

# Stages of grieving in fathers of autistic children: a qualitative study

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**Abstract. – OBJECTIVE:** The grieving process in parents of these children is an ongoing and cyclic one since there is no real end to it. We explored the experience of grief and feelings of loss in fathers of children diagnosed with autism spectrum disorder (ASD), in the west and northwest of Iran.

**MATERIALS AND METHODS:** This qualitative study was conducted using content analysis. Fourteen fathers took part in a semi-structured interview.

**RESULTS:** Six categories were identified in relation to the stages of grief: 1- “Uncertainty of dealing with the unpleasant unknown”; 2- “Being hurt and broken inside”; 3- “Isolation and concealment as a consequence of the pressure caused by ignorance”; 4- “Search for cause”; 5- “Search for a cure”; 6- “Breaking or blooming”.

**CONCLUSIONS:** Fathers of children with ASD go through intense and continuous sorrow and grief. According to our findings, it is recommended that health care professionals work collaboratively with fathers and provide support upon receiving the diagnosis of their child.

#### Key Words:

Autism spectrum disorder, Qualitative research, Grief and Loss, Chronic sorrow, Fathers.

#### Abbreviations

ASD: Autism spectrum disorder; ADHD: Attention deficit and hyperactivity disorder; WHO: World Health Organization.

## Introduction

Autism Spectrum Disorder (ASD) is a group of syndromes associated with neurodevelopmental problem<sup>1,2</sup>. It is a lifelong disorder that affects individuals of different ethnicities and socioeconomic groups<sup>3,4</sup>. The WHO reports that one in 160

children worldwide has ASD<sup>5</sup>. The prevalence in Iran has been reported to be 1.1 per 1000 cases<sup>4,6</sup>.

Parents involved not only in caring for their autistic children but also in understanding and supporting them<sup>7</sup>. Nowadays, fathers share in caring for their children has highly increased due to rapid and radical socioeconomic changes as well as changes in society’s perceptions of and expectations from the role of fathers<sup>8</sup>.

In fact, after the diagnosis of autism and after dealing with child’s behavioral problems, parents’ lives will be subject to profound changes in terms of their health, work, and leisure activities<sup>9</sup>. Fathers’ caring responsibilities may threaten their emotional, physical, and social health. Fathers of children with autism typically experience higher levels of psychological distress and poorer quality of life<sup>10</sup>.

Raising a child with ASD is complex and associated with a change in family dynamics. Researchers have highlighted the emergence of excessive and recurring physical and emotional health problems in parents. An important part of this emotional response is associated with feelings of loss or grief<sup>11</sup>. At the onset of diagnosis, fathers’ reaction is different from that of mothers<sup>12</sup>. Compared to mothers, fathers seem to experience anger rather than sadness and try to suppress their negative emotions<sup>13</sup>.

Fathers with children with ASD describe their lives as a difficult and emotional experience, equating it with the grief associated with the loss of a child they expected<sup>13</sup>. When a member of family is diagnosed with ASD, a painful assimilation process ensues those experts compare to the grieving process, where the grief of losing a “typical child” is experienced<sup>14</sup>. This feeling means the loss of a real child with whom they have lived for several years and formed emotional bonds<sup>11</sup>. This feeling of loss is comparable to the death of a family member<sup>13</sup>.

The process of ‘normal’ mourning is adaptive and characterized by feelings of sadness, guilt, anger, helplessness, despair, and hopelessness. In fact, not mourning after a loss may be considered as a maladaptive behavior<sup>15</sup>.

Grief may be termed chronic sorrow or non-finite loss that begins with the loss of the expected child<sup>16</sup>. To seek answers to exploratory questions about the experience of a grieving individual, qualitative research methods are the most promising options available for researchers<sup>1</sup>. Chronic grief, particularly when experienced by parents of children with chronic physical disorder, is currently well-understood in nursing research and practice<sup>16</sup>. However, there is still a dearth of research on recurrent mourning in respect to autism. The aim of this study was to bridge this gap in the literature. The move towards accepting ASD, along with a subsequent improvement in coping, has already been investigated in research on mothers, but this topic has barely been addressed in fathers<sup>13</sup>. Most of the research has focused on the views and experiences of mothers of children with ASD<sup>17</sup>. However, it is important to explore this experience from the fathers’ point of view in order to see whether or not they have experiences and needs similar to those of mothers<sup>18-21</sup>. Given the alarmingly high prevalence of ASD in children and the fact that parents react differently when they first become aware that their child is diagnosed with ASD<sup>22</sup>, this qualitative study was conducted to discover the grieving experiences of fathers of children with ASD.

