Raising a deaf child and a child with ASD from the mother’s perspective during the COVID-19 pandemic

Wychowanie dziecka niesłyszącego i dziecka z ASD z perspektywy matki w sytuacji pandemii COVID-19

Abstract:
The aim of the article is an attempt to learn about the subjective experiences of mothers related to the impact of the pandemic on the essence of raising a child with communication disorders, in this case a deaf child and a child with autism spectrum disorder (ASD). Addressing this issue is important from the scientific point of view due to the important role of the process of bringing up a child and its perception by mothers of children with communication disorders. The article examines the role of the family, and addresses the deficit of empirical research and scientific studies on upbringing and parenting issues affecting mothers of children with communication disorders. The work uses the method of individual case study, as well as the technique of narrative interview and in-depth individual interview. Ten mothers participated in the study: five mothers of deaf children and five mothers of children with Autism Spectrum Disorder (ASD). The analysis revealed three significant areas indicated by mothers related to upbringing issues: the first area concerned upbringing as a process of supporting the development of their children; the second — the process of shaping desired social attitudes; and the third — dealing with threats caused by the COVID-19 pandemic.

Keywords: upbringing, mother, deaf child, child with autism spectrum disorder, COVID-19 pandemic

Introduction

Since March 2020, a new pandemic reality has created a new situation in society in which we are experiencing an intense psychosocial upheaval. The multidimensionality of the negative consequences of the “perfect storm” entails rapid changes in our lives, and causes unprecedented problems of adaptation in an unstable, uncertain situation, as well as exposing us to increased fear, and even social panic. This variety of changes has led to the intensification of unprecedented problems and the particularly noticeable effects of loss of health, and difficulty in maintaining a job or social position (Brown, Schuman, 2021). This unusual time, full of dangers and an unforeseen future, requires different skills in children, but above
all, it involves searching for the meaning of life so that there is no regression of the values that make up a child’s humanity. During the COVID-19 pandemic, values important in a child’s upbringing, apart from categories conducive to intellectual and social development, began to be dominated by the right to preserve one’s own life, to focus on struggling with difficulties and the mercantile nature of survival in the world (Długosz, 2021).

Therefore, due to the observable unfavourable changes in this period of socio-cultural trauma, influences in the family environment may become a kind of antidote which creates social conditions supporting the child’s subjectivity and its development potential. Repelling the threats caused by this new social situation requires from the child not only intellectual abilities and mental openness, but above all rare moral qualities such as patience, responsibility and conscientiousness.

Based on the research tradition of Polish pedagogy, and in particular on the teleological and praxeological approach, it is worth recalling that upbringing is understood as an intentional impact on an individual in order to bring about the desired changes in their personality. This process is related to the nature of humans as free, rational beings capable of gradual self-improvement, and therefore the goals of education have a natural source in real social needs. In the case of raising a child, emphasis should be placed on the integrated totality of influences on its development through broadly understood social factors (from the micro- to the macro-system). The above way of understanding upbringing is exemplified in numerous definitions presented in the last century. Wincenty Okoń (1998, p. 444), writing about the consequences of upbringing “as a conscious social activity” for the improvement of a child’s personality, referred to fundamental changes in the child’s feelings, aspirations and attitudes, namely the understanding of reality and the ability to influence it, as well as the emotional and motivational aspect, which consists of shaping the relationship between humans and the world and other people, our beliefs and attitudes, our system of values and the purpose of life. Currently, the authors are in favour of a broader understanding of the process of upbringing.

Stefan Kunowski (2004, p. 167-169) proposed an attempt to formulate a definition of upbringing, taking into account the relationship with selected scientific disciplines and pedagogical content. The author distinguished the following approach:

- praxeological, in which emphasis was placed on the influence of educators on their pupils,
- evolutionary, focused on the role of the pupil in the process of upbringing and its spontaneous development,
- systematic, emphasizing the importance of the educational environment for the development of the pupil,
- adaptive, emphasizing the achieved effects related not only to the individual development of the pupil, but also to functioning in a specific educational environment.

