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LITERATURE REVIEW

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Parents' Challenges to Health Services for Children with Disabilities during the COVID-19 Pandemic: Literature Review

Nur Fadilah[1], Kadek Ayu Erika[1], Nur Azizah[1]

[1]Nursing Program, Faculty of Nursing, Hasanuddin University, Makassar, Indonesia
Coresspondence Author: fadilah@unhas.ac.id

Abstract:

Health services are important in supporting one's health. Due to social restrictions and regulations during a pandemic, access to health services also adapts to existing conditions. The purpose of this literature study is to identify challenges for parents in providing health services for children with disabilities during the COVID-19 pandemic. This research method used a literature review design using the PubMed, ProQuest, and ScienceDirect electronic databases. It was found that 7 articles were reviewed after fulfilling the inclusion criteria and were analysed. The results of the review found that a number of reasons for children with disabilities not participating in health services were due to several factors such as social restrictions, parents, and technology. Various relevant barriers to accessing health services are identified in this literature review. Challenges to social distancing were the most frequently reported in studies. The description in this study can be used as input in considering access and form of health services for children with disabilities.

Keywords: Parent’s challenges; Health services; Children with disability; COVID-19

Introduction

Health services are fundamental in supporting and contributing to a person's health status. However, when the COVID-19 pandemic occurred, there were a number of impacts and changes that resulted in a new adaptation process in the health service process. The high prevalence rate of this disease makes most people around the world fear and worry because it is one of the deadliest diseases.[1] A number of health services have been hampered or even not carried out. Research in 2021 in East Java found that posyandu services were not carried out at the start of the pandemic, causing no provision of nutrition and monitoring of growth and development in toddlers.[2] Government regulations that issue health protocols that must be implemented by all people, such as people are not allowed to leave their homes for activities without wearing masks, are not allowed to gather in crowds or gather, and people are also encouraged to frequently wash their hands with soap and use running water. changes in order in life including changes in the flow system/process of health services.

Changes in the health service process are marked by the emergence of various telecommunication technology media such as telehealth and telemedicine.[4] The term telehealth refers to a variety of telecommunication methods and technologies used to provide health care remotely where these tools can enhance the delivery of treatment and health education, video conferencing services between health workers and patients, asynchronous data transmission, remote patient monitoring, and healthcare through various communication media such as mobile phones, tablets and so on. [5]

This approach ultimately also has an impact on persons with disabilities who usually depend on their parents or caregivers. [6] Children with disabilities need attention and approaches that are more suitable for the variety of disabilities they have. This is what sometimes causes some parents or caregivers to experience stress in caring for children with disabilities,[7] especially when the COVID-19 pandemic occurs where parents not only experience parenting stress but also changes that affect their mentality, behavior and anxiety. [8]

Understanding the challenges that prevent parents from accessing health services during the COVID-19 pandemic is an important step towards developing effective health service programs for children with disabilities. The purpose of this study is to identify and summarize the challenges that parents or caregivers experience with children with disabilities in various contexts and countries to become a reference for consideration in the preparation of health services in this population group. Based on this, the researcher asked a research question: What are the challenges for parents of children with disabilities in accessing health services during the COVID-19 pandemic.

Research Method

In this study we used a literature review design. Researchers conducted a systematic literature review of the Pubmed, Science Direct and Proquest databases and identified challenges to health services for children with disabilities during the COVID-19 pandemic. We use various search terms, such as health services, children with disabilities, COVID-19 pandemic and challenges (The search strategy uses a combination of keywords: children with disabilities and health services and COVID-19 pandemic and challenges).

The inclusion criteria in this review article are: 1). Focus on health services during the COVID-19 pandemic, 2) children with disabilities, 3). Challenges of parents (caregivers) 4). published from 2020-2022, 5). fulltext, 6). not a research review and 7). English articles. The research question in this article is what the challenges in are accessing health services for children with disabilities during the COVID-19 pandemic. The literature search process is presented in a flowchart (Fig. 1).

Regarding the article process, a search process was carried out in the selected database and the studies were filtered to meet the eligibility criteria. Search findings are entered into Zotero's reference management software, then uploaded to Covidence where independent screening of title, abstract, and full text is performed. The final decision regarding study inclusion and exclusion was made after going through a discussion process.

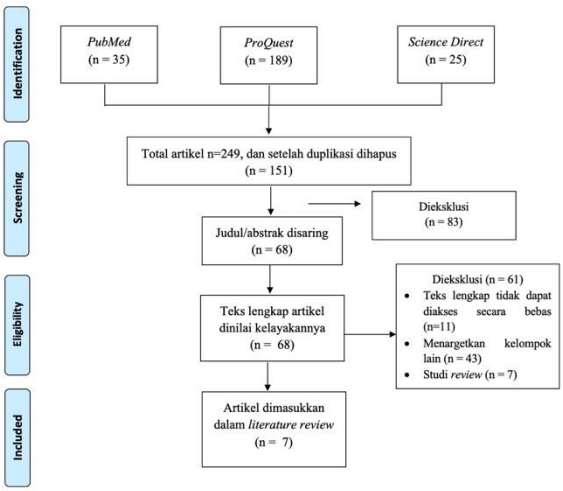

Figure 1 . Proses Seleksi Artikel

Result

After searching articles on three database journals, namely PubMed, proQuest, and Science Direct using predetermined keywords, 249 research articles were obtained published in 2020-2022. The articles were then checked for duplication using the Zotero application and 121 articles were obtained after removing duplicates. Furthermore, the titles and abstracts of the articles were assessed based on their relevance to the inclusion and exclusion criteria that had been set in the study and 68 articles with appropriate titles and abstracts were obtained. The full text of the remaining 68 articles was then assessed for eligibility, then 61 articles were excluded because there were 43 articles targeting other groups that did not comply with predetermined child limits, 11 articles that could not be accessed freely, and 7 articles were excluded because they were in the form of a review. A total of 7 articles were carried out for literature review after fulfilling the inclusion criteria and were analyzed and arranged in a literature review grid synthesis (Table. 1).