## Materials and Methods

This was a qualitative study using conventional content analysis. The conventional content analysis derives categories directly from data<sup>23</sup>.

### Participants

This study was conducted from August 2018 to September 2019. Inclusion criteria included fathers who were willing to participate in the study, having at least one year of experience living with an autistic child aged 3 to 18 years old, and attending the autism association. Exclusion criteria included fathers with a history of substance abuse, divorce, psychiatric disorders, and having another child with different illnesses. Purposive sampling was performed with maximum diversity in terms of opinion, culture, and time of diagnosis, marital status, education level, and occupation.

### Data Collection

The data collection method was individually semi-structured open interviews. In the beginning, general questions were asked: “How did you feel when you found out that your child was diagnosed with ASD?” and “please share your experiences of feeling sad.” During the interview, in-depth questions were posed, such as, “can you, please explain more,” “give an example.” Interviews were recorded and lasted from 45 to 80 minutes<sup>24-26</sup>. Data saturation was obtained after 14 interviews (Table I).

**Table I.** Description of socio-demographic data of the participants.

Participant Number	Age	Education level	Occupation	Marital status	Place of Residence	Age of the autistic child	Number of children
1	42	Bachelor's degree	Office worker	Married	Urban	7	2
2	36	Bachelor's degree	Office worker	Married	Urban	7	1
3	37	High school diploma	Employed	Married	Urban	8	1
4	62	High school diploma	Retired	Married	Rural	14	4
5	45	Associate Degree	Office worker	Married	Urban	9	3
6	57	Associate Degree	Policeman	Married	Urban	15	2
7	47	Bachelor's degree	Teacher	Married	Urban	8	2
8	42	Bachelor's degree	Teacher	Married	Urban	6	1
9	43	High school diploma	Self-employed	Married	Urban	7	2
10	40	Secondary School	Self-employed	Married	Urban	9	3
11	40	Bachelor's degree	Office worker	Separated/ divorced	Urban	8	1
12	36	Bachelor's degree	Office worker	Single	Urban	12	1
13	45	Bachelor's degree	Teacher	Married	Urban	10	2
14	44	Bachelor's degree	Office worker	Married	Urban	14	1

### **Data Analysis**

Data collection and analysis were performed simultaneously. Data were analyzed according to Graneheim and Lundman's method using MAX-QDA-10 R160410 software<sup>20,21</sup>. Immediately after each interview, their content was transcribed, the content was read several times, and then semantic units and the initial codes were extracted. Similar initial codes were categorized into a more abstract category. Finally, the content hidden in the data was introduced as the major theme.

### **Rigor and Trustworthiness**

The data were validated based on the four criteria of credibility, transferability, dependability, and confirmability, following Lincoln and Guba<sup>22-25</sup>. Prolonged engagement in the data and families of autistic children and checking the codes with the participants were used to ensure the credibility of data.

Transferability was achieved by selecting participants with maximum diversity. Also, accurate and purposeful explanations about the steps taken in this research were given in order to provide a picture of the research path and allow a full understanding of the characteristics of the study population.

To meet the criterion of dependability, the interviews continued until the participants used similar concepts and interpretations in answering the questions and explaining their experiences. In addition, advice from experts (including the supervisor and the advisor of the project) was sought.

To assess concepts and categories extracted from the data were presented to two university professors outside the research team.

Finally, for the research to be confirmable, we tried not to let our presuppositions and attitudes interfere with the analysis process, and an attempt was made to avoid as much as possible any bias on the subject before or after the interview. For this purpose, reflective journals were used. To increase confirmability, we provided many quotes from the participants.

## **Results**

Analysis of data related to the experiences of fathers with autistic children led to the extraction of the major theme of 'Stages of grief,' which is divided into 6 main categories, including 'Uncertainty of dealing with the unpleasant unknown,'

'Being hurt and broken inside,' 'Isolation and concealment as a consequence of the pressure caused by ignorance,' 'Search for a cause,' 'Search for a cure' and 'Breaking or blooming.' Each category also consists of several subcategories (Figure 1).

