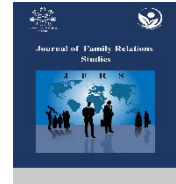




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Research Paper

Ground theory about the psychological reactions of fathers to the diagnosis of autism in their children



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ABSTRACT

Objective: The purpose of this research was to present an explanatory theory about the psychological reactions of fathers to the diagnosis of their child's autism.

Methods: The method of this research is qualitative and grounded theory type. The statistical population of this research is fathers of children with autism spectrum disorder with average functioning. 6 participants were selected by theoretical sampling method and based on theoretical saturation. The data collection tool was a semi-structured interview that was conducted face-to-face. In order to analyze the data, open codes were first extracted from the text of the interviews, and after summarizing, removing and merging the open codes, central codes were extracted. Then, by classifying and summarizing the categories and finding major connections between the categories, selected codes were obtained.

Results: 21 categories and 6 themes were identified, based on which a three-stage paradigm model including diagnosis, reaction, and post-reaction stages was presented. The 6 extracted subjects are in these stages.

Conclusion: Although most fathers accept the issue of autism in their children, this acceptance is mainly due to coercion. This issue doubles the necessity of designing appropriate interventions to prevent psychological injuries and maintain marital and parenting abilities.

1. Introduction

A feeling of joy usually accompanies the birth of a new child; however, when a child is diagnosed with a disability, all the expectations and hopes that parents have for having a healthy child are challenged (Bujnowska et al., 2021). Since any pain or problem that children feel deeply affects parents, it is quite understandable that the diagnosis of a child's disability can be very worrying for parents and be stressful (Krstić, Mihić, & Branković, 2021). In addition to the usual demands of parents, these parents must also fulfill the duties and responsibilities arising from the child's condition, which undoubtedly affect well-being, parent-

child interactions, and family relationships (Barak-Levy & Atzaba-Poria, 2020). Parents of children with disabilities are prone to feelings of shame, guilt, sadness, anger, and despair, and in addition to showing persistent symptoms of depression and psychological problems (Krstić, Mihić, & Branković, 2021), they portray a distorted view of their child's abilities (Barak-Levy and Pariente, 2023).

Meanwhile, autism spectrum disorder is a lifelong neurodevelopmental disability that is characterized by persistent and pervasive disorders in understanding and social communication, poor adaptive functioning, and

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limited or repetitive behaviors and interests (Papadopoulou, 2021). Current epidemiologic studies have shown an increase in the prevalence of autism spectrum disorder over the past two decades, and according to estimates by the Autism and Developmental Disabilities Network, the current prevalence is 1 in 54 children in the United States (Maenner, 2020). In recent years, due to the increase in awareness about autism, the prevalence of autism in other parts of the world has also increased rapidly, and as a result, the probability of diagnosing this disease is increasing. However, raising a child with autism spectrum disorder is a stressful and challenging experience, especially in countries where support services are limited (Shattnawi et al., 2021).

The reaction of these parents to the diagnosis of their child as a child with autism spectrum disorder has been discussed in the theoretical literature. Over time, researchers developed the concept of "resolution" by recognizing the child as a process of acceptance, the end of active grieving, and a refocusing on present and future realities (Barak-Levy & Paryente, 2023). This is despite the fact that parents who could not "resolve" this issue were involved in continuous mourning (Reed et al., 2019) and were more depressed and stressed than parents who had recovered (Sher-Censor et al., 2017).

The research literature shows a relatively large number of parents who are well adapted to the issue of having a child with autism and who function effectively, but at the same time, a number of parents have difficulty achieving acceptance (Barak-Levy & Paryente, 2023). Parents who have accepted their child and so-called come to terms with this issue support their child's performance and show better quality of parenting, secure attachment of the child to the parents, constructive social life, etc., but parents who could not show a favorable psychological reaction to the child's diagnosis of autism, inadequate coping strategies, poorer health, passive and angry social interactions, false beliefs about the child's diagnosis and a situation that may lead to inadequate or inappropriate decision making (Sher-Censor et al., 2017).

A review of research literature shows that most studies in this field focus on the psychological reactions of mothers of children with autism. For example, the qualitative research findings of Gobrial (2018) on Egyptian mothers of children with autism spectrum disorder showed that the diagnosis of autism has a negative effect on the social life and mental health of these mothers. In addition, taking care of a child with autism increased the stigma of mothers and their children. In this regard, Ferenc, Byrka & Król (2023) also believe that mothers' attitudes towards their children's autism may play a role in mothers' psychological well-being. Also, research shows that

financial concerns, such as economic burden and the need for additional income to cover the high lifetime costs of special education and treatment associated with autism spectrum disorder, are important factors that increase parental fatigue, especially for low-income families help (Güçlü & Hürmeydan, 2024).

