

EMOTIONAL EXPERIENCES OF DEBAR REGION PARENTS DURING THE PERIOD OF DIAGNOSING THEIR CHILDREN WITH SPECIAL NEEDS

Sara Sadiki
University of Tetovo
sara.sadiki@unite.edu.mk

ABSTRACT

The qualitative method was the research method used in this study as the most appropriate to the purpose, objectives, and research questions of the study. The purpose of this study is to examine the emotional experiences of parents when diagnosing their children with special needs. What emotions did the parents experience when their children with special needs were diagnosed? Was the research questions of this study. The sample in this paper consists of 13 respondents, citizens of Debar parents of children with special needs. The interviewed sample consisted of 10 Mothers and 3 Fathers. Results: that 61.5% of parents have experienced excessive anger, 30% have reported a lot of anger and 7.7% have experienced a normal level of anger; while 46.1% have experienced excessive pain, and 53.8% have experienced a lot of pain; likewise, 53.8% have reported excessive fear, while 38.4% a lot of fear; excessive frustration is reported by 38.4% of the parents, while a lot of frustration by 23%. Regarding the level of denial of the information about their children, 61.5% of parents report a high level of denial, while an excessive level of denial was reported by 30.7%. As of loneliness, 53.8% of parents have felt very lonely, 23% have reported excessive loneliness, and 15.3% have felt a little lonely in the period of diagnosing their children.

Keywords: Special needs, parents experiences, diagnosis.

INTRODUCTION

Parents of children with special needs face particular challenges interacting with their children and have been shown to have higher levels of stress than parents of children without disabilities (Peer & Hillman, 2014). A number of studies have attempted to understand the emotional climate in the home of children with special needs by examining parental Expressed Emotion (EE). EE is a construct that encompasses the familial emotional climate, particularly parental attitudes about the child and their relationship (Magana-Amato, 2015).

Below are stages of grief that families with children with disabilities commonly experience. There is no specific order for these stages, nor do all families experience every single one of these emotions (The IRIS Center, 2008). Some families may feel these emotions on the inside but try to mask their feelings to others. Denial: Families may not believe the news that their child has a specific condition or learning need. This can be especially true when the news is a surprise. An individual's culture, acceptance of people with disabilities, and knowledge of a specific condition can impact how one copes with the news. Those in denial may try to discredit the doctors or specialists involved in the process. Family members in denial may make statements about how their child, "never acts that way at home" or "that doctor doesn't know how to be around kids." This is especially true when the condition is based on a behavioral

assessment rather than by an objective test such as bloodwork or genetic workup (Barnett et al., 2003).

Guilt: Some families feel as though they did something wrong or are responsible for their child's disability; as a result, these families can begin to question their past decisions. Families may feel as though professionals talk down to them or are critical of their decisions and parenting, which may increase any existing feelings of guilt. While professionals do not intentionally make families feel this way, be aware of your own biases towards families and their decisions (Lowe & Lyne, 2000) It can be difficult to hide your feelings and opinions when you communicate with families, but keep in mind that your role is to be supportive of their decisions. **Anger:** Parents and caregivers may feel angry about their child's disability. Some describe feeling as though it's not fair to their child or that they have bad luck. They may take their anger out on others. Remember that this anger may help families cope and eventually create plans for how to help their child in the future. **Fear:** Parents of children who have a lot of medical needs may fear for their child's life or fear that other caregivers will not know how to keep their child safe. Some primary caregivers fear that no one will love and care for their child the way they do. If a primary caregiver of a child with a disability seems critical of your care for their child, know that fear may be the root cause of such behavior or beliefs.

It can also take a long time until parents emotionally accept this knowledge (Gallagher, Fialka, Rhodes, & Arceneaux, 2002). Parental acceptance of the child's condition and adaptation to it are slowed down or prevented by many factors, the most important of which are

METHODOLOGY

The qualitative method was the research method used in this study as the most appropriate to the purpose, objectives, and research questions of the study. This qualitative research consists of collecting, analyzing, and interpreting data using words and images to delve deeper into a particular phenomenon we are interested in (Bloomberg & Volpe, 2008; Robson, 2011). Data collection in the qualitative method is based on flexible instruments (Maxwell, 2005), and the researcher in this study used in-depth structured interviews with parents of children with special needs. This method provides information from people's personal experiences of specific issues or phenomena that we are interested in when the researcher put efforts to understand something from the subjects' point of view and discover the meaning of their experiences (Kvale, 1996).

