of contracting other diseases that are due to social restrictions. This child is at risk of contracting other diseases that are common in this country.

Children who do not have access to proper sanitation facilities are very high, especially those living in slum areas, and will not follow the recommended handwashing guidelines. In terms of Indonesia’s capacity to deal with the increasing number of cases, although the government focuses on health, it was still overwhelmed. The government ensures that those working on the front lines receive adequate personal protection. Good equipment on health protocols was very important for continuity of service. Especially family care services during the pandemic, especially maternal, child and nutrition health services. A further recommendation was to meet the basic daily needs for food through cash transfers and vouchers.

Family poverty had a tremendous impact on household food security, limiting the accessibility, availability, and affordability of healthy food. An online survey shows that food insecurity has increased: 36 percent of respondents reported that they “often” eat less than they should because of financial constraints. Loss of household income creates a high risk for a spike in micronutrient deficiencies in children. Hunger was a very dangerous form of malnutrition, increasing children’s risk of death by almost 12 times compared to well-nourished children.

Children who survive starvation may continue to have developmental problems throughout their lives. If the necessary actions were not taken today, the long-term nutritional impact was likely to be stunting. The prevalence of overweight and obesity occurs due to limited physical activity and increased consumption of processed foods high in sugar, salt, and fat. Little information was available on how children were coping with pandemics in institutions, including children in orphanages, shelters, social welfare institutions, and Islamic boarding schools (pesantren). Likewise, what happens to children with special needs?

Education And Child Protection

The COVID-19 pandemic had caused unprecedented disruption to children’s education. Most schools in Indonesia were still closed. Students were forced to continue their learning remotely. Home learning occurs in 68 million students. It was a major change in behavior for many children who are still accustomed to conventional learning methods. Using TV as their primary learning method rather than online learning apps or educational websites occurs in 75% of children. It also happened to children with special needs. The impact had not been felt evenly. Disproportionate closure of schools for children with disabilities, they had been disadvantaged. According to household survey data (SUSENAS 2018), in 2019, nearly 140,000 children with disabilities aged 7-18 years dropped out of school. Children with disabilities were less likely to benefit from distance learning solutions. Many lack effort, internet access, and accessible learning software and materials.

The cost of internet or data packages and poor connection quality made it difficult for teachers, parents, and children to continue the education services. A total of 72% of children reported feeling bored secluded at home in the last two weeks. Children also begin found it difficult to concentrate. Changes in online learning had left many children without internet access and those who cannot read or write. According to SUSENAS 2018, about 9.4% of children aged 5-17 years can not read or write because of the high illiteracy rate in the young age group (5-6 years), reaching 51%. Those with disabilities and their families face significant challenges. They also presented a unique opportunity to address long-standing systemic inequalities in education during a pandemic.

Class-based learning in Indonesia was suspended. Students had to rely on smartphones, computers, and the internet to connect with their teachers. However, many families – especially those from lower economic backgrounds – couldn’t afford internet data or devices and live in areas with limited internet connectivity, excluding those from distance learning and life-saving information about COVID-19. Closing the connectivity gap would provide a major effort to build a more inclusive world.

It happened at Madrasah Ibitidaiyah Keji (MI Keji) Ungaran, Central Java, Indonesia. Empty classrooms at Teachers at MI Keji received training on inclusive education, and the school was now accepting 25 children with disabilities. However, like most schools in the country, MI Keji closed in early March to prevent the spread of COVID-19. Even before the pandemic, almost 3 out of 10 children with disabilities in Indonesia had never been to school. Moreover, when applying, there was a schools significant gap in educational attainment. Only 56 percent of children with disabilities complete primary school, compared to 95 percent of children without disabilities.

Learning for children with intellectual disabilities, children received video calls from their teachers. Teachers demonstrate activities they used to involve physically
and intellectually disabled children in the classroom. Children with disabilities often rely on routine therapy as well as aids and learning materials at school. They need ongoing efforts to access adaptive technologies and learning adaptations that met their specific needs during and after a pandemic.25,28

Children with physical disabilities were assisted in wheelchairs. The lack of accessible infrastructure and learning materials was a significant barrier to learning for children with physical, intellectual, and learning disabilities during the COVID-19 pandemic. Universal design in learning infrastructure—which includes accessibility of buildings, reading materials, and sanitation facilities—will suit the needs of children with various types of disabilities during the COVID-19 pandemic. In a recent survey, a majority of parents (81 percent) said they were ready to send their children back to school. While most (90 percent) believe that their children know how to follow health protocols, many also said that schools need to have clear policies in place to implement health protocols based on children’s needs and capacities. However, not all schools were ready to provide the ideal facilities and infrastructure for learning during a pandemic.26-30

Even children who were accustomed to taking non-formal education still feel challenged. A community learning center that caters to the most deprived children, especially those living with disabilities, whose abilities need to be adapted and cannot be easily supported through distance learning. Alternatives to online learning need to be quickly available for rural, remote, and vulnerable children. Meanwhile, teachers need to be supported to adapt to new technologies and a more reflective self-taught learning process.25,28,30

The COVID-19 pandemic was causing many problems in Indonesia. Children were exposed to further vulnerabilities, including child labor, violence, child marriage, and out-of-school. Every year over 300,000 students drop out of school because of this problem, putting the current generation at even greater risk. One in 4 households experienced a decline in income. Children were forced to engage in income-generating activities. Recently, the ten provinces in Indonesia where the number of child labor was high were also the locations with the highest COVID-19 cases. This data supports assisting families with their daily needs. Offering important cash assistance will reduce negative family coping mechanisms. In addition, children begin to lack proper care when family members had been quarantined or died from COVID-19. Areas should be advocated, supported, recommended plans at the household and community or village level that consider appropriate protective measures for children.25,28

Children with Autism Spectrum Disorder (ASD) had pervasive developmental disorders that show difficulties in communication, social interaction, behavior, interests, and limited and repetitive activities. The prevalence of ASD also continues to increase worldwide, followed by an increasing need for early intervention in children with ASD. The limited services available make early intervention a challenge. The long COVID-19 pandemic had resulted in limited therapy because therapy in treatment service facilities cannot be carried out as before. It was important to involve parents in the intervention in anticipation of limited intervention due to the pandemic situation. Parental Training could be carried out to provide information, education, and skills to parents to provide intensive, comprehensive, sustainable education and early intervention.21,22

CONCLUSION

Family efforts to prevent COVID-19 are efforts to the provision of knowledge, local area authorities, services, mental health, finance, nutrition and health, education, and child protection. Implications of the research COVID-19 have occurred in children with special needs even though the cases are not many parents have made efforts to prevent it.

CONFLICT OF INTEREST

The authors declare there were no conflicts of interest concerning this article.

FUNDING

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

ETHIC APPROVAL

Ethic approval is not applicable in this article.

AUTHOR CONTRIBUTION

AS, DA, and M developed the concept research. The US and the DA conducted an electronic search. M reviewed the literature search results. Complete papers of potential studies assessed by AS and DA. The US conducts assessment quality and risk of bias. All authors discuss the final results to reach a consensus, write the manuscript and agree to be responsible for all content.

REFERENCES


This work is licensed under a Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License.