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Perception about autism among parents with autistic child: Qualitative study

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Abstract

The goal of this study was to determine how parents with autistic children felt and thought. The participants in this qualitative study are four parents. The data gathering tool was demographic data, with the theme being their feelings and how they are dealing with situations in their daily lives. The majority of the parents stated that they had little knowledge of autism, its causes, or how to handle the illness. They stated that they had a lot of difficulties with the children because of the autism, and they didn't know whether or not to seek medical help. Parents believed the disease was curable until they learned it was not and that they should manage their lives with their autistic child rather than accept it. Parents have expressed concern that while they are currently caring for their child, who will care for the child once they are gone is their greatest concern.

Keywords: autism, autistic child, neurobiological

Introduction

Autism is a neurobiological defect that manifests before the age of three years and has a significant impact on social interaction, communication abilities and other cognitive functions [6]. Boys are four times more likely than girls to have autism spectrum disorder, which affects one in every 150 children [2]. The family is one of the most important environments in the growth and education of a child. The addition of a new-born to a family alters the current dynamics and way of life of the family. Families go through a period of adjustment to their new situation, which can be tough and unpleasant for all family members, especially mothers, especially if the infant has special needs. When parents first receive the news, they may suffer sadness, bewilderment, sobbing, confusion, unwillingness to accept, shock, helplessness, fear, and frustration [7].

The child's autism diagnosis may have an impact on the entire family's life and generate stress among family members. Parenting an autistic kid can have a significant impact on a family's psychological well-being, particularly if it causes issues in the mother's employment and social relationships [4]. Families may require educational, psychological, and social assistance for themselves and their children, as well as struggle to overcome their unfavourable ideas about autism. A difficult adaptation time is in issue, particularly for families of autistic individuals with autism's specific difficulties (for instance; intense behavioural problems).

During this time, family members attempt to cope with negative feelings such as acute worry, burnout, and future fears, as well as a variety of challenges (such as obtaining educational support and explaining ASD to others)[8]. The purpose of this qualitative research was to uncover the thoughts, feelings, and problems of families with autistic children.

Material and Method

The study was qualitative in nature and was conducted at Muhayil city (Saudi Arabia) private educational institutions. The study's universe consisted of parents who lived in Muhayil and had at least one autistic child. According to the notion of "data saturation," the study sample contained four parents with varying levels of education, social and economic factors.

One-on-one interviews with parents who volunteered to participate in the study were conducted using a "Personal Information Form" and a semi-structured "Guide Interview Form." The "Personal Information Form" included sociodemographic characteristics of the

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parents in the study (age, education levels, occupations, socioeconomic status, and number of children, marital status, kinship status, family type) as well as some features such as the autistic child's sex and age of diagnosis. Interviews were conducted in the private education school's parent's room. This location was favoured since it was where individual teacher-parent interviews took place, where they felt comfortable and protected, and where there was no one else in the room. In this way, a conducive environment was created for parents to provide accurate, full, and sincere responses during the interviews. The purpose of the interview was first explained in the setting in which it would be conducted. Parents were told

about the interview's potential duration and confidentiality, and their consent was obtained. Before beginning interviews, the parents filled out personal information forms. Parents were given the opportunity to describe their perspectives in detail during the interviews using qualitative interviewing approaches. To avoid interrupting contact with the parents, observational notes were gathered regarding their responses and behaviours. The interviews with each parent lasted between 20 to 30 minutes. When the same statements were made by all four parents, the interviews were ended.

Results

Table 1: Demographic characteristics of the parents

Characteristics	n
Education status of the mother	
Elementary school	1
Middle school	1
High school	1
University	1
Education status of the father	
Middle school	1
High school	1
University	2
Occupation of the mother	
Housewife	3
Officer	1
Occupation of the father	
Officer	3
Worker	1
Socioeconomic status	
Income is equal to the expenses	2
Income is more than the expenses	2
Number of children	
1	-
2	-
3 & above	4
Kinship status	
Yes	4
No	0
Family type	
Large family	3
Nuclear Family	1

Table 1 shows the demographic data of the parents with autism, majority of the parents were educated, economic status were good,

living in the large family.