The purpose of the study

The purpose of this study is to examine the emotional experiences of parents when diagnosing their children with special needs.

Research questions

- What emotions did the parents experience when their children with special needs were diagnosed?
- How did they cope with the diagnosis situation of their children, what were their challenges?

Hypotheses

H1. The emotional experiences of parents during the time of diagnosing and communicating the child's disability are strong.

H2. The period when the diagnosis of a child with special needs has taken place has been very difficult to handle by the parents. Parents haven't been able to find appropriate strategies to cope with this situation.

Study sample

The sample in this paper consists of 13 respondents, citizens of Debar and the Center Zhupa, parents of children with special needs. The interviewed sample consisted of **10 Mothers and 3 Fathers**. The children's age was from 5 to 28 years. In terms of marital status of the respondents, it resulted that 12 were married, while 1 parent was divorced.

The sample selection strategy in this study was purposeful.

Table 1 Descriptive data of the study sample

No.	Place of residence	Interviewed parent	Age	Employment	Economic status	Gender of the child	Age
1	Debar	Mother	57	Unemployed	Average	Male	28
2	Center Zhupa	Mother	45	Employed	Average	Female	7
3	Debar	Father	59	Employed	Good	Male	24
4	Debar	Mother	35	Employed	Good	Female	9
5	Debar	Mother	39	Employed	Average	Male	10
6	Debar	Mother	31	Unemployed	Good	Male	7
7	Debar	Mother	55	Unemployed	Average	Male	20
8	Debar	Mother	55	Employed	Average	Male	17
9	Debar	Father	31	Employed	Good	Male	5
10	Center Zhupa	Father	59	Employed	Average	Male	16
11	Center Zhupa	Mother	42	Unemployed	Low	Female	12
12	Debar	Mother	31	Unemployed	Good	Male	5
13	Center Zhupa	Mother	47	Unemployed	Average	Female	17

RESULTS

Experiences, attitudes, adaptation styles

Based on the results collected from interviews conducted with parents of children with special needs, we analyzed emotional experiences when they have learned their children's diagnosis. From the table we can see that 61.5% of parents have experienced excessive anger, 30% have reported a lot of anger and 7.7% have experienced a normal level of anger; while 46.1% have experienced excessive pain, and 53.8% have experienced a lot of pain; likewise, 53.8% have reported excessive fear, while 38.4% a lot of fear; excessive frustration is reported by 38.4% of the parents, while a lot of frustration by 23%. Regarding the level of denial of the information about their children, 61.5% of parents report a high level of denial, while an excessive level of denial was reported by 30.7%. As of loneliness, 53.8% of parents have felt very lonely, 23% have reported excessive loneliness, and 15.3% have felt a little lonely in the period of diagnosing their children. Based on the table below and the results, we can claim that anger, fear, pain, and denial have been the strongest emotions which are experienced by parents of children with special needs when they have learned their child's diagnosis.

Table 2. The percentage of emotions when learning the diagnosis of their children

No.	Not at all	A little	Normal	A lot	Excessive
1.Anger	0 %	0 %	7,7%	30%	61,5%
2.Pain	0%	0%	0%	53,8%	46,1%
3.Fear	0%	0%	7,7%	38,4%	53,8%
4.Frustration	0%	23%	15,3%	23%	38,4%
5.Denial	0%	0%	7,7%	61,5%	30,7%
6.Loneliness	0%	15,3%	7,7%	53,8%	23%

a). What was your reaction when you first learned about your child’s diagnosis, describe how did you feel?

The data analysis regarding when parents have first learned about their child’s diagnosis shows that 85% of parents have felt really sad and angry, as well as a large number has denied this information and it has been the most difficult moment they have experienced. These are some of their responses.

“I felt very bad and experienced great anguish, says a mother, she says that she, as a mother, and her husband have felt really bad and was hard to believe that we found ourselves in this situation, it was hard to believe and we couldn’t accept the fact that our son is not as the other children. I was extremely angry at that moment, my soul was in huge pain, fear, I was thinking of how will my child face with that kind of life, what will his future be, and this was destructive for me” (5, Mother, Debar).

“I have felt really bad, me as a father, as well as my wife, have experienced our son’s situation very badly, we have faced many difficult situations, I don’t know how to describe how difficult it was for us as parents, I felt a lot of anger, pain but I was still trying to keep myself together since it was my son who needed my time” (3, Father, Debar).

