



Life History: Parental Adjustment in Children with Autism Spectrum Disorder

Hana Bertha Ullly; Sigit Sanyata

Guidance and Counseling Department, Yogyakarta State University, Indonesia

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Abstract

DSM-V states that autism spectrum disorder (ASD) is a neurodevelopmental disorder that obstruct children's development in terms of communication, socialization, and behavior (American Psychiatric Association, 2013). With the limitations of ASD children, parents need to adjust to ASD children. There are four factors that affect parental adjustment, which is the characteristics of ASD children, social support, perception of the problem, and coping strategies (Poza et al., 2011). The purpose of this study is to see and understand how parents adjust with ASD children. This is a qualitative study using an interpretative phenomenological paradigm, which is to understand the experiences of the participants. The approach in this study is by using life history to examine the lives of parents from the birth of the child to present time. Collections of data were achieved by semi-structured interview. The participants involved in this study are married couples who have ASD children. This research shows that emotion focused coping is one of the factors that parents with ASD children used to adjust themselves. With gratefulness, rejoice and surrendering their difficulties to God.

Keywords: *Autism Spectrum Disorder; Coping; Parental Adjustment*

Introduction

Children are a gift given by God to every parent, with the hope that the child will be born in a healthy and normal condition. But in reality, sometimes a child who is born is not necessarily all born normal. There are children who are born in accordance with expectations and some are not, in other words, children with special needs. The number of children with disabilities in Indonesia according to statistical data is around 2.197.833 people with an age range of 5-19 years (Novrizaldi, 2022). Children with disabilities are not only physical, but also mental. One of them is autism spectrum disorder (ASD). According to the DSM-V, individuals diagnosed with ASD have difficulties in communication, such as inappropriate responses to conversations, misinterpreting non-verbal communication, and having difficulty building friendships (American Psychiatric Association, 2013). The Autism and Developmental Disabilities Monitoring (ADDM) Network explains that in 2020 there were approximately 1 in 36 children identified with ASD in the United States (Centers for Disease Control and Prevention, 2023). In Indonesia, ASD sufferers are estimated to increase by 500 people every year (Kemenkes, 2022). Generally, the picture or state of parents who have ASD children feels sad and disappointed. In addition, they feel a sense of rejection in themselves towards the child. In addition to rejection of the child, the

emotional crisis of the ASD child can also be in the form of frustration in raising the child, anxiety of helplessness, anger, upset, financial problems, and family focus only on short-term goals compared to long-term goals (Apostelina, 2012). Parents who have children with developmental disorders, such as attention deficit hyperactivity disorder (ADHD) and ASD tend to often show high levels of parenting stress and mental health problems and it is not uncommon to find poorer marital adjustment and family dynamics compared to parents of other normal children (Wang, 2021). So the situation of parents who have children with ASD, usually has changes in family dynamics that have an impact on all family members (Kim et al., 2020). Indeed, families have a special role in the process of building and shaping children, but the entire family cycle changes when a child is born with a disability; parents have to reorganize, create new expectations, and create new realities (Martins et al., 2015).

The role of parents is needed in caring for and guiding children into adulthood. According to the American Psychological Association, parents of ASD children face many challenges related to the symptoms of ASD children (Hickey et al., 2017). Parents experience enormous challenges in managing the complex needs of ASD children (Kurzkrok et al., 2021). In addition, parenting an ASD child is a stressful process and sometimes parents need support from professionals (Cetinbakis et al., 2018). Therefore, parenting an ASD child requires parental adjustment related to the family's effectiveness in using their resources and social support (Felizardo et al., 2016). According to (Poza et al., 2011), parental adjustment is not only influenced by the characteristics of ASD children, but also by social support and psychological factors, such as perceptions of problems and coping strategies. One factor that makes parents able to adjust to their children is the way parents respond to their children's conditions both cognitively and behaviorally, which is referred to as coping (Benson, 2014). Many parents can not adjust to the presence of ASD children, but it is also undeniable that there are some parents who are able to adjust. Thus, the purpose of this study is to find out and understand how parents adjust to ASD children.