Although extensive studies have been conducted on the consequences and challenges of the presence of a child with autism spectrum disorder for the mothers of these children, the psychological reaction process of fathers after the diagnosis of autism in the child has not been given much attention (Fauziah, & Indrawati, 2024). This is despite the fact that, according to Opoku et al. (2024), due to the key role of fathers in support, self-care training, financial support, and education of ASD children, their active participation in raising these children has positive effects on cognitive, social and emotional development.

Having a father's perspective can provide insight that informs psychologists and psychiatrists about resilience, family and childhood development, and the positive aspects of parenting. Based on this, the aim of this research is to qualitatively explain the psychological reaction of fathers of children with autism spectrum disorder using the ground theory method.

2. Materials and Methods

The method of this research is qualitative in terms of the type of data, which was done with the grounded theory method. In this method, a theory is extracted from multiple data sets, and the detailed interpretation and analysis of the data are of particular importance for formulating the theory (Strauss and Corbin, 2015). In other words, by regularly collecting and analyzing data, a series of categories and themes are extracted, and by establishing a logical connection between them, it is possible to explain a phenomenon and present a theory. The statistical population of this research is fathers of children with autism spectrum disorder with average functioning. 6 participants were selected using theoretical sampling based on theoretical saturation. Theoretical sampling is a method for collecting data for theorizing, in which coding and designing the questioning method to continue the path are done at the same time. That is, in each step, while analyzing and coding the data, the researcher identifies clues to continue the process of questioning and data collection. Since theoretical saturation is more important than the number of samples in qualitative research, network sampling was continued until theoretical saturation and the necessary sufficiency to formulate the theory. The demographic characteristics of the participants are given in Table 1.

Table 1. Demographic characteristics of the participants

	Father's age	Education	Number of children	Autistic child's birth order	Autistic child age
1	38	Masters	1	First	13
2	45	Masters	3	Third	12
3	46	Diploma	1	First	15
4	33	Masters	1	First	8
5	50	Masters	2	Second	14
6	42	Masters	1	First	12

The data collection tool was a semi-structured interview conducted face-to-face at the school for autistic children. The questions of the interviews were designed according to the available scientific sources and based on the opinions of experts. In the interviews, to get to the core of the issues and understand all aspects of the issue, the fathers were allowed to talk about all the details and express their feelings. Sometimes, the interviewees became very emotional, but the researchers did not limit them. With the prior knowledge of the interviewees, the interviews were recorded to guarantee the reliability of the data and to have access to the interviews at any time. Finally, the interviews were handwritten, and the desired codes were extracted in three steps.

- Open coding: First, everything possible was extracted from the text of the interviews as open codes.

- Axial coding: regardless of the main text of the interview, open codes were extracted only by classifying and summarizing them and finding the connection between them. By removing some codes and merging some of them, categories or core codes were extracted.

- Selective coding: Again, by classifying and summarizing the categories and finding the major connections between them, themes or the same selected codes were obtained.

To increase the validity of the data, the extracted codes from each step were checked again with the previous step. All the codes were reviewed by the researchers in a two-way round trip between classes and sub-classes, and the final categories and themes were reviewed by several university professors and researchers.

Table 2. Semi-structured interview questions with fathers of children with autism spectrum disorder

1. When did you find out that your child has autism spectrum disorder?
2. What thoughts and feelings did you have in the first moments after learning about this issue?
3. After being diagnosed with autism, did you have any negative emotions such as guilt or remorse?
4. What are your dominant feelings and emotions in the process of raising a child?
5. As a mother/father of a child with autism, what worries about the child's future occupy your mind?
6. Have you coped with a child with autism spectrum disorder as a fact of life? Why and how?
7. Has raising a child with autism spectrum disorder caused psychological pressure in your daily life? If the answer is positive, what factors and dimensions have caused psychological stress?
8. Are there things in your life that you can help with this stress?
9. What are the difficulties and difficulties of raising a child with autism spectrum disorder?
10. Have the problems and issues raised had an impact on your relationship with your child? / Explain.
11. What are your reactions to the child's behavioral or social problems?
12. What effect has the birth of a child with autism spectrum disorder had on your relationship with your wife?
13. What is your feeling and experience of raising and educating a child with autism spectrum disorder?

