



Children with disability and their families during the COVID-19 pandemic - literature review

Dzieci z niepełnosprawnościami i ich rodziny podczas pandemii COVID-19 – przegląd literatury¹

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Abstract: The difficult situation into which the whole society suddenly found itself as a result of the SARS-CoV-2 pandemic causing COVID-19 has disintegrated everyday life, creating fear and numerous negative effects. Children with disabilities and their families, for whom the pandemic crisis is linked with other disability-related problems, have found themselves in a difficult position. The main aim of this article is to present the actual situation of children with disabilities and their families during the COVID-19 pandemic. The functional characteristics and selected problems of this group, as well as the negative effects of the pandemic are presented with regard to the review of the current literature based on the EBM (Evidence-Based Medicine) paradigm.

Keywords: COVID-19, children, disability, family

Abstrakt: Trudna sytuacja, w jakiej nagle z powodu pandemii wirusa SARS-CoV-2 wywołującego chorobę COVID-19, znalazło się całe społeczeństwo, wpłynęła na dezintegrację życia codziennego, budząc lęk i niosąc ze sobą wiele negatywnych skutków. W trudnym położeniu znalazły się dzieci z niepełnosprawnościami wraz z rodzinami, dla których na kryzys pandemiczny nakładają się też inne problemy związane z niepełnosprawnością. Głównym celem artykułu jest przedstawienie faktycznej sytuacji dzieci z niepełnosprawnościami i ich rodzin, jaka ma miejsce podczas pandemii COVID-19. Na podstawie przeglądu aktualnego piśmiennictwa opartego o paradygmat EBM (*Evidence-Based Medicine*) przedstawiono charakterystykę funkcjonowania oraz wybrane problemy tej grupy, a także negatywne skutki pandemii ją dotykające.

Słowa kluczowe: COVID-19, dzieci, niepełnosprawność, rodzina

Introduction

The first case of SARS-CoV-2 infection in Poland was detected on 4 March 2020, while already on 11 March 2020, WHO Director-General Tedros Adhanom Ghebreyesus announced that the COVID-19 disease could be referred to as a pandemic. This was the beginning of an exponential and dynamic process of introduction and application of various restrictions that were significantly reducing the quality of life (Clair et al., 2021) and changing the way people around the world functioned, exacerbating at the same time

social inequalities and compounding the problems of groups somehow discriminated against or excluded (Armitage, Nelums, 2020). Current observations confirm that disease caused by the SARS-Co-2 virus can be characterized with a diverse clinical picture, the most common of which is severe pneumonia (Dong et al., 2020). Due to the rapid spread of the disease, various types of epidemic restrictions were implemented worldwide, which were mainly related to movement and restriction of social contacts. Globally, suddenly, during a similar period, people began to experience problems in daily functioning.

¹ Artykuł w języku polskim: <https://www.stowarzyszeniefidesetratio.pl/fer/2022-1Zalew.pdf>

Children with disabilities, due to their underlying medical conditions or disorders and their frequent need for contact with people supporting treatment and therapy, are a particular risk group during the COVID-19 pandemic. They may be at higher risk for coronavirus infection, and at risk of a more severe course of the disease. Before the pandemics they and their families functioned in society for example with the help of specialised facilities, counselling centres or institutions providing support for people with disabilities. Literally overnight they were deprived of this opportunity, which required the long-term commitment of parents and carers (Pinkas et al., 2020).

The spread of the SARS-CoV-2 virus and the declaration of a pandemic have made it necessary for the public authorities of individual countries to adapt their system of assistance to people with disabilities, their families and carers in view of the unforeseen and sudden need to change existing forms of interaction in the area of care, education, rehabilitation and revalidation. Unfortunately, children with disabilities have at some point been omitted considering actions undertaken by the government. The Government's actions took into account the needs of healthy children especially in the introduction of online education. The needs of children with disabilities were forgotten at the same time. When disability measures were introduced, the situation of children was ignored (Kociejko, 2021).

The main objective of this article is to present the current situation of disabled children and their families during the COVID-19 pandemic. The characteristics of functioning and selected problems of this group, as well as the negative effects of the pandemic are presented in terms of the review of the current literature based on the EBM paradigm (*Evidence-Based Medicine*).