Method

This research is a qualitative research with a life history approach. The paradigm used in this research is the interpretative phenomenological paradigm. The purpose of this research is to know and understand how parents adjust to ASD children. This study discusses the life experienced by parents of ASD children, especially parental adjustment from the birth of the child to the current development of the ASD child. The criteria for participants in this study are married couples who have ASD children and live in Indonesia. The preparations made by researchers before carrying out the research, namely

Table 1. Research Preparation

No	Pre-Field Preparation	Instrumental Preparation
1.	Determine the research topic	Prepare questions to be asked
2.	Determine the purpose and focus of the research	Prepare a phone as a tool for recording
3.	Search for theories relevant to the topic	Prepare paper and pen to notes important things
4.	Develop an interview guide	

Data collection in this study was through semi-structured interviews. By using semi-structured interviews, the researcher has the opportunity to listen to participants talk about certain experiences or aspects of their lives. The interviews were conducted by asking questions that were organized in an interview guide, after which probing the answers given by the participants. The data analysis method in this study uses thematic analysis, which serves to get the themes that appear in this study. Credibility in this study was carried out by triangulation, namely interviewing participants at different times in the sense that they were not simultaneously interviewed.

Results

The results of this study contain four themes, namely:

First Childcare Experience

When the wife became pregnant, both husband and wife felt very happy, joyful, and thought that the pregnancy was a miracle from God because they had been waiting for about six years. When the child is born, the husband and wife welcome the child with joy and excitement. This is also how the participants in this study felt when their first child was born, as they said,

"I'm so happy, it's indescribable." (H/FCE01)

"I'm very happy but also worried about whether I'll be able to raise this child well." (W/FCE01)

According to (Kuhn & Carter, 2006), before the child is born parents already have beliefs and expectations for parenting and the parenting changes as the child develops. From this study, it was found that when the child was born, both the husband and wife felt happy but the wife also felt worried about whether she could take care of and raise the child well. In other words, the wife was not fully confident in herself to take care of the child. According to (Russell & Ingersoll, 2020), parenting self-efficacy is a belief that parents have in their ability to care for children. Parenting self-efficacy itself is beneficial for parents' well-being and plays an important role as a psychological resource (Lin et al., 2018). As can be seen from the interview excerpt above, the wife was worried about whether she could raise her child well or not. In other words, she was not fully confident in herself to take care of the child. Over time, the child's development go down and their child was diagnosed with ASD. Before being diagnosed with ASD, the child could sing and memorize some songs, but could not speak such as calling "Mama" or "Papa" and could not sit up at the age of six months. According to the husband, their child had a decline in abilities at the age of 10 months. When they noticed a decline in ability and behavior that did not match other children of the same age, the husband and his wife had their child examined by a doctor. The child's behavior that was not in line with other children his age included not being able to play with toy cars and no eye contact in daily activities, as illustrated in the following interview quote:

"At that time, maybe he was like normal at first. But his younger sister was born immediately when he was 10 months old. So when he was little he could say for example "bobok" (sleep). But once his sister was born, his ability seemed to go down. I think so..." (H/FCE02)

"If I'm not mistaken, his behavior does not match that of other children his age." (H/FCE03)

"What I remember is that he couldn't play with toy cars at that time." (H/FCE04)

"Running here and there and no eye contact." (W/FCE02)

There are several characteristics to diagnose ASD children according to DSM-V including deficits in communication and social interaction such as no eye contact, difficulty making friends and repetitive and limited behaviors and interests such as not being able to assemble toys or turn objects (American Psychiatric Association, 2013). These criteria are in accordance with the results of interviews from participants, that their children can not play with toy cars and there is no eye contact in daily activities.

Siegel and Sullivan suggest that when a mother finds out her child is diagnosed with ASD, they experience shock, anger, sadness, worry, fear, and guilt (Kuhn & Carter, 2006). This is similar to what the wife experienced when their child was diagnosed with ASD, she felt sad and surprised. Feelings that were initially happy when having the first child, turned into sadness. Thoughts also changed when the child was diagnosed with ASD. At the beginning of the ASD diagnosis, the husband immediately thought about

how to help his child to recover. According to (Pozo et al., 2011), there are four factors that influence parental adjustment, one of which is the perception of the problem. From interviews that have been conducted previously, the husband has the perception that the child can be cured. The perceptions held by participants affect the way they care for their children.