The main categories and subcategories are presented in each subheading using the participants' own words.

### **Uncertainty of Dealing with the Unpleasant Unknown**

When fathers in the present study learned of their child's disorder, they became upset since the concept of autism was new to them. They tended to question the diagnosis and sometimes looked for another doctor to give them less threatening news. Eventually, they became perplexed and were left to wonder what treatment to choose, where to go, and where to get help from. They did not know how to deal with their child. Although uncertainty was a key element experienced throughout the disorder process, our findings showed three main dimensions of uncertainty.

### **Feeling Perplexed in Dealing with an Unfamiliar Diagnosis**

Confusion over the news of diagnosis was reported by fathers who did not have sufficient knowledge about the nature of autism (e.g., the causes and factors affecting its development, the problematic and abnormal behaviors of the child, the treatment methods, the role of parents in dealing with the disorder, and the way these behaviors are managed). Being in a torment of perplexity after knowing of the diagnosis, the fathers sought help, guidance, and information in relation to ASD. Although all fathers conceded that they felt a problem when comparing their child with other children, all acknowledged that they had heard the word autism for the first time.

"Our world has changed; we did not know what autism was." (P6)

"Early on, we were very upset because we didn't know how to deal with his behaviors ... we were very confused at the beginning." (P11)

### **Doubt and Struggle to Invalidate the Diagnosis**

Doctors' diagnosis was based solely on a checklist evaluating the signs and symptoms of ASD. They paid little, if any, attention to interviewing parents and obtaining a history from them, and this caused fathers to doubt the accuracy of the diagnosis.

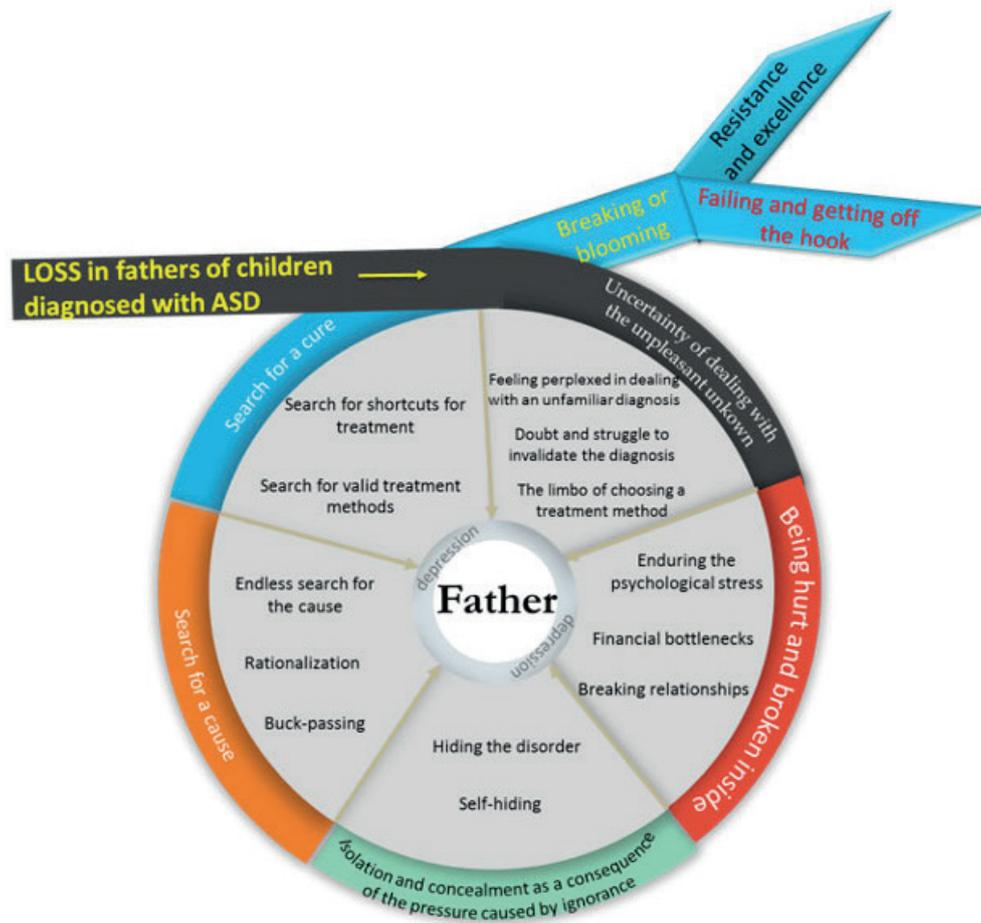


Figure 1. The six stages in fathers of autistic children.

