

Parenting Experience of Mothers with Children with Autism Spectrum Disorder: An Analysis of the Mothers' Diaries

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Abstract

Background/Objectives: This study was conducted to examine the parenting experience of mothers who have children with autism spectrum disorder. **Methods/Statistical Analysis:** Colaizzi's (1978) qualitative phenomenological method was used. The research subjects were seven mothers with children under seven years of age who were asked to participate in a mother-child attachment promotion program after their children had been diagnosed with autism spectrum disorder. The data used in this study were the three-month diaries of the mothers, which were collected from May to June in 2015. **Findings:** Colaizzi's (1978) analysis method was used to analyze the data. From the analysis of the data for the parenting experience of mothers with autistic children, 6 categories and 12 sub categories were identified. The research participants seemed to find meaning in raising autistic children from the relationships with their autistic children, other children, spouses, family members, and other close people. The parenting experiences of the mothers with autistic children were summarized as "difficulty in accepting limits imposed by the disease", "discouragement", "suffering and the responsibility of a mother", "changes in the family system", "appreciation for small changes" and "hopes and promises for the future". **Improvements:** Nursing care that can help to improve the quality of life of autistic children, their parents, and other family members is needed.

Keywords: Autism Spectrum Disorder, Diary, Experience, Mother, Parenting

1. Introduction

1.1 Necessity of Research

Autism Spectrum Disorder (ASD) causes serious defects in social interaction and verbal/non-verbal communication¹. According to a list of registered disabled in Korea released by the National Statistical Office, the number of ASD patients steadily increased from 14,888 (12,575 males and 2,313 females) in 2010 to 18,133 (15,438 males and 2,695 females) in 2013².

This study aims to examine the parenting experience of mothers who have autistic children through their diaries³. This study stated that a diary is a useful tool that

gives a deeper insight into how to raise children, provides solutions for unresolved past emotional problems and helps to improve parenting skills. The most important benefit of keeping a diary is that the individual can develop the ability to look at their problems from their own perspective by looking back on a particular day. In addition, writing about their daily life, thoughts, and feelings generates a personal historical record. Thus, a diary is a daily record of actual experiences, observations, and inner experiences. By analyzing this record, the writer's psychological and behavioral experience can be objectively explored and described⁴.

It is necessary to investigate the parenting experience

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of mothers with autistic children through their writing. In the diaries of mothers who have children with ASD, favorite topics, description methods, and unique ways of thinking can be identified. Modes of thought and behavior exhibited by mothers with autistic children greatly differ from those of other mothers. Mothers of children with disabilities put in more effort and sacrifice more free time to solve their children's problems⁵. In addition, they encounter various demands and restrictions, which can cause family crises, such as psychological conflict among family members. They also suffer from endless sorrow, a sense of loss, depression, and guilt for their children. As such, the parents of autistic children consistently experience a variety of social, economic, psychological, and familial stresses.

In order to understand the thinking, behavior, and emotion of individuals, psychological diagnosis, personality traits, and the House-Tree-Person test have frequently been used. However, few researchers have attempted to use the personal writing of their subjects. Some studies have attempted to examine child-rearing experience, parenting stress, and changes in the reflective thinking of parents using parental diaries^{6,7}. Of these, only a few have analyzed the writings of parents of children with disabilities such as autism.

This study attempts to understand the parenting experience and lives of mothers with autistic children through their personal writing. Their diaries, which honestly reflect their lives in detail, will be analyzed. Through descriptions written in their diaries, this study will investigate their parenting experiences. Based on this, the direction of education for not only autistic children but also their parents can be determined, and methods of nursing intervention can also be developed.

2. Research Methods

2.1 Research Design

In order to understand the parenting experience of mothers with autistic children as described in their diaries from their point of view, this study used Colaizzi's phenomenological method⁸.

2.2 Research Subjects

The research subjects of this study were ten mothers with children under seven years of age who had participated in the autism spectrum disorder treatment program run by

the South Korea Institute of Applied Behavior Analysis at N College, all of whom agreed to participate in this study. After excluding three mothers who withdrew during the data collection period for personal reasons, such as relocating or employment, seven mothers made up the final research subject group. The mothers in this study are labelled with the numbers 1 to 7 according to the order of their participation to protect their privacy.

2.3 Data Collection

The data collection period of this study was from April 1 to June 30, 2015. The three-month diaries of the mothers were collected with their consent. Prior to the data collection, the purpose of the study and the issue of confidentiality were explained to the research participants. They were asked to fully express their parenting experience in their diary entries.