The above definitions emphasize that a child is brought up by functioning in a natural reality and in a purposefully created educational environment subordinated to its developmental and educational needs. The nature of upbringing lies in itself, in its imperfection, and at the same time in the strength and quality of the possibility of continuous development. John Paul II (1989, p. 390) emphasized that education is a proven means that makes a person capable of authentic fulfilment of their life in harmony with their dignity, and allows them to shape fraternal relations with their neighbours. It is an indisputable fact that from the social point of view, educational influences that are acceptable are those that stimulate the development of the child’s subjectivity by assimilating such norms, value systems and ways of behaviour that are representative of a given social system.

Parents’ educational responsibility can take the form of raising, guiding, governing and discipline, allowing for growth, adaptation and help in life (Kron, 2012). The results of their work reflect the family’s resources, adapting to developmental changes not only in the systemic context, but also in the relational context, in terms of the personal ties that exist between spouses, as well as between parents and children. The multifacetedness of mutual interperson-
relations in individual subsystems, as well as their type and arrangement, determine the dynamics of the entire system and the quality of life of individual members (Liberska, 2021). In addition, the style of upbringing, the way family roles are fulfilled and the presented attitudes determine the involvement of family members and are also a source of numerous experiences. The natural process of upbringing in the family, with norms and rules, patterns of behaviour and ways of achieving them are of particular value in stimulating the child’s development. In the literature on the subject, the impact of upbringing carried out in the family environment in order to instil in the child socially recognized values and teach them social skills, is referred to as socialization in the family (Liberska, Matuszewska, 2021, p. 128). However, in terms of general development tasks, these are higher and broader goals. The most beneficial solution from the perspective of the development of a child, including a child with a specific disability, will be the actions of parents who are focused on expanding their own parenting competences and believe in their abilities (Zasępa 2018, Niedbalski, 2020).

1. Methodological basis for the research

The aim of the qualitative research was to learn about subjective experiences related to the impact of the pandemic on the understanding of the essence of upbringing. The focus was on the following research question: How do mothers perceive their experiences related to creating a space for the process of bringing up a deaf child and a child with autism spectrum disorder (ASD)? In order to obtain an answer to the research question, secondary analysis of qualitative data was used. This approach made it possible to look deeply into the studied phenomenon while searching for a new perspective. This study uses the method of individual cases, as well as the techniques of narrative interview and in-depth individual interview (IDI – Individual In-Depth Interview). Selected excerpts from the interview questionnaire for parents by Henryk Cudak (1995) were used as a tool to examine parents’ parenting skills, their attitude towards children and the upbringing atmosphere in the family. The research participants were hearing mothers and mothers of children with ASD.

The research was conducted in April and October 2022. The authors met with the women (mothers of deaf children, mothers of children with ASD) remotely using the Microsoft Teams application, as well as face-to-face at the Specialist Clinic for People with Autism in Leżajsk. Each of these meetings lasted approximately one hour on average. The empirical material obtained during the interviews was recorded on video or using a voice recorder, with the prior written consent of the study participants.

2. Characteristics of the study participants

Ten mothers raising a child with communication disorders participated in the research project. In both groups, the situation of the respondents was similar in terms of the age range of the respondents and their children, their professional situation and the structure of family life. Below is a brief description of the women studied:

- five mothers aged 30 to 40 residing in the Małopolskie Voivodeship raising one deaf child. The age of the deaf children was of early school age, i.e., from between 5/6 and 8/9 years of age. One of the research participants was Maria, who has secondary education and is not working. Another mother was Jolanta, who also has secondary education and runs her own business. The other three mothers (Ewa, Grażyna, Zofia) have higher education and are professionally active. All the women are married to hearing men and described their material situation and living standard as good.