All the participants of the present study participated in the study with full consent. Before starting the interviews, all the participants were given full explanations about the objectives of the research and they were free to withdraw from the research process at any time. They were also assured that their personal information would be completely confidential and only some general information would be used for research purposes.

3. Results

In the current research, after collecting data from semi-

structured interviews with 6 fathers of children with autism spectrum disorder, coding and then analyzing them into 6 themes (selective code) and 21 categories (core code) was extracted, which is specified in Table 3. According to Table 3, which shows the themes and categories extracted from data coding and analysis, we continue each of the underlying themes and categories along with statements and documents from the participants, and at the end We present a paradigm model of the process of parents' psychological reactions to the diagnosis of autism in their child:

Table 3. Themes and categories resulting from the coding of semi-structured interview data

Themes (selective codes)	categories (core codes)
Diagnosis of autism in children	1. Unfamiliarity or incomplete understanding of autism 2. Doubts about the abnormal behavior of the child 3. Regression or lack of progress of the child 4. Referrals to doctors and psychiatrists
Denial of the child's disorder	1. Not believing in autism 2. Hope that the child will get better 3. Denial of any disorder in the child
Negative emotions and mental conflicts	1. Great and sudden sadness 2. Parental depression 3. Worrying about the uncertain future of the child 4. Guilt and torment of the parent's conscience
Individual and social limitations	1. Ignorance and misunderstanding of autism by others 2. Disconnection and limitation of interactions 3. Restrictions on parental function 4. Changing the function according to the autistic child
Support and support	1. Spouses' support 2. Support from those around you 3. Hope for the child's future
Acceptance and coping with autism	1. Accepting autism disorder in a child 2. Accepting that the child is not normal 3. Coping with the reality of life

• Diagnosing autism in a child

Unfamiliarity or incomplete understanding of autism:

In general, it can be said that there is no complete understanding of this disorder in fathers, and the lack of information in this field was evident. Some fathers had not even heard the word autism before the diagnosis. For example, sample 5 says: "We were in the city, and there a psychiatrist told us that there is a disease called autism. We had never heard this word before, and with the follow-ups, we found out that our child has autism." Also, sample 2 says: "At first, I did not know exactly about this disorder, but later, I found out about it by asking and talking to the doctor." Sample 1 also says: "Even though I was a nurse myself, I didn't know anything about autism."

Doubts about the child's abnormal behavior: When autistic children show some mysterious signs related to this disorder during childhood, parents have a lot of doubts about these abnormal behaviors, and in the end, it is these doubts that lead them to the presence of this disorder in their child leads. For example, sample 6 says: "My child used to say a number of words like daddy and such until he was about one year old, but suddenly he stopped speaking. After that, I doubted, and a sense of pessimism overcame me; after searching on the internet, unfortunately, I realized that my child has most of the symptoms of autism".

Regression or lack of progress of the child: Regression or lack of progress of the child is probably the first reason that arouses doubt in parents. This lack of progress leads them to understand the abnormal behavior of their child. For example, we can refer to the statements of sample 6 in the previous category, as well

as sample 1, which says: "From the beginning, my child did not walk, did not crawl, did not sit up, was very restless and we could not communicate with him".

Referrals to doctors and psychiatrists: Usually, many fathers continue to have doubts regarding the child's abnormal behavior, and when this doubt turns into confidence, a reliable authority such as a doctor or psychiatrist issues a diagnosis of autism in the child. For example, sample 2 says: "At the age of 3, I found out that my child has an autism spectrum disorder with a doctor's diagnosis." Example 3 also says: "We wanted to enroll our child in kindergarten, but they did not cooperate and sent us to special education, from there they referred us to a psychiatrist, and the psychiatrist diagnosed autism, and we found out that our child has autism".

• Denying the existence of a disorder in the child

Not believing the autism disorder: When fathers find out that their child has an autism spectrum disorder, it is hard for them to believe that their child has this disorder. Some fathers cannot accept this matter deeply, which is not believable to them. For example, sample 4 says: "First, when they told me that your child has autism, I didn't accept it, I couldn't accept it at all."

Hope for the child's recovery: Usually, when fathers find out that their child has autism spectrum disorder, they spend some time in a state of disbelief, still hoping that their child will return to the original state and hope for their child's recovery. Sample 4 says very clearly in this context: "I resisted for six months, and every time I said it will get better! It will get better!".