2.4 Data Analysis

The data were analyzed using Colaizzi's phenomenological analysis method⁸, which focuses on examining the vivid experiences of subjects. The specific analysis methods were as follows. First, in order to grasp the overall parenting experiences of mothers with autistic children, the diaries of the participants were read several times. Second, phrases and sentences directly related to the parenting experience were selected from the diaries. Third, the meaning of those selected phrases and sentences were classified by theme. Fourth, categories were created based on the classified themes. These research results were fully integrated and described in relation to research phenomena. Fifth, a validation process was carried out to verify whether the final descriptions matched the actual experiences of the seven research subjects.

2.5 Rigidity of Research

The evaluation of the rigidity of this study was carried out based on Guba and Lincoln's evaluative criteria⁹ composed of credibility, transferability, dependability, and confirmability. For credibility, the analysis results for the parenting experience were shown to the research participants in order to confirm that the results matched their actual experience. For transferability, in-depth data collection was conducted by collecting data until no new information was found. For dependability, mutual inspection and review were conducted during the

analysis process. A nursing professor with experience in qualitative research and two nursing professors who had obtained their doctorates in autism spectrum disorder reviewed and evaluated the research process and results. To maintain research confirmability, an intentional effort was made to ensure the results would not be affected by researcher subjectivity.

3. Results

From the analysis of the data for the parenting experience of mothers with autistic children, 6 categories and 12 sub categories were identified. The research participants seemed to find meaning in raising autistic children from the relationships with their autistic children, other children, spouses, family members, and other close people. Raising an autistic child was perceived by mothers as including “difficulty in accepting limits imposed by a disease”, “discouragement”, “suffering and the responsibility of a mother”, “changes in the family system”, “appreciation for small changes”, and “hopes and promises for the future” shown in Table 1.

3.1 Difficulty in Accepting Limits Imposed by the Disease

3.1.1 Disappointment and Intangible Hopes

The research participants were disappointed with the everyday words and actions of their children, but some had hoped that they would get better (Participants 4 and

7). In addition, the participants had a lurking anxiety about whether their autistic children would be able to grow like other children (Participants 4, 6, and 7).

At the beginning of the treatment when my child was 8 months old, I thought that it would end before 30 months. But, nowadays, I feel that it may take a little longer. My husband said that we can be a happy family if I become a little less greedy about my child, which is really difficult for me (Participant 4).

When will he be able to speak? I would be less worried if my child could say something (Participant 6).

There was a great improvement in my child’s condition. Although I feel that my child may grow into a normal child with some more effort, I’m still worried (Participant 7).

3.1.2 Difficulty in Accepting Disability

The research participant experienced difficulty accepting their child’s disability. They were also deeply confused and frustrated about their child’s development (Participant 7).

Will my child become like other kids someday? Will he become normal before enrolling in elementary school? It doesn’t look like autism or mental retardation (Participant 7).

3.2 Discouragement

3.2.1 Keeping Distance from Others to Prevent Possible Emotional Distress

The research participants could not tell anyone that their

Table 1. Raising autistic children as perceived by mothers

Categories	Theme Clusters
Difficulty in accepting limits imposed by the disease	<ul style="list-style-type: none"> Disappointment and intangible hopes Difficulty in accepting disability
Discouragement	<ul style="list-style-type: none"> Keeping their distance from others to prevent possible emotional distress Alienation from social relationships
Suffering and the responsibility of a mother	<ul style="list-style-type: none"> Confusion and guilt as a mother Confusion about responses to change
Changes in the family system	<ul style="list-style-type: none"> Changes in interactions with family members Guilty feelings towards other children Marital conflict caused by child rearing
Appreciation for small changes	<ul style="list-style-type: none"> Happiness from changes in daily life Being impressed by increased attachment behavior
Hopes and promises for the future	<ul style="list-style-type: none"> Growth through parenting

child had developmental disabilities. They even kept their distance from their parents and siblings (Participant 3). They were nervous about others' opinions of their children and shutting themselves away from society (Participant 6).

I couldn't tell anyone that my daughter has a developmental disability. It's been a year since I stopped contacting my friends, parents, and siblings for that reason (Participant 3).

My child is enrolled in a culture center. He is in a class for 13 to 24 month-old children who are younger than him. What if other mothers think that my child is abnormal (Participant 6)?

3.2.2 Alienation from Social Relationships

The research participants felt a sense of alienation from the opinions, criticism, and sympathy of others. They experienced deep sorrow and severe emotional distress (Participants 1 and 6).

I felt like I was alienated from people around me and left out on a deserted island. My mother cried again (Participant 1).