- five mothers aged 30 to 40 residing in the Podkarpackie Voivodeship raising one child, communicating verbally, with aggressive and autoaggressive behaviour, aged 5.4-8.8 years. The children had a diagnosis of autistic spectrum disorders, at level 1 of severity of symptoms A and B requir-
ing support according to the DSM-5 criterion. It is worth noting that raising a child with ASD is associated with the occurrence of difficult behaviours: aggression and autoaggression, which is a very stressful challenge for parents, especially during the Covid 19 pandemic, when access to specialist therapy was limited. One of the study participants was Alicja, who has a university degree and is professionally active. Another two mothers, Ewelina and Monika, have secondary education, do not work professionally and receive child care benefit. The other two mothers (Urszula and Joanna) have higher education, are also not professionally active and receive child care benefit. The respondents described their material situation and living standard as good.

3. Results of analysis of the research material

The qualitative analysis revealed three significant aspects of upbringing noticed by mothers, that is reflections on: upbringing as a process of supporting the development of their children, as a process of shaping desired social attitudes, and counteracting the dangers caused by the COVID-19 pandemic.

1. The mothers’ reflections on upbringing as a process of supporting the development of their deaf children related to such categories as:

   - The actual developmental needs of the child,
   - Appropriate support.

2. Reflections on the upbringing process as shaping desired social attitudes in deaf children and children with ASD allowed the following categories to be distinguished:

   - Socially desirable character traits,
   - Prosocial patterns of conduct.

3. Reflections on upbringing as counteracting the dangers caused by the COVID-19 pandemic were expressed in such categories as:

   - Dealing with a new social situation.
   - Preventive actions.

3.1. The actual developmental needs of the child. Appropriate support

Qualitative interpretation of the mothers’ statements proves that from the beginning of the situation related to the COVID-19 pandemic, the mothers engaged in various forms of assistance tailored to the development and educational needs of both their deaf and autistic children. Bearing in mind the high dependence of the development of the child’s personality on the overall behaviour of people in the immediate environment, it is worth noting the upbringing atmosphere created by the mothers and the appropriate level of support to satisfy even the simplest needs, such as the selection of appropriate food and comfort of sleeping. The experiences of the mothers also became an opportunity to critically evaluate distance learning. They noticed not only didactic and substantive problems, but also that their children lacked the skills for independent learning and individual organization of the school day. First graders did not have the opportunity to develop these skills. Before the pandemic, the school organized classes and supervised the implementation of the material. During the pandemic, the mothers felt obliged to meet the educational needs of their children and therefore supported the activities of the school by monitoring the child’s school activities and following the teachers’ recommendations. The mothers complained that they spent a lot of time helping their children with their homework. As a result of the pandemic, the time for doing homework together increased significantly. In addition to the problems associated with covering the material provided, there was also a struggle with Internet communication. In the case of children with autism spectrum disorders, there was also an increase in aggressive and autoaggressive behaviour, a gradual withdrawal from social contacts and an increase in anxiety reactions in new previously unencountered educational and social situations. Here are some excerpts from the mothers’ statements:
When they closed the schools and counselling centres in the first period, it was dramatic, everything we had worked out for Frank was in vain. The screaming and banging his head against the wall came back. This situation destroyed his world, which was already ordered and safe. I didn't even watch the news, because I was afraid of the conversations with him and his questions, I didn't know what to say and how to explain. I tried to work with him, we practiced motor skills, but attempts to learn remotely using the Internet made him angry and afraid. Then he got used to it and there was another problem because of children going back to school, and he does not like group work or games (Urszula).

During the pandemic, when further restrictions were announced, it was hard. It was terrible to sit at home, and my daughter likes cycling so much. The most important thing was to make her feel safe. She didn't understand what coronavirus was. I explained the news from the TV to her, the meaning of what they said, because she didn't understand. Usually, in the evening, I would lie down next to her, cover my legs with a blanket and talk. We were not prepared for remote learning. We dealt with these new techniques together. There were problems with the Internet (Jolanta).