Parenting Control of the ASD Child

The care given to ASD children is one form of adjustment made by the participants of this study. Both husband and wife treat ASD children according to their knowledge about autism and do not expect their children to respond like normal children. This is reflected in the results of the interviews that were obtained:

“I treat him specially according to the fact that my child is not normal.” (H/PCAC01)

“I treat him according to our knowledge about autistic children, not expecting him to respond like a normal child.” (W/PCAC01)

The adjustment process that occurs is when participants do not expect ASD children to respond like normal children, meaning that both husband and wife have adjusted to the situation of children diagnosed with ASD. The experience of parenting an ASD child includes positive and negative aspects ranging from increased resource needs, increased stress levels, and positive growth of each member (Estes et al., 2019). The interview also found that as a child, the ASD child had lived in a hyperactive autism dormitory to undergo acupuncture treatment. The dormitory was located in a different city from where the participants lived. In the dormitory, the ASD child was only accompanied by two caregivers provided by the participants. However, the acupuncture therapy was stopped because the participants could not bear to see their child being pricked with needles every day and did not meet their expectations. After the acupuncture therapy was stopped, the ASD child returned to live and be cared for by his parents. Both husbands and wives argued that the care of autistic children is better done at home by their own parents.

“Yes, so that’s how it is. Until now, there is nothing else, again we read that autistic children are still good at home, the basic is not a dormitory or nothing...” (W/PCAC02)

According to Haber & Runyon (1984), one of the characteristics of effective adjustment is an accurate perception of reality. The acupuncture therapy performed was a real event that occurred in their lives. Participants knew their children were diagnosed with ASD and needed help, but when they tried to help, their expectations did not match the reality that their children had limitations as ASD children. They had hope that their child would recover and when this was not the case, they stopped the acupuncture therapy and took the ASD child home. After being brought home, no more interventions or efforts were made to help the ASD child because they believed that their child was better off at home and cared for at home. This affected the coping done to overcome the stress felt by the participants.

Coping Stress

Every individual experiences changes in life, both expected and unexpected changes. When individuals experience changes, individuals must be able to adjust to these changes. If not, they can experience stress as a result of these changes. Stress is a result of demands that can not be met and are beyond individual control (Hendriani, 2018). Just like parents of ASD children, they must be able to cope and adjust to the conditions of ASD children. There are four factors that influence parental adjustment, one of which is coping strategies (Pozo et al., 2011). Coping is a way for a person to regulate their thoughts and behaviors continuously in the face of changing situations both internally and externally and overcome the demands faced (Lazarus & Folkman, 1984).

“I’m sad too, even now if I imagine him, how dare he live in this world... How dare he be here, so I just surrender to God...” (H/CS01)

“Again, because I waited a long time for this pregnancy and after the miracle, I have to be grateful and rejoice whatever the condition of my child.” (W/CS01)

“I was finally able to accept my son because we felt that he was part of us and a gift from God so it was our duty to nurture and raise him.” (W/CS02)

There are two types of coping according to (Lazarus & Folkman, 1984), namely problem focused coping (an attempt to relieve stress by doing an activity) and emotion focused coping (an attempt to reduce the emotional impact of stressful events). As the husband has said, when he feels sad when thinking about the ASD child, he copes by surrendering to God. And when the wife was disappointed, she overcame the disappointment by being grateful and rejoicing, she felt that the child was a gift from God and part of their family so it was an obligation for her to love and raise her child whatever the circumstances. Coping carried out by participants, both husband and wife, is emotion focused coping, by being grateful, rejoicing and surrendering to God to manage the emotional impact that occurs due to their child being diagnosed with ASD. In contrast to research conducted by Grant & Whittell which shows the results that using problem focused coping, becomes more effective to overcome problems (Poza et al., 2011). There is also research on parents and caregivers of ASD children conducted by Abbeduto et al., Aldwin & Ravenson, Seltzer et al., which shows the results that using emotion focused coping is usually associated with mental health that tends to be worse than using problem focused coping (Benson, 2014).