“When I first learned the diagnosis, I felt very bad, my anger was beyond limits, enormous anger, those were unanticipated moments and every day, even today, I am worried, I bear a huge worry in my soul and it hurts every day” (4, Mother, Debar)

b). What do you recall during this period, what were the accompanying feelings, what did you do, who did you contact (in the first days, the first month, continuously) what were your needs?

The data analysis showed that around 63% of the parents have first contacted their spouses and then their relatives, that they have been quite stressed out and upset and some of them have even cried denying this fact. This is how some of them describe it:

“I contacted my husband first, I remember noticing some behavior of Nadire and Nazmije, as they are twins. My daughter Nazmije seemed not focused appropriately, which made her different from my other daughter Nadire. We discussed this first with my husband and then with our relatives. We were very upset and I have gone through all this crying, but it was all in vain as nothing was changing” (11, Mother, Centar Zhupa).

On the other hand, about 30,7% had contacted their close family members as they had a profound need and this had caused them a lot of stress and great pain accompanied by crying whenever they had talked about their children, and some parents said:

“Regarding this period, I remember that I just needed to talk to someone, to tell the plight that I was facing with, it was very difficult for me and my husband, I contacted my parents and I told them about my plight, I cried hard every time I was mentioning it, I had a profound need to cry to free my soul from this pain that had rapt me and my family” (5, Mother, Debar).

“I remember many, many things during this period, many things that bother me and remind me of that time which I had a hard time coping with, I was very upset and lonely, I did not know what to do, I contacted my family who have supported me immensely, as it was a very difficult situation for me, which had gripped me and stressed me a lot, I did not know what decision I should make” (1, Mother, Debar).

c). How did you perceive it, what was the meaning of the diagnosis, what diagnosis did they show to you? Did you require further information regarding this diagnosis, if yes, which resources did you obtain this information from?

The interview analysis shows that about 85% of the parents have learned the diagnosis of their child from the medical staff, but they have required information from different doctors, read different literature, but also searched the internet. Here are some responses:

“I asked for help from people who are adequate for these children, I contacted a special educator, speech therapist, various doctors, I experienced my child’s diagnosis very badly and we found out all this from the medical staff, it was very painful when I heard that my child suffers from autism. As a mother, with the support of my family and my husband, I never stopped looking for help, information, I was reading on the internet hoping that I will find the best way to help her, my hopes were many and even today I still hope that one day she will get even better” (5, Mother, Debar).

“We asked for help from medical staff, i.e., specialists, we did the impossible, the doctors began to calmly explain what is going on with our child, but it was still very upsetting for us. I found different information from the internet, from different books and from the information I gathered, I learned a lot, I tried to be stronger and more stable as a massive challenge in life awaited me” (6, Mother, Debar).

While 15% of the parents said that they knew their child’s diagnosis and did not ask for information from different doctors. They expressed the following:

I knew the meaning of the diagnosis because, from the day I gave birth in Skopje, the doctors (pediatricians) told me that my child is not like the rest and has mental issues but he also has a disability, this was a shock for me, crying accompanied me everywhere, it was a very bad moment to the extent that I do not know how to describe it, everything was over for me, my hopes for life were lost, I could not find peace, I could not sleep, so everything bad had gripped me” (1, Mother, Debar).

d). How did you adapt to the new situation, what were the ways you used to handle this situation, what means did you use to overcome this issue?

Data analysis showed that about 69% of parents had difficulties adapting to the new situation, coping difficulties since they did not know how to behave and help their children to overcome these difficulties as easier as possible:

“For me, as a single mother, since I am divorced, I felt very bad, extremely lonely, unprotected, I lacked my husband’s support, and my son did not have his father’s support (cries out), because my son was the only thing I have in my life. I had faced many difficult situations, above all, I decided to be strong and devote all my attention to my child since he was my only one. I also used all the techniques and methods that I received from the doctor, just as various literature related to my son’s illness, which helped me” (8, Mother, Debar).

“In the beginning, it was quite hard and difficult for me when I learned about it, I was trying to calm myself down because I needed a lot of courage, now I deal with my daughter, since I was not able to provide everything as we were in the village and the economic living conditions were difficult as my husband is the only person working and we only provided the medication recommended by the doctor, so this situation was very difficult for me as we live in a place where the mentality is very limited and society is very prejudiced, do not understand the problem you have and this has made the situation more difficult for me –to have a daughter with disabilities in this place” (13, Mother, Centar Zhupa).