Table 2: Theme

S.NO	Theme
1	The feelings of the parents when they first heard about this condition (autism) of the child
2	What kind of problems parents experienced during the care of the children
3	Can you tell the way that your children communicate with you and others in the family
4	How your child maintain relationship with others
5	When you feel very connected to your child
6	How is your relationship with your autism child different from your other children
7	What advice would you give to other parents
8	What type of emotions the child shows when you are not understand their communication
9	Tell about their understanding about the basic instructions given to the child
10	How do you feel when you are taking your child outside

Theme: 1 the feelings of the parents when they first heard about this condition (autism) of the child

1. I was devastated, and it was difficult for me to comprehend and accept the fact that my baby has autism. My wife and her family have had no idea how

to cope with him until now. I'm his father, and I'm also his mother. (Father is 52 years old and has four children).

2. At first, this disease had a huge impact on me. Even I couldn't accept it and said it was impossible. When I

initially learned of the diagnosis, I thought I was alone in the world, and I still feel that way. (Father is 55 years old and has 5 children).

3. When he was diagnosed with autism at the age of six months, I felt a mixture of rage and denial. This was a difficult thing for me to accept. I was depressed and had never heard of autism. I've been struggling on the inside till I accept this reality. Later, I consult with a psychiatrist and a doctor who specializes in treating children with autism. He explained the situation to me and helped me comprehend it. He also stressed the importance of the parent's involvement in helping the child act normally. We began treatment; he experienced drug adverse effects, but the treatment enabled him to return to school. He started school at the age of nine, in the same class as his younger sister. His sister assisted him in playing and studying with other children (Mother is 38 years, 6 children).
4. I was devastated when I first learned. We were obliterated. I couldn't acquire it for my child in any way, and it took me and my husband a long time to realize that he was autism (Mother is 35 years, 4 children).

Theme: 2 what kind of problems parents experienced during the care of the children

1. It takes all of my energy to find out how to get my son to look at me and communicate, and I spend the most of my time with him, assisting him in speaking, cleaning, eating, and standing up for himself. He is presently doing well in school, receiving special education, and is in the fifth grade. (Father is 52 years old and has four children).
2. I have issues with his fundamental needs, such as eating habits and nail clipping. We used to trim it while he was sleeping, but now we do it while he is awake. However, we continue to have issues with his eating habits, housekeeping, and concentration. (He like tea and massage, and he feels quite secure when his father massages him, therefore he enjoys his phone and YouTube.) He used to be unconcerned about people, but now he gives hugs and kisses, and when he sits with me, he makes eye contact. (Father is 55 years old and has 5 children).
3. Society is the major issue. My child being bullied at school, which is having a negative impact on him right now. I sincerely hope that online education will continue to exist in the future. However, I always encourage him, and I informed my son that because he is smarter than his peers, they are jealous of him. (38-year-old mother with six children).
4. At the age of three, he abruptly stops talking and playing with his siblings, and he has no idea what his name is when we call him. (35-year-old mother with four children).

Theme 3: Can you tell the way that your children communicate with you and others in the family

1. He communicates with us by talking, although he is sometimes unable to recall the names of certain products. He also communicates well with his other family members.
2. When he wants tea, he takes his mother's hand or his sister's hand and leads them to the kitchen; if he needs

anything, he gestures to it and bites them if they don't understand him. He uses sign language to communicate.

3. He can converse with other members of his family as well as school friends, but he always speaks loudly and becomes irritated if we do not understand what he is saying.
4. He refuses to speak verbally. He didn't know the names of the objects he wanted, so he simply pointed them out and asked for what he wanted. He doesn't know how to call me; instead, he grabs my hand and points to the items he desires.

Theme 4: How your child maintain relationship with others

1. He maintains positive relationships with people and enjoys playing with his siblings and other family members.
2. He is unconcerned about others, has no intention of harming anyone, and will flee if the door is opened. He sometimes screams at other family members who are terrified of what he is doing.
3. He enjoys playing and swimming with other members, and he appreciates and is happy when he goes swimming.
4. He does not converse with others and is always playing with himself; if any of his play items are grabbed by another sibling, he takes the stuff from them right away. He always takes things off the shelf and has no idea what they're called or what they're for.

Theme 5: When you feel very connected to your child

1. When I teach him and assist him with his homework, I feel connected to him. He also got more receptive to rewards. He liked going out with me and swimming. He does not react well to aggressive individuals; he expects everyone to treat him with respect; if he is spoken to loudly, he becomes enraged and bites the people.
2. When I play with my child and give him cuddles and tickle him, I feel more connected to him. I also feel really calm when I give him a massage. Furthermore, he enjoys drinking tea and makes us feel quite happy when we do so with him.
3. I am concerned about his condition when he becomes enraged and shouts at everyone. So I always backed him up and talked to him softly, handled the matter well, and he used to be extremely happy and at ease with me in comparison to his other family members.
4. When he wants something, I can tell he's connected to me, and when I give him hugs, he makes eye contact with me. I used to obtain more of the foods he enjoys because he expresses his happiness by eating more of them, and I, too, am happy to see him.