“The doctor said I could not say it was not autism.” (P1)

In addition, the variety of different opinions and diagnoses by therapists intensified parents’ doubts about their child having autism.

“I went to the psychologist for a second time, and he said no, there is no problem and said he is slightly hyperactive.” (P5)

Fathers had frequent visits to various physicians due to their skepticism about the diagnosis and because they hoped for a change in diagnosis.

“Within six months, we visited five pediatric psychiatrists, two child psychologists, and a neurologist. But the further we went, the more confused we got.” (P7)

### **The Limbo of Choosing a Treatment Method**

Upon their initial encounter with the diagnosis and in a struggle to invalidate it, fathers inevitably had to make appropriate decisions about treatment methods. Lack of sufficient information

about treatment methods and fear of getting in the wrong direction gave them new doubts and confusion.

“We are in a limbo now; I don’t know which treatment to go for, and which treatment is right” (P5)

### **Being Hurt and Broken Inside**

All fathers described the diagnosis of autism as a very difficult experience that caused confusion and stress in various aspects of their lives.

### **Enduring the Psychological Stress**

The effects of the grief caused by this painful experience could be seen even in the interview sessions when the fathers recalled those moments. Parents experience negative emotions such as fear, anxiety, and anger after their child is diagnosed with ASD. Participants experienced depression from the moment their child had been diagnosed, and this feeling recurred each time they heard the word autism throughout their lives.

“After a consultation with a specialist, we received the diagnosis of autism. The body of our new joint life was struck by a fatal blow. It was so rapid and shocking that it denied us an opportunity for logical and rational reactions for months. And it was so intense that its destructive consequences still cast a dark shadow over our present and future life.” (P14)

### ***Financial Bottlenecks***

From the time a child is suspected of having a disorder, several costs are imposed upon the family. The costs of diagnosis, treatment and care were often beyond the family’s means. On the other hand, no government funding is defined for this group of patients. As a result, the family alone and sometimes even the fathers alone are responsible for reimbursing the expenses. In this way, the father, who is in the emotional crisis of dealing with the child’s disorder, has to work on solving this cost-budget imbalance by redoubling his work.

“Autism is not even considered a specific disease and is one of most expensive diseases. We have to pay 30,000,000 IRR each month for the medications and classes. Now you imagine how we can handle this with the salary I receive as a teacher.” (P13)

### ***Breaking Relationships***

The child’s disorder affects the fathers’ daily life and their interaction with society. They reduce their social activities and relationships with others due to the need to devote time and energy to seeking treatment and caring for the child. The breakdown and loss of family and social relationships exacerbates these distressing situations.

“Because the child was like this, we were also involved, we had no interaction with the relatives. It was very difficult for a while.” (P2)

### ***Isolation and Concealment as a Consequence of the Pressure Caused by Ignorance***

According to the statements of the fathers participating in our study, society’s ignorance of the nature of this disorder led to misinterpretations, misunderstandings, and misapprehensions about the signs and symptoms of the disorder that are evident in the child’s behavior.

“Others think that this child is behaving rudely, and this is because his parents did not raise him well.” (P4)

In addition, exposure to others’ immoral and inhumane behaviors during social interactions created a sense of harassment among the participants.

“We are being harassed by those around us because they have no idea what autism means at all. They make fun of him, and he gets disturbed. I know that he has felt this because when he is harassed, he pulls a long face.” (P11)

Within such a social context, families consciously sought to increase their distance from it. This gap was created in two ways.

### ***Hiding the Disorder***

Hiding the disorder was a strategy that protected the fathers from the onslaught of labels and stigmas. Fear of others’ misjudgments and feelings of embarrassment in these fathers were so intense that they even avoided uttering the word “autism.”