Initially there was panic, fear. Gradually, my daughter got used to it. Thanks to the fact that we spent a lot of time at home, we were close to each other. I made sure her meals were healthy and varied, despite the difficulties of shopping. As the specialists from the counselling centre taught me, I spoke to my daughter a lot, slowly and clearly. I talked about what was happening in Poland and in the world. We played board games, Monopoly. We cooked meals together, I taught her to prepare different dishes, to bake cakes for the holidays. She likes it. I was glad that she quickly mastered the ways of conducting lessons via the computer (Maria).

Jasiu never asked and was not interested in our conversations about the pandemic. He was focused on what I organized for him, and actually I made sure that he did the material as he had planned. I devoted a lot of time to him learning to read and write. The time was not lost as I had it for my child, I could take care of everything and be with him. We drew together, cooked together, he helped me a lot and liked being with me. We became very close, I worked remotely, it was our time that we appreciated (Alicja).

It's good that we have each other. It would be wrong to overcome the difficulties of the pandemic alone. It was a time when I read children's comics and poems to my son. He preferred comic books because the illustrations helped him understand the content. Then we talked about what I was reading. He had a lot of trouble understanding what we read. Michał spent many hours watching a series of movies about superheroes. I didn't forbid him. It interests him. Distance learning imposed a work discipline on him. But it was also a burden for me. There were times when they had to prepare a lot of different tasks. Everything had to be explained from the beginning. There was a great lack of a supporting teacher. His presence on Zoom wasn't helpful enough. There really was learning overload. But it was the result of the teacher's preferred way of teaching. She assigned a lot of tasks and chores to be done, as if she wanted to make up for a lost month (Zofia).

During the pandemic, I was overburdened with everything. Karol did not go to kindergarten, I conducted speech therapy classes by phone and worked on the tasks that I had to do. On the Internet I found a lot of materials that I used. When Karol was afraid and he asked about diseases, I explained it to him. He also had more difficult behaviours then, sometimes he pinched himself, but I had good contact with him, we were together (Ewelina).
When remote classes started at school, it was easier to manage my free time. But in turn, my husband and I joined in helping with homework, completing the exercises recommended by the teacher, translating any incomprehensible content in textbooks, exercise notebooks, and correcting notes written in notebooks. It turned out that Ola did not understand everything that the teacher dictated during the lessons and it was necessary to correct her mistakes. I felt sorry for my child as she said that the Internet was down again and she could not actively participate in lessons. Then she admitted and was ashamed that the teacher spoke too quickly and hence those mistakes. Ola requires a special approach due to a hearing impairment, although she can hear everything thanks to a hearing implant (Ewa).

Tymon is a smart boy, but he has difficulties and he needs help, as he did during the pandemic. He couldn’t sit in front of the computer in class and got angry playing computer games. I couldn’t be with him, and Tymcio doesn’t take separation well (Monika).

The coronavirus pandemic took us by surprise and forced us to change our daily lives. The school, and mainly the teacher, shifted the responsibility of teaching the child onto us, the parents. Remote teaching was tiring and even boring for Arek. He hardly saw his friends, because when he started learning in the first grade, he was sick a lot, and then you know, the government introduced restrictions. They saw their friends on the screen, but it’s not enough to get to know each other. My role was to motivate him, encourage him to learn and show his good side. I also talked to the mothers of other children to make sure we kept in touch with one another (Grażyna).

During the pandemic, Filip’s contacts with classmates suffered the most, and he did not know them well yet, so he had great difficulties in group work. He studied well, but he did not play with anyone, he was only with me. Every day was the same. I took care of everything at home, although the apartment was small, it was always clean and I always cooked dishes that Filip likes (Joanna).

