EXPERIENCES OF PARENTS OF CHILDREN WITH SPECIAL NEEDS DURING THE COVID-19 PANDEMIC PERIOD

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ABSTRACT

This paper provides a qualitative analysis of the experiences of parents of children with special needs during the Covid 19 pandemic period. The purpose of this study is to answer the research question regarding the experiences of the parents of children with special needs during the COVID-19 pandemic. Qualitative methods for data collection were used in this study and the main instrument was a semi-structured interview. The sample in the study consists of 12 parents from the cities of Tetovo, Gostivar and Skopje. Parents of children with special needs had difficulty with their children managing the situation created during the COVID-19 pandemic. Many mothers said it was indeed a very difficult time as they felt trapped by a multitude of problems and factors that negatively affected them and made it impossible for the situation to be managed properly. One such factor was the restriction or inability to move outside their home and to develop the activities that for those children had become commonplace and a kind of routine in itself.

Based on the discussions and conversations we had with these parents, despite the difficulties during the quarantine, the parents eventually got used to that type of condition and began to manage it a little better than at the beginning of the pandemic

Keywords: experiences, emotional experiences, covid 19, quarantine restrictions, parents of children with special needs.

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Introduction

According to the Center for Disease Control and Prevention (CDC, 2020), one of the categories with the highest risk of experiencing stress during this situation are people with disabilities. Consequently, these people are more prone to experience mental health problems such as depression, which may not always be noticed by family members, because they can also be manifested as physical (such as headaches or abdominal pain) or cognitive (difficulty concentrating) complaints. ***Experiences brought by COVID 19 lockdown***

The suspension of all activities led to the disruption of the necessary evolutionary paths, a concrete damage to the developing potential. Many family members today face the fear of seeing regressions or losing the ability to deal with dedication and effort. The fear and insecurity of the parents increases even more only from the possibility of infecting these children knowing the sensitivity to face such a situation. Fear and non-cooperation with medical staff is one of the main concerns for parents and even more so if there will be a need for hospital treatment. On the other hand, for family members the drama of who will take care of the child when the parents pass away is always present, a disturbing thought now emphasized especially in single-parent families or the elderly who are most vulnerable to Covid-19. Extraordinary events like the COVID-19 pandemic can significantly affect the life cycle of families with disabilities and become a cause of significant stress. Generally, for an adult, physiological exit from the orphanage does not occur and concern for the future and the need to continue to care for him is always present in both parents and others. Expectations about improving aptitude state diminish along with opportunities for social inclusion. Therefore, for an adult, breaking the habits and relationships that support them risks stressing out feelings of loneliness, fueling isolation and depression.

2. RESEARCH METHODOLOGY

The qualitative research method was used in this study was the qualitative method as it is the most appropriate method in relation to the purpose and research question of the study. In order to have a better reflection of the situation and to organize in detail the research, we divide the same into three parts. The first part of the intervention includes questions about general data (adress, occupation, age, number of family members). In the second part we focused more attention to see the reactions, experiences, attitudes and adaptation styles that parents had during the pandemic. From the alternatives offered, parents could choose between sadness, frustration, insecurity, fear, isolation, anxiety, etc. The third part of the interviews was full of direct questions to see how they managed the situation and what difficulties they faced. In the first part we asked the questions to see how they managed the situation, what differences they saw, what were the most significant difficulties they and their children faced, how much this whole situation with the pandemic has made difficult and influenced lifestyle, etc. Other questions were of the nature of psychological adaptation, respectively the management of psychological states of children (mood changes, emotional state, changes in behavior, relationship with parents)

2.1. The aim of the research

The main goal is to understand what experiences parents of children with special needs had during the COVID-19 pandemic.

Research question

What experiences did the parents of children with special needs have during the COVID-19 pandemic period ?

Study Hypothesis

Parents of children with special needs had difficult experiences with their children managing the situation created during the COVID-19 pandemic.

Study sample

The sample consists of 12 parents from Tetovo, Gostivar and Skopje, who have children with special needs. The sample selection strategy in this study was intentional. The descriptive aspect of the study sample is presented in the table below.