I took my child to a wedding the other day. I had not taken him to crowded places since he was little. People say, "He is not interested in anything at all. What a cold child," about my child after trying to speak with him. I hear it often, but it still hurts a lot every time (Participant 6).

3.3 Suffering and the Responsibility of a Mother

3.3.1 Confusion and Guilt as a Mother

The research participants experienced difficulty and guilty feelings while raising their autistic child. They said, "I should not have had him" and "I feel sorry for her". In addition, they experienced role confusion and guilt about the idea that their children may have become abnormal because of their poor parenting (Participants 3, 4, and 7).

The sounds of temper tantrums and crying... My head aches whenever I hear these sounds. Child rearing is really the biggest pain for me. Why did I give birth to two children when I was uncertain about it (Participant 3)?

Mothers of slow children need great patience, but I think that I still lack it. I feel really sorry for my child for my insufficient support (Participant 4).

I used to yell at and drag my child around harshly. Is

that why my child established an unstable attachment? Why is my child abnormal? Did I commit a sin in my previous life (Participant 7)?

3.3.2 Confusion about Responses to Changes

The research participants were sorry and frustrated for being unable to understand their child's feelings well. They were confused about responses to changes in their attachment behavior (Participants 2, 4, and 7).

These days, my child follows me around even more when his dad or grandmother is there. He even hates to close the bathroom door. I am afraid his disease is getting worse (Participant 2).

My child tries to do many things lately. I am afraid if I stop those activities to take him home, he'll take it as a rejection. I feel really sad because I'm not able to understand his feelings well (Participant 4).

My child was whining a lot when we went to the sledding slope on Christmas. We had to come back home because of him. I am frustrated at being unable to understand him (Participant 7).

3.4 Changes in a Family System

3.4.1 Changes in Interactions with Family Members

The research participants were impressed and encouraged by the improved attachment behavior of their child, such as playing with their father, sleeping beside their father, and playing with siblings (Participants 1, 2, 3, and 4).

My child seems to recognize his dad now. He comes and gives a kiss to his dad when asked. Sometimes he comes out of his room to greet his dad when he comes back from work, and looks at him several times while playing (Participant 1).

Now my child falls asleep next to his dad, putting his legs on his dad's belly, which was awkward for him before. It is wonderful and touching (Participant 2).

It is fun to play with my autistic child and her sister nowadays. It was sad to see her play alone while her sister was playing with me. I feel really encouraged now (Participant 3).

My child, who used to follow me around, seems to have begun forming an attachment to his dad these days. He started playing with his dad, and his relationship with his little brother is getting better (Participant 4).

3.4.2 Guilt towards Other Children

The research participants felt sorry for their other children for not being able to pay them as much attention compared to their autistic child (Participants 3, 4, and 6).

The elder sister of my autistic child is jealous of her younger sister because I am always with her and she seems engrossed in my love (Participant 3).

I feel very sorry to my second child for doing nothing for him. He is jealous of his elder brother, and even hits him when I am away (Participant 4).

My second child seems to get upset because he is always told to concede to his elder brother. I was angry with him at first, but then realized that it is not his fault. I feel sorry for him (Participant 6).

3.4.3 Marital Conflict Caused by Child Rearing

The research participants were upset and disappointed because their husbands were not interested in child rearing (Participants 1, 4, and 7).

Today is the day of the school program for dad. I told him several times before, but he came home drunk at dawn. Hence, I had to go there for my child. All the other kids were with their dad, except my child. I cried in front of his teacher (Participant 1).

I wonder if this is the man whom I loved. He is too cold to my child, and acts as if he is angry at me. He doesn't even talk to me anymore. What did I do wrong (Participant 4)?

I am upset with my husband. He doesn't seem to be interested in parenting (Participant 7).

3.5 Appreciation for Small Changes

3.5.1 Happiness from Changes in Daily Life

After enduring the long wait while raising children with no or slow reactions, the research participants admired and appreciated small changes in their autistic child (Participants 1, 3, 4, and 6).

While eating supper, my child firmly grabbed his spoon and scooped up two pieces of rice with great difficulty. I'm so grateful (Participant 1).

My child finally started to eat rice and soup with a spoon by herself. She also used a toilet for the first time. It makes me so happy (Participant 3).

My child put a baby bottle into his younger brother's mouth. I was also surprised to see that he cried after a

little boy on TV. I was grateful to see his development even though it was a little slow (Participant 4).

Whenever reading Pinocchio to my child, I pretended to stretch my nose. Today, he pretended to stretch his nose while reading Pinocchio. Since he hardly imitates actions or shows body expressions, this kind of small change makes me really happy. It may not be a big deal for others, but it is a great change for us (Participant 6).