1. Problems of children with disabilities and their families during a pandemic

The situation of families bringing up children with disabilities is complex and diverse. The very definition of disabled children includes a heterogeneous group due to their problems and needs. Different difficulties

are faced by children with motor disabilities, sensory disabilities, intellectual disabilities, and different difficulties are encountered by their families. There is no doubt a child with a disability changes the life of a family at all levels, usually forcing a change in the life goals of all its members (Dołęga, 2010). Suddenly the reality of the pandemic, changing completely the previous everyday life, had a significant impact on the functioning of individuals in the family, as well as on relationships or on the way time was spent. The pandemic was the cause of creating or exacerbating crises in families due to increased levels of anxiety in all family members. In the case of parents, anxiety may have been exacerbated, for example, by the lowered immunity often present in children with disabilities, but also by the fear of losing a source of income. The whole situation of the pandemic and the spread of the SARS-CoV-2 virus was often incomprehensible to children with disabilities. The unexpected change in the rhythm of functioning, lockdown, tension from other family members, contributed to the appearance or intensification of difficult behaviours, particularly troublesome during the pandemic (Buchnat, Wojciechowska, 2020).

The main difficulties of children with disabilities during the COVID-19 pandemic, which according to the researchers are not observed in such severity in their peers without disabilities, are:

- mental health problems and increased exposure to violent situations,
- problems with access to education,
- problems in accessing rehabilitation and other services to facilitate daily functioning (Aishworiya, Kang, 2020).

2. The impact of the pandemic on mental health

The COVID-19 pandemic and its associated short- and long-term consequences should be regarded as an intense stressor (Wierzbinski, 2020; Heitzman, 2020). At this point, its psychological effects cannot be precisely estimated. It is presumed that they will be

severe, as indicated by the results of ongoing research (Elbay et al., 2020; Shader, 2020). The pandemic affects mental health in children and adults both with and without disabilities (Ciciurkaite et al., 2021). Studies conducted worldwide show that most quarantined individuals had distressing mental health related symptoms such as depressive states, depression, emotional exhaustion, insomnia irritability, PTSD features (Kumar, Nayar, 2021).

Unfortunately, children with disabilities (mainly intellectual disabilities and autism spectrum disorders) belong to the group which is mostly affected by the psychological consequences of the pandemic in the form of e.g.: prolonged low mood, depressive states and anxiety, phobias, psychotic states. This is due to the problems with understanding dynamic changes of everyday life and breaking safe routines, such as going to school or participating in different activities and other specialist support (Patel, 2020). One of the biggest problems for children turns out to be feelings of loneliness, associated with being cut off from peers and teachers from institutions and changing functioning environments (Bartoszek et al., 2020; Glac, 2020; Elmer et al., 2020; Raviv et al., 2021). During isolation, children with disabilities are much more likely than children without disabilities to experience all forms of violence (Lund, 2020).

In contrast, other studies show a high prevalence of depressive symptoms in caregivers of children with disabilities significantly impacted by the COVID-19 pandemic (Dhiman et al., 2020). Special attention is also given to the significant increase in parental stress levels in families with special needs children (Bentvenuto et al., 2021). Due to the so-called lockdown, many industries came to a standstill, many people had to take a break in their jobs or simply lost their jobs. This had a significant impact on the economic situation of numerous families, being another source of stress among parents.

3. E- learning

In accordance with the Regulation of the Minister of Education of 11 March 2020 on the temporary restriction as for the functioning of educational

system units in connection with the prevention, counteraction and eradication of COVID-19, the functioning of all educational institutions was suspended (Regulation of the Minister of Education, Dz.U. of 11 March 2020).

Parents of a disabled child are usually actively involved in the education and therapy process from the moment of the child's birth being more involved due to the child's various developmental difficulties. During the pandemic, however, it became apparent that it was the parent who had to take proper responsibility for the process and work with the child on a regular basis, using guidance and tools usually provided electronically by teachers and therapists. The greater requirement for the parent to be active was correlated with the child being less independent (Doroszuk, 2020).