“I never use the word autism, because of embarrassment and being judged; I’d rather say that my child has cancer or diabetes.” (P13)

### ***Self-Hiding***

Another protective strategy that participants adopted in order to protect themselves from the labels, criticisms, judgments, and social consequences of having a sick child was to distance themselves from society and isolate themselves. In this way, the parents’ social relationships with others were further damaged when the parents were ridiculed, attached to labels, and misjudged.

“Once, he stepped on a guy’s shoe. The guy said: ‘This child is crazy. ...’ Can you imagine how one would feel at that moment?” (P10)

Despite these children’s serious need for social interaction, their parents were forced to confine them at home because they wanted to protect their children from inquisitive stares and unfair labels.

“I would take my son to the park and out, but now I cannot stand those people’s looks at all.” (P10)

### ***Search for a Cause***

Knowing the cause of the disorder or rationalizing it was the focus of many participants’ experiences. Mental conflict and confusion about the cause of the disorder were two important experiences for fathers in their search to find the cause of the disorder and rationalize it. In addition to seeking scientific evidence, they sought to identify someone on whom to put the blame.

### ***Endless Search for the Cause***

One of the father's experiences was an ongoing search in various ways to find the cause of the disorder. One of the most common questions fathers ask is, "What is autism, and how does it occur?" Due to the chronic nature of this disorder and the long-term involvement of parents, the search for answers never ends.

"I was very persistent in finding out the cause.... I am always searching to see where autism comes from (P2).

Fathers are persistent in finding the cause of the disorder in order to escape the sense of self-blame and guilt and to be freed from accusations and blames of society. In addition, they intended to help prevent this disorder in the community by knowing the exact and scientific cause of the disorder. Participants used a variety of sources to search for scientific information, including asking specialists and physicians as well as Internet searches.

"When the doctor said 'autism,' I did not even know what it was. My daughter browsed the Internet to see what it was." (P4)

"We talk to psychologists about the causes of autism, about the fact that autism is a random phenomenon, a gene mutation, or something which can happen to anyone." (P2)

### ***Rationalization***

The participants' experiences showed that in parallel with searching for the cause of the disorder, they made hypotheses. The most common hypotheses put forward by fathers involved attributing the disorder to issues such as fear or head trauma.

"My son was healthy until five years old. After that, the neighbors said it was because of fear that he had become like this. The doctors said that it was probably a blow from the outside to the forehead, which all happened in one day." (P3)

Sometimes fathers tried to discover the cause of the disease by relating it to their wife's pregnancy behaviors

"Her mother used to chew frankincense during her pregnancy. She did this to boost the baby's intelligence, but unfortunately, she used to consume too much, and I think it had a negative effect." (P1)

### ***Buck-Passing***

An important part of the participants' traumatic experiences, which further complicated the situation, was the search for the culprit. The parents

blamed themselves for the disorder. Most parents asked whether their behavior may have contributed to the disorder.

"I blamed myself. I accused myself and said maybe I did not take good care of my children." (P2)

They tried to find different reasons for their guilt. Some believed that their child's disorder was the consequence of past sin.

"At first, I thought that I was atoning for a great sin. Maybe I have violated someone's right or been backbiting someone." (P2)

Some reported that they sometimes blamed the other parent for the child's disorder for behavioral or biological reasons. In this way, by blaming the other, they relieved their guilt of causing the child's disorder.

"Sometimes I tell my wife that I saw this disorder in your family, and she says no, you have a problem." (P13)

"Sometimes my husband tells me that "What kind of a mother are you; you always left the child alone and went to work." (P5)

### ***Search for a Cure***

Parents reported that their search for a cure began after their confusion subsided and the disorder was initially accepted. Fathers had two types of goals in seeking treatment, finding quick cures and finding valid treatment methods. For this purpose, they used a variety of information sources such as experts and the Internet.

### ***Search for Shortcuts for Treatment***

Most fathers sought quick treatment. The consequences of their attempts include unnecessary tests, overuse of medication, frustration due to failure, waste of time, and exorbitant extra costs for the diagnostic and treatment process.

"We are willing to do anything, take him anywhere in the world, give him a pill or an injection so that he becomes OK." (P13)

### ***Search for Valid Treatment Methods***

Another way for fathers to seek treatment was to seek information from psychologists who specialize in providing behavioral, psychological, educational, or skill training interventions.

"We visited three clinics for special children and talked to their experts." (P13)

Fathers who did not find psychologists' treatment convincing searched the Internet for new and faster treatments as well as a better understanding of autism.