3.2. Socially desirable character traits. Pro-social patterns of conduct

The COVID-19 pandemic became a test of family resources. In fact, the mothers were forced by these external circumstances to propose solutions to help deaf children and children with ASD to adapt to the new social situation. It is also worth emphasizing that each of the mothers reacted naturally in order to maintain a balance so as to ensure the quality of functioning of their families. Isolation and remote education could have become determinants of inappropriate social and moral attitudes. In order to prevent the deterioration of well-being, and to physically and cognitively activate their deaf child or ASD child, the mothers introduced new forms of activity aimed at shaping a socially desirable character and behavioural traits. In addition, by rewarding socially desirable behaviours and punishing other, unwanted examples of attitudes, they created the foundation for a space where certain norms and rules are observed and values recognized in the family are cultivated. Here are some examples of the mothers’ statements:

I made a schedule for the day. I rewarded my daughter for her progress, diligence and hard work. She did her homework by herself. Colouring books and sticker books were an effective method of rewarding her (Jolanta).

Karol needs clear rules and he works well in such a system. I used all the principles of therapy at home. My husband also tried because he saw the effects and knows that Karol needs reinforcement, and it was Marek who prepared model toy cars for him. Karol was so happy and tried, although there were very difficult moments because he had a lot of difficult behaviour (Ewelina).
My sister and I agreed in Ireland that we would help each other and our children. Twice a week our girls talked to each other in English. They talked about what they do, what kind of cake they had baked, what they are doing in class. I spent a lot of time with Lenka and then I taught her how to crochet. We made sets of napkins for family and friends. For holidays, for Children’s Day, we prepared colourful boxes with serviettes as gifts (Maria).

Filipek read a lot, I ordered him books via the Internet and we read together. We also wrote a funny story about cavemen (Joanna).

Michał would prefer to spend the whole day in front of the TV and playing on the computer. I had to come up with something to make him happy to spend his free time differently. We had fun together, playing board games, assembling Lego bricks (Zofia).

To be honest, there were days when Tymuś watched cartoons all the time. I know it’s not allowed, but I was so tired and didn’t know what to do, I knew I had to do something about it. That’s when we discovered board games, and in the evenings, we played with the whole family (Monika).

I am a physical education teacher. My husband and I attach great importance to being active. During isolation, I developed a set of self-exercises for Arek from Tuesday to Thursday. On Monday he practiced with me and on Friday with my husband. Yes, up to an hour. I noticed that he not only got used to these exercises, but he liked them. He reminded me when we should start. Of course, my husband and I tried to make it fun (Grażyna).

I organized all the activities for Jaś, I taught him to read. He made great progress thanks to the fact that I was with him and I really wanted to help him not to waste this time together (Alicja).

During isolation, my daughter continued speech therapy classes, of course remotely. The speech therapist gave me tips for working at home. I kept a baby progress diary and my daughter kept a diary. Ola loves to play with dolls. For her progress, I rewarded her with clothes for her dolls, which we chose together in online stores (Ewa).

It’s amazing that there were also good moments in lockdown. We danced and sang songs, drew, cooked and lazed around. The rhythm of the day had to be the same, otherwise there would be a scream (Ursula).

3.3. Dealing with a new social situation.
Preventive actions

In the process of social adaptation caused by the COVID-19 pandemic, the special value of the family as an educational environment was revealed. Every child, including deaf children and children with ASD, need stability, acceptance and a sense of security in order to be able to develop properly, and this should be provided by people in their closest environment. The mothers faced new tasks related to preventive measures because social isolation meant that deaf children and children with ASD began to spend their free time at home surfing the web, playing computer games or using other electronic media. The challenges of everyday life meant that, despite the closure of educational institutions, mothers tried to motivate their children to make an intellectual effort, change their habits and convince them that systematic work is necessary for individual development. Here are more examples of mothers’ statements:

At the beginning of isolation, Michał spent many hours watching a series of movies about super heroes. It interests him. Another problem was games. I started to get nervous so I took control. He had set hours. And the worst thing was just sitting, we live in a block of flats, we have two rooms. Often it was sitting in one position, whether in front of the TV, computer or smartphone (Zofia).
During the pandemic, Tymuś had a lot of behaviour problems, and watched cartoons and played games on the computer during remote classes. It was terrible, but we managed. I had to come up with something so that he would not look for the remote control but do something else. We did puzzles together, played board games, it helped us (Monika).