Denial of any disorder in the child: At first, when fathers are faced with an autism disorder in their child,

they deny the existence of the disorder. This issue is completely understandable, considering the awareness they gain about autism. It seems that denying any disorder is the easiest mechanism for fathers to escape from reality. In this case, sample 6 says: "I didn't feel very good, and even when I brought it up with my wife, she was in denial and didn't accept it."

• **Negative emotions and mental conflicts of the parent**

Great and sudden sadness: When parents find out about their child's autism, after a while, great sadness and sadness fills their entire being. This sadness is not temporary and is continuous. In some fathers, this grief happens very suddenly, which can be attributed to the term "shocking". But according to their father's feelings in this case, the phrase "great and sudden sadness" is a better description of their situation. For example, sample 1 says: "When I found out my child has autism, the world collapsed on me." Also, sample 5 says: "When I found out my child has autism, I thought the world was over." Example 4 says: "Autism was the scariest word I ever heard".

Depression: Usually, fathers go through periods of depression after they find out about their children's autism, which manifests itself with reluctance towards events and a lack of regret in life. Example #1 says: "I had been very depressed for a while because of my child's autism." In some parents, this depression goes as far as ending their lives and that of their children. In this case, sample 5 says: "There was a time when I was looking for cyanide to give the child to eat first and then eat it myself."

Worrying about the uncertain future of the child: Most fathers of children with autism disorder are afraid and worried about the uncertain future of their children. They have many concerns about this; what will happen to their children after them? Who will help him? Can their child live without them in the future? What happens when their child grows up? In general, how will their child's future be? Some fathers generally do not imagine a bright future for their children and are disappointed with their uncertain future. Example 2 says: "Unfortunately, I find it unlikely that these children will have the future we envision." Sample 3 says: "I think about what I should do for my child when he grows up, how he wants to live in this society."

Guilt and pangs of conscience of the parents: Guilt and pangs of conscience are very evident in parents of autistic children. On the other hand, parents' incomplete understanding of this disorder can fuel this feeling because parents may consider their own behaviors and defects to be the cause of this. However, the feeling of guilt and pangs of conscience are widely seen in parents. In this case, sample 6 says: "I had a strong feeling of guilt,

and I was telling myself, what mistake did I make? What mistake did I make that made this happen?"

• **Individual and social limitations**

Ignorance and misunderstanding of others about autism: Fathers of children with autism spectrum disorder, who have gained full knowledge of their children's disease, suffer from the ignorance of others about autism. Probably, this ignorance of others about autism causes these children not to be understood as they should be. Example 3 says: "My child does not behave normally and according to his age, and everyone who looks at him is surprised. Unfortunately, sometimes others make fun of us." Sample 4 says: "I think the biggest problem that families of children with autism have is that others do not have a complete understanding of autism; although the situation has improved a little now, this problem still exists."

Communication interruption and limited interactions: Many fathers with autistic children are forced to limit their relationships and interactions with them, and sometimes completely, due to incomplete understanding or ignorance of others and even relatives. Unfortunately, autistic fathers sometimes have to do this despite the fact that others are aware of autism because their children's parents take permission to communicate and interact with them. Example 5 says: "I used to care a lot about others and people around me, but now it's not like that, and I even broke up with some of my close friends because of this issue." Example 1 also says: "Even sometimes the people around us do things to keep us away from them, maybe these things are unwanted, but they make us not to have a relationship with them."

Limitations in the father's performance: In general, any child with a disorder can limit the performance of the parents in various areas to some extent, and this is inevitable in the case of autistic children, considering their characteristics. Their parents often have more limited functioning than other parents in many areas. In this case, sample 6 says: "We haven't watched TV for a long time now; we are very limited." Example 5 says: "Having an autistic child takes away the ability to focus on other things; when my child is with me in the store or somewhere else, I focus on him."

Changing the function according to the autistic child: those fathers who live with their autistic child have to have more limited relationships and functions. They accept these conditions voluntarily or out of compulsion, change their performance according to their child, and step on their expectations and desires. For example, sample 6 says: "In the last few years, my wife and I have defied the circumstances in such a way that the welfare and comfort of our child is a priority so that it does not break up, while we used to resist."

• **Parental support and advocacy**

Spouse's support: After fathers with autistic children find out about their child's disorder, they usually have challenges with their spouses. But with a better understanding of autism, they usually become the first supporters to cope with their child's condition. Example 1 says: "My wife is wonderful; she is a great encouragement to me." Example 4 also says: "After our child was born and we found out that he has an autism spectrum disorder, not only did our relationship not get worse, but it got better."