“I tried to get information from the Internet as to which treatment is better.” (P9)

### ***Breaking or Blooming***

In the present study, fathers’ getting along with their child’s disorder can be placed on a spectrum. At one end of the spectrum, there were fathers who withdrew from the family. They tried to forget about the disorder. At the other end of the spectrum, there are fathers who had struggled to stay with the family and even by going beyond their family duties to help fellow human beings with the same disorder.

### ***Failing and Getting Off the Hook***

Children with a severe type of autism suffer from difficult conditions, and their parents need to look after them around the clock. Some of them have severe learning difficulties that sometimes make it impossible for them to take care of their personal hygiene by themselves without help, even in adulthood. So some fathers react to these kinds of problems by going off into a huff or withdrawing.

### ***Inadequate Collaboration***

The special needs and behaviors of the child, along with the unfavorable prognosis of this disorder, caused fathers to go through an enormous amount of stress which may have affected their relationship with the child and the whole family, leading to disrupted or even conditional father-child relationship.

“If I’m in the mood, then I can spend more time with my child with more peace and serenity.” (P9)

In addition, fathers struggle with sadness, grief, anger, and despair. This is because of the fact that repeated referrals to health care facilities and insurance companies require a great deal of time, energy, and money and lead to exhaustion and financial pressures.

“She always comes with her mother for occupational therapy sessions. This is the second time in the past months that I have come here. I’m trying to take care of the costs so that the treatment plan proceeds without flaw.” (P1)

In the meantime, the rehabilitation procedures do not yield results as fast as fathers expect, which leads to fathers’ exhaustion in proceeding with the treatment of their children. This is manifested in the form of fathers’ poor cooperation in entertaining, educating, and caring for their children, and they fail to accompany their children in the

treatment sessions. The following are examples of these subcategories:

“Taking care of his bathroom is on his mother because she is so devoted; very rarely when his mother is not at home, I do it.” (P7)

“Unfortunately, I could not work with him that much. I used to do this before, but now I devote no time to him.” (P11)

### ***Inability in Getting Along with the Disorder***

Given that autistic children are classified at three levels, and in most cases, they do not have obvious physical symptoms, it takes time for the parents to accept the diagnosis of ASD, and usually, one parent (in most cases fathers) does not accept autism. The father’s long stay in the stage of denying the disorder of the autistic child with a normal appearance is one of its subcategories. Regarding the long-term denial of the disorder by the fathers, Participant 13 said:

“Fathers stay longer in the denial stage. In comparison with mothers, fathers are more likely to tell their wives that: there is nothing wrong with the child; you are attaching labels to him” (P13)

Participant 4 commented on not accepting the child’s disorder with a normal appearance:

“I did not like to be told that my baby is sick; he was normal as of the first day he was born. He was physically healthy, and he had normal development.”(P4)

### ***Forsaking a Life***

The ramifications of the damage of the disorder go beyond the child and severely affect the husband-wife relationship. In most autistic families, the high pressure caused by the child’s abnormal behaviors can lead to communication problems between the two parents, problems in their relationship with other children, and sometimes even a divorce where the child is kept by a single parent. In most cases, the mother assumes the primary responsibility for caring for the child.

“I have seen many fathers leaving their families because of autism, and the mother is left with countless problems.” (P10)

### ***Resistance and Excellence***

Some of the Fathers reported using the available resources to learn more about ASD and their child. They came up with different strategies to help them accept their children the way they are and help them lead a normal life.

### ***Trying to Stay***

As parents move out of the denial stage of this disorder, many fathers try to support their children.

“And we were compelled and left with no choice, to follow a path to which there is no end.” (P13)

Getting along with the diagnosis takes time because autism is one of those disorders that are time-consuming to treat and lasts a lifetime.

“I think it took five or six years for me to accept that my child is sick and has a problem or that I can take my child somewhere.” (P6)

Some fathers also tried to accept their child’s disorder and created a suitable environment for their wives and children by relying on religious beliefs and spirituality.