Jasiu used to steal my phone and install games, especially when I was cleaning and not looking. It annoyed me, but I knew that in addition to studying, we also had to play with. In the dining room, we made a ping pong table on the table and my husband played with it. And I could take care of our house (Alicja).

Disputes arose between Ola and her five-year-old hearing sister. Such nonsense. Because Ala did not want to play with her, because playing with dolls is not for her. Because Ala has a prettier dress, a hair band. Of course, I told them not to argue. I explained that Ala is older, wiser, she should be an example for Ola, they should help each other (Ewa).

Lenka does not like monotony, she began to get bored. She had no one to play with. Grandma couldn’t visit us, and her friends were at their homes. The smartphone came into action. I found out that she used it not only for writing text messages and receiving e-mails, but also for searching the Internet. That’s what I was afraid of; in case she came across some inappropriate content. Images affect her very much, it’s because of her hearing damage. At some point, she began to ask about what was happening in Italy. Why so many coffins? Are the old and the young dying? I understood that the media message on the smartphone exposed her to anxiety and fear. I explained it simply to her. In addition, I asked my husband to install special software, one that protects against dangers and blocks harmful information (Maria).

Yes, the smartphone was something that Filip asked for all the time, whether we would buy him one or if he could play with it. When he got it, he was no longer with us and it was a problem to take it away from him. He even deleted parental applications and used the phone without my knowledge, so I took it away as a punishment and he was calm. The phone acted on him like a drug (Joanna).

There were drastic situations when Karol insisted on using the tablet, but I didn’t give in. I asked my husband to use it when Karol was already asleep, because there were many arguments and screaming about it (Ewelina).

Arek really liked spending time on his smartphone. During the pandemic, it was a problem, whenever he found a free moment, the smartphone was in his hand. He used it often in bed. He even started blackmailing me that he wouldn’t practise if we didn’t give him more phone time. There was a lot of conversation, even a bit of nervousness, but everything worked out because we introduced rules. He was not allowed to keep his phone overnight in the room where he slept. And we set a time limit (Grażyna).

The number one problem was the smartphone. I knew I had to take it on board. I restricted access to dangerous information. I did it deliberately so that only the basic apps were on the phone screen. There was a phone book, a calendar, a clock and a calculator. I stashed all the crap in invisible directories. It was more difficult to access there, but my daughter knew about it. We talked it over. In addition to hearing damage, she has serious visual impairment. I was afraid that it would get worse from this constant use of the smartphone (Jolanta).

Like every child, whether healthy or sick, it was the laptop and mobile phone that attracted him the most. The worst thing was...
Conclusions

The research shows that an important feature of a family in a difficult situation, such as the COVID-19 pandemic, is the ability to adapt, and precisely the readiness of the members of the microsystem to change. The mothers’ narratives show that they subordinated their natural skills so as to influence both their deaf and autistic children, and took actions aimed at inducing the desired changes in their psyche. At the same time, it should be noted that mothers have a special ability to understand and perceive the emotions, needs or states of their children. Despite such strong emotional reactions, the mothers tried to understand the social situation in which deaf children and children with ASD function, so as to create an atmosphere conducive to a good upbringing in the family, and to demonstrate pro-social attitudes to stimulate the development of their children. It is worth recalling that children at early school age are guided by emotions in their behaviour. Therefore, the development of mothers’ style of upbringing worked in the axiological dimension, in particular in the time of the pandemic, in order to ensure real and systematic implementation of activities strengthening, above all, the emotional state of their children.

The mothers, as significant people in shaping their children’s personalities, used their own privileged position and at the same time acted as educators, basing their relationships on the principles of positive motivation and partnership. The consistency in their educational activities and preventive interventions allowed the behaviour of deaf and autistic children to be optimized on an ongoing basis. The special social situation during the COVID-19 pandemic created a space for educational interactions, in which mothers supported the development of deaf and autistic children, shaped their desired social attitudes and avoided dangers associated with manifested undesirable patterns of behaviour.

Bibliography