3.5.2 Being Impressed by Increased Attachment Behavior

The research participants were impressed and excited by the increased attachment behavior of their autistic children. For example, children kept eye contact with their mothers and called them mom (Participants 1, 2, 4, and 5).

I was very impressed with my child today because he called me mom, looking at me. He used to push me away, but he pulls my hand nowadays, which makes me happy. While I was folding the laundry, he brought my clothes and tapped me on the chest with them, smiling. It seems that he brought them to me to wear them. It impressed me so much (Participant 1).

There's more eye contact between me and my child these days. I feel happy because he looks at me with his lovely eyes. He usually runs here and there in the supermarket, but today he was holding my hand. I am so pleased (Participant 2).

He seems to trust me now due to increased attachment to me. I am satisfied because he doesn't reject me much anymore (Participant 4).

She holds my face with her hands and smiles when our eyes meet. She repeats it several times. Her smile makes me happy (Participant 5).

3.6 Hopes and Promises for the Future

3.6.1 Growth through Parenting

Probably God sent you to me to make my life valuable. I swear again that I will be a strong mother for you, watching you sleep (Participant 1).

I was often frustrated because I didn't know much about parenting. But now I am learning little by little from many of my child's teachers (Participant 3).

There is a long way to go and there are so many things to worry about, but I hope that my child will get better.

I am discouraged at little things now, but I will be less sensitive someday (Participant 6).

I began to think expansively about my child these days unlike before. Did my indifference make him suffer? Am I doing okay now? I am trying to make a plan and follow it to improve my behavior (Participant 7).

4. Discussion and Implications

This study was conducted to examine the parenting experiences of mothers with autistic children. It was found that they have experienced difficulties in accepting the limits imposed by the disease, discouragement, suffering and a sense of responsibility as a mother, and changes in a family system due to their autistic children. They also feel gratitude for their children's developmental changes, growing through parenting, and moving towards the future.

Descriptions in the "Difficulties in Accepting Limits Imposed by the Disease" section show the past, present, and future lives of research participants. These were consistent with¹⁰, who found that mothers experience mental exhaustion through the process of rejection, passive conquest, and acceptance with maternal love after their children are diagnosed with autism. Also, influential factors of mother's parenting stress were mother's depression and their children's negative temperament^{11,12}. Study also supports the parenting experience of mothers with autistic children revealed in the present study. They conducted a study on the experience of disability acceptance by mothers with autistic children, and found that mothers experience anger and confusion about their children's and their own lives after their children are diagnosed with autism. People who have children with disabilities may actually be experiencing these feelings, and the findings of the present study are significant in that it enables us to understand their emotional distress.

The research participants also kept their distance from others whom they could trust and rely on. They shut themselves away. This was shown in their descriptions: It's been a year since I stopped contacting my friends, parents, and siblings; I feel like I am left out on a deserted island. This finding was consistent with previous research. Reported that mothers with autistic children experience emotional frustration and depression, social inactivity and a sense of alienation¹².

The present study found that mothers with autistic

children experience confusion about their parental role while feeling responsible for their children. They were confused about their parental role, and worried if their children had become unstable due to their poor parenting. They expressed their difficulties in parenting as follows: Why did I give birth to him? It seems that I can't understand his feelings. However, they tried to understand their children (My child was different from the beginning), and were aware of the importance of their role as a parent (I must overcome). According¹⁰, Asian mothers with autistic children experience even more distress due to the patriarchal family environment and the pressure on the responsibility of mothers for sick children. It seems that a support system where the parents of autistic children can share their experiences and encouragement is needed.

It was also found that mothers of autistic children were impressed by and grateful for small changes in the development of their children. They grew through parenting and saw promise and hope for the future¹³. Methodological study on the psychological adaptation of mothers with autistic children showed that mothers with autistic children held the hope that their children would get better if they put in more effort. Through the cases of three families with autistic children¹⁴, emphasized the important role of family cohesion and resilience, which enabled mothers to find courage and hope even in desperate situations. The research participants of the present study also said, "I was grateful to see his development even though it was a little slow" and "It may not be a big deal for others, but it is a great change for us¹⁵". Proposed that hope is a fundamental characteristic required for human living. It is an important factor determining restoration and available to anyone in any situation. The research participants of the present study grew through parenting and saw promise and hope for the future. They experienced pain due to their autistic children, but they were able to be stronger for the future because of their children. It seemed that their children gave their lives meaning and purpose.

This study has helped attain a better understanding of the parenting experience of mothers with autistic children. Nursing autistic children is a very important issue, but their parents also need help. Continuous concern and care are needed for the improved quality of life for autistic children, their parents, and other family members.

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