Support from the surrounding people: usually, after the wife, friends, and relatives provide the necessary support to the father. The first step that these people can take for the fathers of children with autism is to accept them together with their children, and the next step is to tolerate them. This is certainly valuable and encouraging for parents of children with autism. For example, sample 1 says: "After my wife, my family, especially my mother, give me a lot of encouragement and support me". Example 6 says: "Although no one will be the mother of my child, the people around me and the family are really tolerant."

Hope for the child's future: Hope for the child's future and recovery, as well as sometimes coping with the child's condition, is a huge source of support for fathers of autistic children. It can be said that hope for the child's future and his recovery is the most valuable source of support for fathers with autistic children, which calms them down and reduces the tension in their relationship with their child. In this case, sample 4 says: "I have hope for my child's recovery until the last moment of my life, and I will do everything I can for him. In general, we sleep with this hope every night." Example 2 says: "Coping with this situation is a hope, and it is important to hope for the future."

• **Accepting and coping with autism**

Accepting the child's autistic disorder: Finally, fathers with autistic children accept this disorder in their child, but it seems that this acceptance is not deep and heartfelt and is forced and imposed on them. In almost all the interviews, the fathers stated that they had no choice but to accept. For example, sample 3 says: "Is there a solution? We had no choice but to accept, we had to burn and build". Sample 2 says: "There are many restrictions for us, but we have to deal with this situation, and there is no other way."

Accepting that the child is not normal: many fathers of children with autism, in addition to accepting autism itself as a disorder in their child, also recognize the signs that distinguish the child from others and that he is not normal. They inevitably accept. They accept that their child is not normal, and naturally, they cannot treat him like normal parents. For example, sample 6, after expressing a memory about his child, says: "My wife and I accepted that our child is not normal, so we cannot be normal parents either. We understood that an abnormal child needs an abnormal parent."

Coping with the reality of life: fathers with children with autism have accepted this disorder as a part of their lives. They cannot turn back the clock of life and prevent the birth of their child. They know that what happened is beyond their will and interpret life and its phenomena as a whole with pleasant and unpleasant situations. For example, sample 4 says: "With all the problems that my child has, he also has his own sweets that fascinate us." Example 5 says: "We must accept that this phenomenon in our lives is a test and an opportunity, although it is very difficult." Sample 6 says: "We have to accept that this is a very involuntary matter and it was out of our hands."

In the following, a paradigm model is presented to explain the process of fathers' psychological reaction to the diagnosis of autism in their children.

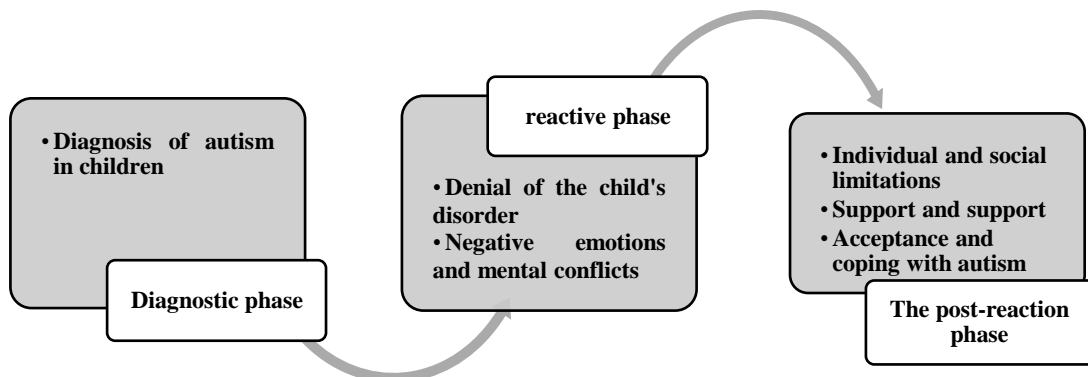


Figure 1. Paradigm model of fathers' psychological reaction process to the diagnosis of a child's autism

1. Diagnostic stage: The diagnostic stage is usually the first stage that fathers deal with. This stage includes any kind of diagnosis or doubt regarding the existence of a disorder in the child by the parent, doctor, psychologist, psychiatrist, teacher, or any other person, which initially appears due to abnormal behaviors, lack of progress, or regression of the child. At the end of this stage, a definitive diagnosis of autism is usually issued by an authoritative authority such as a doctor or a psychiatrist, and parents enter the reactive stage.