Meanings and Expectations for Children (ASD and Non-ASD)

Every individual has meaning and hope in life. Likewise with parents, of course, have meaning and hope for their children.

“Just like family. A gift from God.” (H/MEC01)

“In my opinion, the meaning of children is a part of living life.” (W/MEC01)

According to (Kagitcibasi & Ataca, 2015), there are three values of children: economic value, psychological value, and social value. Children are considered as economic value, meaning that children contribute materially to the family; from a psychological value, children are considered as happiness, love, pride, and joy in the family; from a social perspective, children are expected to maintain and continue the family lineage in social life. Based on the results of the interviews that have been conducted, participants interpret children as psychological value because when the child is born they feel happy even though over time, the child's development decreases and is diagnosed with ASD and they still feel grateful.

If parents have a normal child and a child with ASD, their expectations will be different. Expectations for ASD children will usually be more modest than those for normal children because normal children can do all activities by themselves while ASD children can not. ASD children will be more dependent on their parents, siblings and other people.

“There are no expectations for the child. He’s fine, happy in his own way, that’s fine. After all, humans are different. We can’t be the same. Both he (ASD children) and his two siblings have their own ways of happiness. What we hope is that he can support himself actually for these two, for his siblings.” (H/MEC02)

“There was no expectation before birth, at that time I think I thought having a child is only once. But now the hope is that he can help himself, can be independent... Independent for his own needs” (W/MEC02)

Participants did not have expectations for the child before birth, because initially the wife thought of having only one child. However, now the wife has hopes for the ASD child to be able to help himself and be independent of his own needs. Meanwhile, the participants' hopes for the two younger siblings of the ASD child were different from their hopes for the ASD child.

“Because if they can't support themselves, how can they take care of their brother? So what I hope is that his younger siblings will help his brother. Paying attention, not necessarily physically. But I do prepare them financially. So later I believe there will be a system even though there is a system for ASD children. The important thing is that the siblings can monitor. With today's technology, monitoring seems to be very possible. (H/MEC03)

“My hope for the two younger siblings of the ASD child is that they remain friends in Christ and want to listen to God. That's the hope, besides that I also hope that from them they can be economically independent because when we are no longer able to take care of their brother, if possible directly or at least they oversee the management of their brother. If possible they can also form a family, they can be happy in their adulthood, they live a long life and want to help each other in their adulthood and old age.” (W/MEC03)

The husband has hopes for the two younger siblings of the ASD child to be able to support themselves. According to him, if the two siblings can support themselves, they will be able to take care of their brother. Meanwhile, the wife hopes that the two younger siblings can remain friends in Christ, want to listen to God, can form a family, want to help in adulthood and old age, and they can be economically independent because according to the wife, when she and her husband can no longer take care of the ASD child, the younger siblings are expected to take care of their brother.

Perception of the problem is very important in improving parental adjustment. The husband had the perception that the child could recover, so because of this perception, it affected his adjustment to the child and the care provided. In addition, participants did different coping from previous studies. If previous studies conducted problem focused coping to cope with perceived stress, participants conducted and interpreted emotion focused coping as their way to cope with perceived stress and adjust to the ASD child. They prefer to be grateful, rejoice, and surrender to God.

Conclusion

This study has several weaknesses. This study did not discuss in more depth other factors that influence parental adjustment such as social support, characteristics of ASD children, and perceptions of problems. The results of this study emphasize coping done by participants so that it does not discuss other factors. The advantage of this study is that it emphasizes the meaning felt by participants. Suggestions for future research, can discuss more in depth related to other factors and aspects of parental adjustment, namely parenting self-efficacy, parenting stress, and perceived satisfaction with the parenting role. Researchers realize that in this study there is a lack of discussion about the aspects of parental adjustment so that if the aspects of parental adjustment are discussed in more depth, it is expected to get new and more detailed results regarding parental adjustment.

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