Theme 6: How is your relationship with your autism child different from your other children?

1. Because I know he's different, he's always with me so I can keep my eyes on him and help him grasp the world. I assist him in all aspects of his daily activities and play.
2. He is the family's final kid, and because of his condition, all of his family members support him in any way they can. His siblings also play with him to help him comprehend other aspects of life. We are making every attempt to help him learn how to live a good life.

3. He is a hard worker who needs to be rewarded in order to be motivated. As a result, everyone in the family began to encourage him to study and participate in each activity. If he's pleased, he'll listen to us and grasp what we're saying, and he'll learn quickly.
4. I kept a constant eye on him and checked on his requirements because he is different from his siblings in that he is unable to perceive danger and is unable to communicate. His siblings assist him in all of his daily duties.

Theme 7: What advice would you give to other parents?

1. Parents should assist their children and provide them time to study and grow while also involving them in activities.
2. Parents must accept their children's situation and accept reality.
3. Parents should seek early intervention and not dismiss the issue. They should assist their children in receiving an education.
4. I advise parents to keep an eye on their children and to intervene early if they spot any autistic symptoms. Unfortunately, I realized my child was not smiling or crying at 6 months, but I ignored all of the signals until it was too late.

Theme 8: What type of emotions the child shows when you are not understand their communication

1. He gets angry when we do not understand him
2. He gets angry and bite us when we do not understand him.
1. He insisted to explain for us what he wanted until we understood. Even if we pretend that we do not understand him he explained and insist on demand
3. He gets angry and screaming if we do not understand him.

Theme 9: Tell about their understanding about the basic instructions given to the child

1. He is good in understanding basic instructions and can speak and understand
2. He is good in understanding basic instructions. He knows Do, Do not do, Yes, No.
3. He is good in understanding basic instructions
4. He can understand basic instructions if we use with him sign language.

Theme 10: How do you feel when you are taking your child outside?

1. Yes, I used to take him outside to play because he enjoys being outside, so I kept him with me the entire day. He enjoys swimming with me, his brothers, and uncles. In addition, he has a gym membership. My greatest fear is who will look after him after I die?.
2. He enjoys going out. He enjoys being outside with others, yet he refuses to play in the park with other children. He like to spend time with his siblings but not with other family members.
3. He enjoys going to the park to play. He may play with other children at times, but he also enjoys playing alone, so his siblings may join him depending on his mood.
4. When we take him outside and he stops screaming and weeping, he is delighted. He enjoys playing in the park

with his sibling, having automobile toys, and seeing the vehicle; he used to be happier in the outdoors than in his home.

Discussion

While the majority of the parents in the study expressed their dissatisfaction when learning that their child was autistic, some parents stated that they knew nothing about autism and assumed it was a temporary condition, while others expressed shock, collapse, and disbelief that their child had such a condition.

Despite the fact that some of the parents in the survey claimed to know nothing about autism and believed it was a transient disease, the majority of them exhibited significant displeasure, uncertainty, despair, disappointment, non-acceptance, and shock. Families have expressed worries over not knowing what to do. All of these emotions could be a result of their dread of the unknown.

Families experienced sadness, despair, and worry when they were first diagnosed with autism, according to a study by Üstüner-Top^[9]. In a study conducted by Bilgin and Kucuk^[2], nearly half of the moms stated that they were concerned about their autistic kid and that they were stressed. They claimed that they had been unhappy, that they didn't know how to deal with the circumstance, and that they believed it was a treatable ailment. They stated, however, that they felt terrible when they found that it was not a transient ailment and that it was causing them problems. The majority of the moms stated that they could not accept this scenario at first, but that as they met the families of other autistic children in the education facilities, they began to accept it. Gürel-Selimolu, Ozdemir, Töret, and Ozkubat^[5] found that when their children were first diagnosed with autism, they experienced great sadness, obscurity, crying, uncertainty, non-acceptance, shock, despair, and worry in their study with the parents of 50 autistic children. Similar studies exist in the literature, and when a diagnosis was first delivered, families expressed shock, non-acceptance, denial, and negative attitudes^[1,3].

The majority of the parents in the research stated that they had no idea what would happen to their child if they died, and that they believed no one would care for them; they also expressed their anxieties and fears about how their children would continue their lives. Fears of parents can be explained by the fact that they cannot receive enough aid even when they are living, and they believe that no one will adequately care for their children if they die.

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