While about 30% of the parents, i.e., the fathers, stated that this was a difficult situation for them, it has been much more difficult both physically and mentally for their wives since they have been at work and the entire burden of taking care of the child has fallen on their spouses. Here are some of the responses:

“The adaption was very difficult for me as a parent, but mostly for my wife who had to stay with our son all the time, to deal with him, to help him in every step, we would take our son and play with him, take him outside and since he was three years old, we also sent him to kindergarten, and my wife had to deal with all this as I was very busy working” (9, Father, Debar).

“At first I could not believe that my family had to face this difficult situation, for us it was very shocking, tense and hard since I was at work and the whole burden fell on my wife, she got different information from the internet, literature, consulted doctors who prescribed different medications, so the most exhausting situation was on my wife, who took care of everyone” (3, Father, Debar).

e). What have been the resources and coping strategies, support systems? What is the most difficult challenge you face at home?

The analysis of interviews conducted with the parents of children with special needs shows that about 62% of the parents found support in the immediate circle of the family, who were there for them, i.e., the in-laws of both spouses, while the most difficult situation the parents have faced has been when their children have become aggressive, nervous and when the child could not meet personal needs without the parents' help, and all these have been very difficult for the parents and accompanied by crying out. This is how some parents expressed themselves:

“I had great support from my family who gave me a lot of courage and willpower, they have supported me whenever I needed but I still had an emptiness in my heart. Thus, I have support from both families, my husband's and mine. The most difficult challenge we had at home was when the child has personal needs that he cannot meet on his own and always needs help and then I feel difficulties because the boy is growing up and I feel an indescribable worry, I wish nobody faces this” (8, Mother, Debar).

“The support from the family has been enormous; we have put much effort into facing this situation. Everyone has supported me, especially family members who have given me hope and courage. My biggest challenges were when my son showed aggressiveness and nervousness, particularly when was the time to give him the medicines, and sometimes I have cried with him” (6, Mother, Debar).

About 38% said that the resources and coping strategies have been the motivation and hopes they had thinking that one day it will get better, so their strength has been what has accompanied them, so as the great hope that everything will be fine. Here is how some of the parents expressed:

“The motivation, the hopes that one day it will be fine have been my thoughts and strength, I have had support from the daughters who have supported me the most. The biggest challenge for me is when my son needs to meet personal needs and he needs my help” (1, Mother, Debar).

“My motivation and strength were the coping strategies and resources and gave me the strength for me so the child would have maximum support from us as parents. The most difficult challenge is him ignoring the food and being focused only on certain foods and only wants that” (9, Debar, Father).

DISCUSSION AND CONCLUSION

As discussed previously (Deault, 2010; Multhauf et al., 2016; Vernhet et al., 2019) current findings contribute to our knowledge about parents' emotional experiences when learning the diagnosis of their children with special needs. The study finds that parents of children with special needs have experiences excessive anger, pain when learning their child's diagnosis, with this being the most difficult moment of their life for them, where they emphasize that having a child with needs special is not easy, both for the parents and the family, thus the pain, fear had gripped them completely, they always recall the moment when they learned the diagnosis. Their reaction and difficulties were inevitable and this has been very difficult for the family, particularly parents. The needs they had were many, but they emphasize that for them this was unbelievable until they went to the clinics asking for a specialist to prove what they need because for the parents this was *hard to believe*. The diagnosis, as well as the period after it has been very difficult for parents and has often been accompanied by crying, the feeling of something unexpected, despair, doubt, fear, guilt, as well as rejection of the diagnosis. Most of the parents emphasize that they understood the diagnosis from the doctors, and the despair has been even greater with its confirmation. They emphasize that even after that they never stopped looking for help, they read different literature, information from the internet to get to know more about this and so the help they need to provide for their children is easier and more productive. The parents adapting to their children has been very difficult both for the parents and the family; at the beginning, this has been very stressful and they emphasize that they didn't know what to do in such a situation, they have become very much attached to their children with the idea of devoting maximum time to them, they have tried to make them happy to determine what do they like and dislike, in other words, they have tried to enter their children's soul (Heiman, 2002). Various studies have shown that parenting a child with special needs comes at a high emotional, financial and familial cost (Craig et al., 2020; Hayes & Watson, 2013). Moreover, the parents say that what gave them strength was the motivation and great hopes they had for their children that one day they will see improvements as the rest, although the success has been small (Dobson, et.al 2001). The prospect of lifelong parenting to children with special needs is accompanying with increases psychological difficulties and pressure experienced by the parents and is likely to shape their perception of parenting and of the entire family's future (Bekhet, 2018; Karst & Van Hecke, 2012).