The eight articles reviewed in this literature review are research published in 2020-2022. There were three studies from America, and the other four were studies conducted in Malaysia, Brazil, South Korea and South Africa. The articles reviewed aim to identify challenges for parents with children with disabilities to health services during the COVID-19 pandemic. Three studies are qualitative research, two studies use quantitative research, and two studies use a mixed method.

Table 1 Grid literature synthesis reviewing challenges to health access during the COVID-19 pandemic

Researcher (year)	Country	Study Design	Number of Sample	Respondents/participants	Parent's challenges
Zhang, S., et al (2022)	USA	Quantitative Study	101	parents/caregivers who have children with disabilities	Social distancing; telehealth is less effective than direct health services, especially in diagnosis, diagnostic accuracy, and the effectiveness of treatment; communication privacy with health workers is lower for telehealth compared to face-to-face services (privacy issues)
Fadzil, et al (2021)	Malaysia	Explanatory Sequential Mixed Method	197	Caregivers of children up to 17 years of age with developmental disabilities	Parent's commitment; schedules that overlap between school and health service appointment; inflexibility in arranging appointments with health workers; transportation barriers (congestion, parking) and public transport accessibility; and social distancing
Medeiros, et al (2021)	Brazil	Qualitative Study	11	9 mothers and 2 grandma of children with special healthcare needs	Social isolation which effects the continuity of care; and parents' fear of transmitting the virus to children considering the vulnerability of children with special needs
Kim, et al (2021)	South Korea	Qualitative Study	19	18 mothers and 1 father of children with intellectual disabilities	Concern about children's vulnerability to the COVID-19 virus; restrictions on children's activities, and changing daily schedules of children
Pinkerton, et al (2022).	USA	Mixed method (survey and grounded theory)	171	Parents of children with disabilities below age 22	Technological barriers: poor response of children to telehealth services, lack of parental training and preparedness
Mupaku, et al (2021).	South Africa	Qualitative Study	9	three caregivers and six care leavers and of young people with intellectual disabilities and/or autism spectrum disorder	Sudden changes in routine that require parents in full-time child care; confusion in caring for children;
Kowanda, et al(2021).	USA and several other countries	Quantitative Study	391	Caregiver of children with neurodevelopmental disorder	caregivers experiencing stress and anxiety; telehealth services are unable to meet the needs of those with complex medical needs

Discussion

Based on a review conducted by researchers, it was found that Large-Scale Social Restrictions (PSBB) were intended to prevent the further spread of COVID-19 as regulated in Government Regulation Number 21 of 2020.[3] The problem of social isolation makes it difficult for parents to access health services, as a result, children with disabilities who should get consultation or therapy sessions will be hampered.[9] A survey conducted in France found data that as many as 77% of children experienced delays or cancellations of medical consultations where the remaining 18% via telehealth and 4% face-to-face during social restrictions. [10] In addition, social restrictions during the pandemic have resulted in the closure of access to facilities and communities that previously provided support to families with children with disabilities. Such as schools and special recreation programs for children with disabilities which had to be stopped during the pandemic, where parents rely on this support to help their children with special needs continue to develop.[11]

The results of this review of the literature show that during the COVID-19 pandemic, parents play a very important role where they need to be committed to fully caring for children with disabilities while at home.[12, 13] This is because it is the parents or caregivers who understand the condition of children with disabilities. So there is a need for training or education for caregivers or parents in carrying out care at the child's home on an ongoing basis.[14] If this is not done, parents involved in care may experience parenting stress which can also impact the health of their child.[7,8]

Another challenge from the parents' side is the fear and concern of parents about the transmission of the COVID-19 virus to their children.[15] This is in line with research conducted in Israel which found that as many as seven children experienced delays in treatment due to appendicitis caused by one of them, namely parents' concern about the COVID-19 pandemic.[16] This is also in accordance with research conducted in Saudi Arabia, which found that if there was no emergency, a number of mothers hesitated to take their children to the dentist because they thought it would be easy to catch the COVID-19 virus.[17] This indicates that there is a need for education related to security and safety protocols carried out at health service centers so that parents and children can still get a sense of freedom from fear in accessing health services even in a pandemic.

The increased use of telecommunication technology media such as telehealth and telemedicine have a significant role in replacing face-to-face health service processes which were restricted during the COVID-19 pandemic. However, based on the use of technology during the COVID-19 pandemic for children with disabilities it has not been optimally effective, and accuracy in examinations is one of the challenges for parents using this media.[18,19] The telemedicine platform has not paid attention to technological features that are suitable for a variety of disabilities, such as for groups of deaf or blind disabilities which, if not received attention, can hinder the communication process with health service providers.[20] Thus, it is important to continue to pay attention to the continuation of child care by paying more attention to the accessibility of technology use and also providing support to parents in using this technology. [9]

Pandemic conditions can affect care for children with disabilities or children with special needs. However, delayed health services for children with disabilities need to be maintained because if they do not affect the child's physical status and functional abilities.[10] So that the continuity of the provision of health services needs special attention from all parties, both parents, health workers and related parties. other.

Conclusion

From a review of the articles conducted in this research, it is known that there are several challenges faced by parents with children with disabilities regarding health services during the COVID-19 pandemic. Social restrictions that cause delays or delays to consultation and care sessions, parents' unpreparedness indicating the need for support from many parties, and the use of technology that has not effectively considered the condition of children with disabilities are some of the things that need to be considered in the implementation and provision of health services during a pandemic.

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