Nr	Adress	Parent interviewed	Parents' Age	Employment	Economic Status	Number of family members	Diagnosis of the child
1	Gradec	Mother	35	Teacher	Average	5	Developmental delay
2	Vrapçisht	Mother	32	/	Average	4	Autism
3	Negotinë	Mother	32	/	Low	4	ADHD
4	Tetovë	Mother	35	Teacher	Average	3	Autism
5	Tetovë	Babai	40	Manager	Good	5	Autism
6	Radiovcë	Mother	30	Teacher	Average	3	Autism
7	Shkup	Mother	41	Teacher	Good	4	Autism
8	Neproshten	Mother	44	/	Average	5	Slight mental retardation
9	Tetovë	Mother	34	/	Average	4	Hyper-activity
10	Sllatinë	Mother	41	/	Average	4	Slight mental retardation
11	Strimnicë	Mother	40	/	Low	6	Cerebral palsy
12	Tetovë	Mother	39	/	Good	4	Autism

Tab. 1. Study sample

3. RESULTS AND DISCUSSION

3.1. Experiences, attitudes and adaptation styles

Based on the obtained results from the interviews conducted with parents of children with special needs we have given conclusions about what were the emotional experiences in this period of the pandemic. From the table we can see that 0% of the parents have never been upset,sometimes 32%, often 56% and 8% very often. 16% have never cried, while 32% sometimes, 48% often and 0% very often. 8% of the interviewed parents have never shown frustration, sometimes 40%, often 48% and 0% very often. 8% have never shown withdrawal on their own, 48% sometimes, often 24% and 16% very often. Anxiety has never occurred in 16%, 40% sometimes, 24% often and 16% very often. 16% have never shown insecurity, 24% sometimes, 40% often and 16% very often. Fear has been felt by none of the parents, 32% sometimes, 48% often and very often 16%.

	Never	Sometimes	Often	Most of the time
Boredom	0 %	32 %	56 %	8 %
Cries	16 %	32 %	48 %	0 %
Frustration	8 %	40 %	48 %	0 %
Self isolation	8 %	48 %	24 %	16 %
Anxiety	16 %	40 %	24 %	16 %
Insecurity	16 %	24 %	40 %	16 %
Fear	0 %	32 %	48 %	16 %

Tab. 2. Experiences, attitudes and adaptation styles

3.2 Situation management during the Covid 19 pandemic

Did you experience changes in your daily life during the Covid 19 pandemic compared to your daily life before this period?

The answers received from 3 mothers and 1 father were that the daily life of both children and parents has been much more difficult because the children could not understand the situation they were in and wanted to have their needs met. The answers received from 5 mothers were that the daily life of their children as well as the daily life of the parents themselves was with not very noticeable changes because their children more easily understood the situation and the prohibitions that were put in that period.
The responses received from 3 mothers were that their daily lives and those of their children did not change and continued the same as before the pandemic.

Has this period of child care been the most difficult for you or is it always difficult to care for your child?

The responses received from 10 mothers and 1 father were that caring for a child with special needs is very difficult but the period and chaos caused by the Covid 19 pandemic made it even more difficult to care for

their children. One mother said that the pandemic caught her at the beginning of starting the treatment of the girl, so she did not notice any changes in the care of the girl.

What is the most difficult challenge you faced at home during the pandemic period? Do you live in a house or apartment? Has the place you live in made it easier or harder for you to manage the situation?

The responses from 5 mothers and 1 father were that the most difficult challenge was coping with the new situation, staying locked up at home respecting restrictions and maintaining safeguards. They tried to play and spend time alone with the child so as not to feel bored. They played various games such as coloring, drawing, puzzles, etc. The place where they live helped them to manage the situation more easily. 5 mothers said that the most difficult challenge was the quarantine period because the child did not understand that they had to stay indoors. Another challenge was adapting to the new situation and the new way of living with limitations. They said the place where they lived has made it more difficult to manage the situation.

How did you adapt to the new situation? What were the methods you used to deal with this situation? What tools did you use to overcome this problem?

The answers received from 7 mothers were that it was very difficult to adapt to the new situation. They said they did their best to keep their children from feeling overwhelmed by the pandemic. They used all the ways of playing, even invented a new game to make it easier for children to overcome the problem.

One father and 4 mothers said that at first it was very difficult to convince the children that there were certain prohibitions and restrictions, but then the children adapted to the new situation and everything went the same as before the pandemic. They said they used a variety of games and tools to keep their children from being bored at home. They added that walking in nature helped many children to more easily cope with the limitations of the situation caused by the Covid pandemic 19.

Did you use the exemptions provided by the state for the category of persons with special needs during the time of isolation? How did you use them? Where?

Three of the interviewed mothers said that they used the state concessions for the needs of their children, 8 mothers and 1 father said that they did not even know that the state had issued assistance to children with special needs, they paid all the expenses of their children care themselves.