“Now I think we are at the mercy of God; He wants to test our potentials. We are pleased with what pleases God.” (P14)

Getting along with the diagnosis helped some fathers better understand and support their child’s strengths. According to Participants 12 and 6:

“Fortunately, he has improved a lot in communication and speech. Children with autism have a very keen visual memory” (P12)

### ***Excellence and Efforts Beyond the Family***

Fathers found the existence of a special autism school and social support groups such as autism associations useful. They also believed that this helps to improve their child’s social interaction. Therefore, some fathers had taken a step beyond the level of their family by cooperating in founding the Autism Association and helping to start an autism school, trying to inform the community about autism, and sharing their experiences to help their fellow human beings. Examples of such efforts are listed here.

“The Office of Education intended to start a school, and I said that I can help in designing the classroom myself. I donated our trampoline mattress at home to other children to play with.” (P8)

“We know a little more about autism. I will inform others about prevention, causes and early diagnosis.” (P2)

## **Discussion**

The aim of this study was to discover the experiences of grief in fathers of autistic children. This grief is chronic and is described as “endless and living sorrow”<sup>11</sup>. Grief for ASD is a cycle that the person constantly enters and exits from<sup>26</sup>.

According to the results, participants described “Uncertainty of dealing with the unpleasant unknown” as their first reaction at the time of diagnosis. Lack of visible disability in the child leads to delayed referral to health care professionals. In assessing and obtaining a definitive diagnosis, ASD is associated with a delay of 3-8 years. Many experts report that parents may not be prepared to hear the word autism and often delay diagnosis<sup>27</sup>, which is consistent with our findings because mothers alone often seek a diagnosis in the early stages as opposed to fathers who stay in the denial phase longer<sup>28</sup>. Meanwhile, parents often refer to different physicians due to uncertainty about the assessment of doctors. Physicians should be trained to timely diagnosis and perform early interventions<sup>5,29</sup>.

Receiving ASD diagnosis is a continuous and complex process. Parents describe it as destructive and traumatic<sup>30</sup>. According to Bravo-Benítez et al<sup>14</sup> family caregivers emphasized enduring hardships and stress in caring for and educating these children. They attributed their anxiety to insecurity, their grief and guilt to the feelings of loss, and their anger to difficulty accepting the situation. This is consistent with the present study of “Being hurt and broken inside” as the second response of fathers. Fathers had strong emotions about reaching a definitive diagnosis, lack of information, financial bottlenecks, and breaking relationships. These findings are consistent with the study by Coughlin et al<sup>31</sup> on the effect of autism on parents’ social interactions with others and friends, financial stressors, and the child’s behavioral problems. It manifests itself in the form of feelings of sorrow.

Another consequence, according to Urquhart and Bravo- Benítez et al<sup>14,26</sup> was social isolation, separation from family, and the child. Some of them hide the child’s disease from others to protect stigma<sup>32</sup>. In our study, fathers tended to minimize their relationships with those around them because society has not yet reached a proper understanding and awareness of these children<sup>33</sup>.

All fathers were initially filled with negative emotions. They blame themselves that this can lead to tension between some couples<sup>34</sup>. They may also blame each other for not giving the necessary support<sup>33</sup>. In our study, fathers also experienced “buck-passing” and “feeling of guilt.” This feeling can damage the emotional health of parents<sup>33</sup>. These findings are consistent with Urquhart and Fernández-Alcántara et al<sup>26,11</sup>.

All participants in this study admitted that they had little knowledge of how to help their

children. Fathers sought to obtain the necessary information with the help of professionals and the Internet because no sufficient education was available to help them cope with their children's disabilities, which is consistent with the results of S'lungile et al<sup>33</sup>.

The findings of this study showed the breaking or blooming of fathers. On the one hand, fathers' use of failing and getting off the hook strategies and hinders adaptation to the diagnosis and shows inadequate coping strategies. On the other hand, a small number of fathers were able to overcome their grief and help the community by making "excellence and efforts beyond the family".

'Failing and getting off the hook' was realized by the inadequate collaboration, Inability to get along with the disorder, and forsaking life. ASD affects marital relationships and the dynamism of parents and other children<sup>35,36</sup>. Results of the present study showed that some parents' relationships were strained. There are cases where parents have been separated, and the child with autism is being cared for by a single parent. Unfortunately, as far as rehabilitation of these families is concerned, they do not receive the support they need, and this has exacerbated their problems. If rehabilitation systems help these families, the family will be a perfect haven for the care of these children.