2. Reactive stage: When the definitive diagnosis of autism is issued, fathers show strong reactions that may have existed before the definitive diagnosis of autism, but after the definitive diagnosis, these reactions suddenly become more intense. They do Fathers' reactions include a wide range of anxiety, stress and worry, depression, guilt, and pangs of conscience, all of which can be summarized as negative emotions and mental conflicts. It should be noted that at this stage, fathers are psychologically extremely vulnerable and unstable and have a great tendency to use the denial mechanism. They deny any disorder in their child or prefer not to believe it.

3. Post-reaction stage: In the post-reaction stage, the intensity and tension of fathers decreases. However, fathers face individual and social limitations and support. The first support is usually provided by the spouse and then by close friends. Hope for the child's future is also a rich resource that fathers create from within as a source of support. This stage ends with accepting the autistic child and all its characteristics. This acceptance can be forced and forced, or it can happen deeply and from the heart; usually, most fathers accept the child's autism out of necessity and cope with it. At this stage, parents reach a relatively stable psychological state.

4. Discussion and Conclusion

Today, raising and educating a child with special needs is one of the most important, sensitive, and, at the same time, most challenging tasks parents face. In fact, this process requires facing complex and special situations that not only confuse parents but also involve them in many psychological harms and problems, such as communication crises and parental stress (Yaghoobnezhad, 2023). Meanwhile, the birth of a child with autism spectrum disorder reduces parents' psychological capital (Behnouieh, Hossein Khanzadeh and Shokrinia, 2022) and hope and life satisfaction (Kiani, Mohammadi, Hassanzadeh, Mohsen Lo and Pour Rahmani, 2022). Meanwhile, factors such as the severity of autism symptoms, the level of disability, and the child's intelligence are effective on the stress level

of parents of children with autism. About 92% of children with autism show psychiatric diseases, including attention-deficit/hyperactivity disorder, oppositional defiant disorder, and anxiety disorder (Helland and Helland, 2017) and this has a direct impact on fatigue. The psychology of the mothers and fathers of these children. Also, this issue has a significant impact on parents' interactions and severely limits them. In such cases, parents may experience high stress because they face challenges in managing the deficits related to the child's comorbidities (Miranda et al., 2019).

While many research studies have focused on the mother's role in raising a child with autism, obtaining information from fathers can provide a more comprehensive view of how autism affects the family unit (McCoy & Stillman, 2021). In general, fatherhood is the main cornerstone of adult development that affects men's mental health. The birth of a new child requires fathers to find different roles in their family systems (Hannon & Hanon, 2017). Accordingly, the aim of this research is to understand the views of fathers through a grounded theory study. It provides insight and understanding into how fathers are involved in raising children with autism, how they cope, and what they gain from the experience.

Based on the results of the present research, which was the result of coding data obtained from semi-structured interviews with 6 fathers of autistic children, 6 themes and 21 categories were obtained, according to which a paradigm model of the process of psychological reactions was obtained. Fathers were presented with the diagnosis of their child's autism. This model includes 3 basic diagnostic, reactive, and post-reactive stages that fathers with autistic children go through. This model, along with more explanations, can be seen in Figure 1 of the findings section. In each step, the basic concepts related to it are also explained, which can be seen in Figure 1. These concepts are derived from the 6 main themes of the current research, which include the diagnosis of autism in a child, denial of the existence of a disorder in a child, negative emotions and mental conflicts of the parent, personal and social limitations of the parent, support, and support of the parent and acceptance and rejection. Coming with autism.

In terms of presenting a simple yet rich model to explain the psychological reactions of fathers, the present study can pave the way for more research in this field. According to the results of this research, most fathers accept the issue of autism in their children mainly by force. Based on this, it is suggested that in future studies, the process of psychological reactions of parents (mother and father) and especially the issue of joint

parenting should be taken into consideration. In addition, it is recommended that teachers and specialists in the field of mental health, educators who are in contact with an autistic child and his family, know the process of psychological reactions of parents to the diagnosis of autism and take the necessary measures accordingly.

5. Ethical Considerations

Compliance with ethical guidelines

In the current research, ethical considerations, including confidentiality and informed consent were observed. The study was conducted without external financial support. Regarding authors' contributions, the research was written with the cooperation of all authors. This study does not have any conflicts of interest.

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Authors' contributions

All authors have participated in the design, implementation and writing of all sections of the present study.

Conflicts of interest

The authors declared no conflict of interest.

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