3.3. Psychological management of the child during the quarantine

Did your child behave differently during the quarantine period? Have you noticed any changes in his/her behavior?

One father and four mothers said that during the quarantine they did not notice any changes in the behavior of their chidren. They added that the whole family tried not to have changes in the routine and behavior of the children. Seven mothers said that the behavior of the children was much different from the behavior before the pandemic. The children wanted to go to school or play with friends but due to the inability to get out their behavior grew more aggressive; the children became more attached to their parents. The onset of the pandemic was very difficult until they adapted more or less to that lifestyle.

How was your child's mood during the quarantine period? Did you notice if your child was happier or more upset than before the quarantine?

Two mothers and one father said that their children's mood was generally good. More or less, the children had the same mood both before and during the quarantine. 9 mothers complained that their children's mood in general was not good at all. Their children expressed irritability most of the time, as well as frustration, boredom and fear. They also added that although they tried their best not to upset the children and to always be in a good mood, it was unsuccessful because the children wanted to walk and go to school. This inability to go out changed their behavior significantly.

Has your child been more attached or dependent on you during the pandemic?

Three mothers said their children were more withdrawn from the family, sometimes being more dependent on therapists. One father and 8 mothers said that their children were very dependent on their parents. They added that all the time the children wanted to stay with them, not seeing anyone else, and not having contact with anyone other than the parents.

4. Conclusions

Regarding the issue of mothers and fathers experiencing the problem of the child, the study showed that children with special needs has an impact on both mothers and fathers. There are different ways in which they experience the child's problem. The difference between them was that the mothers show it, they talk about it while the fathers try to hide it. The study also showed that the experience different from mothers and fathers lies in the fact that mothers are by nature more connected to their children. While researching this issue, parents noted that adapting their children to the pandemic circumstances was very difficult because they were unable to understand the limitations and wanted to continue their daily routine as before the pandemic. Caring at this time was extremely difficult for parents and family because the behavior of the children varied from moment to moment. It is worth mentioning that children displayed an even stronger bond with their mothers.

Studies show that parents of children with special needs have a difficult life experience and are more prone to loneliness and more withdrawn from the social circle because sometimes they feel left out and all this comes as a result of leaving the social circle for personal reasons. Regarding the education of children, more than half of the parents state that the difficult part was having to stay with the children in school as their adaptation was difficult. Due to the situation created by COVID-19 learning continued online and this way of learning was more difficult and not very efficient because the children were not always able to understand what was being said.

In an online survey, The Inclusion Technology Lab Berlin and the Fraunhofer Institute for Applied Information Technology (FIT) explored the great burden that families with children with disabilities in particular face in the face of the Covid-19 pandemic. The survey started on May 13, 2020. Within just one week 1767 people participated. The results show that families feel left alone. Even the current school openings do not bring any improvement. While opening schools means a relief to many children and parents, many will not be able to benefit from them, including those who due to physical or mental disabilities can not be exposed to the risk of returning to school. Therefore, more than 46% of respondents

think that caring for their child is very difficult. In addition, 41% of participants stated that their child coped poorly with the restrictions. 46% are concerned about the health of their children with disabilities.40% of parents would like more support from digital learning opportunities.

Twelve parents participated in our research on the experiences of parents of children with special needs during the Covid-19 pandemic. 33% of parents stated that their child's fear of regression accompanied them all the time. 47% of participants stated that caring for their children in this time of pandemic was even more difficult. 56% of them said that their child coped poorly with the restrictions. 32% of parents would like more institutional support for their children with special needs.

Parents of children with special needs had difficulty with their children managing the situation created during the COVID-19 pandemic. Many mothers said it was indeed a very difficult time as they felt trapped by a multitude of problems and factors that negatively affected them and made it impossible for the situation to be managed properly. One such factor was the restriction or inability to move outside their home and to develop those activities that for those children had become commonplace and a kind of routine in itself. Not going to school regularly and the social distance greatly affected the emotional and psychological state of this category of children, and they began to show reactions different from the usual ones. The quarantine created psychological difficulties in children with special needs.

As we mentioned in one of the points of the first hypothesis, we clearly state that isolation or quarantine had a very negative role and bad impact on children with special needs. Therefore in such situations it is logical to understand this type of escalation and it is very normal for difficulties to increase for the people caring for these children, especially their parents.

Based on the discussions and conversations we had with these parents despite the difficulties during the quarantine the prents eventually got used to that type of condition and began to manage it a little better than at the beginning of the pandemic.

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