Children with disabilities suddenly lost the chance to benefit from comprehensive institutional support such as therapeutic classes. Being subject to compulsory education they had to follow a core curriculum and continue therapy at home like other pupils in spite of significant difficulties in independent functioning. It should be noted that being at home disabled children often did not have the conditions to meet special educational needs. The lack of physical contact with therapists and teachers, as well as the online form of conducted classes did not allow for their full implementation and achievement of individual, previously planned goals. The problems of changing established patterns of functioning and breaking the routine, where the routine is the source of their sense of security, became important for children with autism spectrum disorder and their families. (Patel, 2020). The platforms of online activities were not always accessible to children with hearing and visual impairments (Patel, 2020). A Polish study on parents of hearing-impaired children and the accessibility of the online education system during the first lockdown showed that in half of the cases studied, no improvements were made to reduce the barriers associated with online education (Lewandowska, 2020). It should be remembered that any interruption or reduction in the quality of therapy for disabled children can lead to a rapid regression of skills developed in many spheres, e.g.: communication, physical fitness, cognitive sphere (Dunst et al., 2008). Parents

were forced to quickly adapt their home environment to online education and learn how to use new tools and technologies. This initial chaos in online education resulted in the need for even greater parental involvement. Additional problems in distance learning were found to be defective computer equipment and lack of regular internet access (Glac, 2020; Toseeb et al., 2020). The study conducted among parents of children with the autism spectrum showed that almost all respondents experienced problems with the implementation of online lessons, therapy activities and leisure time activities. The surveyed parents also observed greater problems with concentration and a higher incidence of challenging behaviour in their children (Colizzi et al., 2020). It can be speculated (although no such data has been collected in Poland) that some disabled children gave up the education system for a moment due to additional barriers and lack of help to overcome them (Kocejko, 2020).

4. Limited access to health care and specialised therapy

In accordance with the Regulation of the Council of Ministers of 31 March 2020 concerning the establishment of certain restrictions, orders and prohibitions in connection with the epidemic outbreak, the possibility of providing health care services in the field of therapeutic rehabilitation (in the form of private services, as well as those provided under the health care system financed by public benefits) was suspended (Regulation of the RM, Dz.U. of 31.03.2020, item 566).

The pandemic period, the closure of specialist institutions, and the reliance on on-call duty impeded the diagnostic process of children. The correct diagnosis is important in order to introduce early therapeutic intervention (Eshraghi et al., 2020). It was shown that in the situation of children with disabilities, on-call duty is usually not effective (Masi et al., 2020).

Children with certain disabilities present significantly greater health care needs than healthy children. This is related to the disability itself as well as to co-morbidities. During the pandemic, any inconvenience related to access to primary and

specialised health care may have led to a deterioration of children's current, as well as subsequent, health status (Aishworiya, Kang, 2020).

A problem during the pandemic (also due to the increased demand for this type of service in society) is the limited access to psychological support or psychiatric treatment already hindered before the pandemic), which for children with various disabilities and their families is indispensable (Grumi et al., 2021).

In children with physical disability, additional restriction of physical activity and lack of physiotherapy or other physical activities led to deterioration of their physical condition (Toseeb et al., 2020).

5. Siblings of disabled people

Growing up in a family with disabled siblings and facing specific life situations unknown to people without the experience of disability, can stimulate the development of healthy siblings. Some become more socially mature therefore more independent and responsible, as well as sensitive to the needs of others. The fact of having a sibling with a disability, on the other hand, also generates many difficult situations, causing both mental and physical strain (Pisula, 2007). Based on research conducted even before the pandemic, it is known that siblings of disabled people have higher levels of anxiety and tendency to withdraw from interpersonal contacts, as well as higher tendencies to depression than siblings of healthy people (Prata, 2019).

During the pandemic, siblings of disabled people not only had to cope with their own anxiety related to COVID-19, but also with other situations triggered by specific family setting. Increased responsibilities, less time devoted by parents, the accumulation of difficult behaviours of siblings during isolation put too much strain on them. The restriction on extra activities such as sports or extra curricular activities at school often deprived healthy siblings of a safe place to relieve tension. Another burden for siblings of disabled children is online learning. Not only do they participate in online education but also support their brother or sister, especially when parents work off-site. (Buchnat, Wojciechowska, 2020).

Summary

In conclusion, all studies available in the literature unambiguously show the negative impact of the COVID-19 pandemic on the situation of children

with disabilities and their families in all spheres of functioning. Special attention should be paid to the well-being of this group both during and after the pandemic by providing additional interdisciplinary support.

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