- The parents of children with special needs have experienced the diagnosis of their children very badly. This has been a very difficult moment for them. The children's diagnosis might be accompanied by parents' denying it.
- The period after the diagnosis has been very tough for the parents, and they recall it as the most difficult moment. Mothers experience it very badly, accompanying it with pain, anger, fear, and sometimes they even feel guilty.
- They have learned the diagnosis by the doctors and most of them have later looked for different information from various sources.
- The parents' adapting has been very hard in the beginning, they mostly perceive their partners as their greatest strength to adapt to the situation. The fathers have reported that mothers have borne the heaviest burden in terms of taking care of their child.
- The biggest challenge of the parents has been not knowing how to behave with their children. While motivation and hope have been the best coping mechanisms they have used.

REFEREFNCES

1. Barnett, D., Clements, M., Kaplan-Estrin, M., & Fialka, J. (2003). Building new dreams: supporting parents' adaptation to their child with special needs. *Infants and Young Children, 16*, 184-200.
2. Bekhet, A. K. (2018). Depression, Positive Thinking, Personal and Social Resourcefulness among Caregivers of Persons with Autism Spectrum Disorders. *Archives of Psychiatric Nursing, 32*, 823-827. <https://doi.org/10.1016/j.apnu.2018.06.006>
3. Craig, F., Savino, R., Fanizza, I., Lucarelli, E., Russo, L., & Trabacca, A. (2020). A Systematic Review of Coping Strategies in Parents of Children with Attention Deficit Hyperactivity Disorder (ADHD). *Research in Developmental Disabilities, 98*, Article ID: 103571.
4. Deault, L. C. (2010). A Systematic Review of Parenting in Relation to the Development of Comorbidities and Functional Impairments in Children with Attention-Deficit/Hyper-activity Disorder (ADHD). *Child Psychiatry & Human Development, 41*, 168-192.
5. Dobson, B., Middleton, S., & Breardworth, A. (2001). *The impact of childhood disability on family life*. New York: Joseph Rowntree Foundation.
6. Gallagher, P. A., Fialka, J., Rhodes, C., & Arceneaux, C. (2002). Working with families: rethinking denial. *Young Exceptional Children, 5* (2), 11-17
8. Hayes, S. A., & Watson, S. L. (2013). The Impact of Parenting Stress: A Meta-Analysis of Studies Comparing the Experience of Parenting Stress in Parents of Children with and without Autism Spectrum Disorder. *Journal of Autism & Developmental Disorders, 43*, 629-642. <https://doi.org/10.1007/s10803-012-1604-y>
9. Heiman, T. (2002). Parents of children with disabilities: resilience, coping and future expectations. *Journal of Developmental and Physical Disabilities, 14*(2), 159-171. <http://dx.doi.org/10.1023/A:1015219514621>
10. Karst, J. S., & Van Hecke, A. V. (2012). Parent and Family Impact of Autism Spectrum Disorders: A Review and Proposed Model for Intervention Evaluation. *Clinical Child and Family Psychology Review, 15*, 247-277 <https://doi.org/10.1007/s10567-012-0119-6>

11. Lowes, L., & Lyne, P. (2000). Chronic sorrow in parents of children with newly diagnosed diabetes: a review of the literature and discussion of the implications for nursing practice. *Journal of Advanced Nursing*, 32 (1), 41-48.
12. Multhauf, B., Buschmann, A., & Soellner, R. (2016). Effectiveness of a Group-Based Program for Parents of Children with Dyslexia. *Reading & Writing*, 29, 1203-1223. <https://doi.org/10.1007/s11145-016-9632-1>
13. Peer, Justin W.; Hillman, Stephen B. (2014). "Stress and Resilience for Parents of Children With Intellectual and Developmental Disabilities: A Review of Key Factors and Recommendations for Practitioners." *Journal of Policy and Practice in Intellectual Disabilities* (2): 92-98.
14. The IRIS Center. (2008). Collaborating with families. Retrieved from <https://iris.peabody.vanderbilt.edu/module/fam/>)
15. Vernhet, C., Dellapiazza, F., Blanc, N. et al. (2019). Coping Strategies of Parents of Children with Autism Spectrum Disorder: A Systematic Review. *European Child & Adolescent Psychiatry*, 28, 747-758. <https://doi.org/10.1007/s00787-018-1183-3>.