Sethares<sup>31</sup> and Urquhart<sup>26</sup> showed that reaching a degree of acceptance of the diagnosis involved a long and arduous journey that is not without problems. While grief is permanent in mothers, fathers tend to eliminate their grief by looking for coping strategies to adapt to life with an autistic child<sup>31</sup>. Examples of interpersonal coping strategies included "seeing a psychiatrist," "joining a support group," and "talking to others"<sup>37</sup>. The coping strategies mentioned by fathers of the present study include supporting the Autism Association, participating in the establishment of the association, collaborating in setting up and designing an autism school, and informing others.

The results of Burrell et al<sup>13</sup> showed that the fathers' path to acceptance carries on with the father's feelings of frustration, guilt, and embarrassment. In addition to reassuring them that the experience of these feelings is normal, encouraging fathers to express frustration and grief may enable them to move towards acceptance and boost their resilience. Fernández-Ávalos et al<sup>38</sup> reported that parents feel responsible for their children's mental state, and their desire for a happy family compels them to do their best. This will

lead to the overprotection of their children, which means that they devote almost all of their time, money, and other amenities to their children. In this way, parents become solely caregiver. Similarly, 'trying to stay' was observed by most of the studied fathers.

In Brown et al<sup>5</sup>, fathers of children with ASD described how they preferred to receive informal support and found it instructive and helpful. Some of the fathers in our study also tried to make changes at the community level and support their children and their peers (other parents) with an 'effort beyond the family level.' Joining local support groups such as autism associations was comforting and even empowering. A study carried out on 28 fathers of ASD children by Rafferty et al<sup>39</sup> found most of the fathers spoke about the adjustments they have to make in their parenting style such as adopting a schedule to care for their child.

Many fathers in this study discussed the adjustments they had to make to their parenting style, such as adopting a schedule to create a routine for their child. Many children with ASD prefer to follow routines and are distressed when their routines are disrupted.

According to Rabba et al<sup>40</sup> the stages of grief in fathers in terms of their emotional response include Shocked, Overwhelmed, Sad, Depressed, Relief, Perspective shift (optimistic), Acceptance, and Denial. Unlike the stages of grief described in Rabba et al<sup>40</sup>, in the present study, depression was not considered as a stage because participants experienced depression from the moment of diagnosis and throughout life. Therefore, each time the word autism is heard, the feelings of grief may be rekindled. Grief, like other stressors, can lead to depression<sup>11</sup>.

## Limitations

The several strengths of this study, such as data collection from several clinics, there are limitations that may limit generalizability. The present study was limited in terms of its scope and design. In fact, diversity in the range of children with autism, differences in demographic factors, and diversity in access to services may influence the findings. Although many similarities between the fathers were revealed in the results, findings should be generalized with caution, given the qualitative design and small sample size of the study.

Although diversity in the age of the autistic child is a strength for studies like ours, most of the interviewed fathers had young children (before adolescence), so we do not know the structure of feelings in fathers with older autistic children. Children in our study were not classified based on social functioning or the severity of their symptoms, which should be considered in future studies as these can affect the experience of the parents.

## Conclusions

From the moment a child is diagnosed with ASD, family life undergoes dramatic changes. The grieving process begins from the moment of diagnosis and is never completely eliminated. Health care professionals need to understand these feelings as part of a grieving process that may require support and specific emotional interventions. With this knowledge, professionals can develop a more compassionate approach to how to tell (deliver) a diagnosis. They can provide information to families on how to have a better understanding of the diagnosis of the disorder and share their experiences with the goal of helping the families reach acceptance. Publicizing ASD is a basic need in the community. The community needs to reach a level of awareness to know how to deal with a child with autism in any public place to minimize harm to the child and his or her family.

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### Authors' Contribution

MS and RM prepared a study proposal. All authors are involved in the data gathering process and draft the manuscript.

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### Conflict of Interests

The authors declare that there is no conflict of interest.

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### Research Ethics

The Ethics Committee Board of the Urmia University of Medical Sciences approved this study (Approval ID: IR.UMSU.REC.1397.274). At the beginning of each interview, the participants were briefed on the purpose of the research, the interview method, the confidentiality of the data, and their right to enter or withdraw from the study. The time of the interview was arranged to the convenience of the participants so that no disruption was made to their daily schedules.

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### Informed Consent

Informed consent was obtained from all individual participants included in the study.

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