

Living with Hope: Resilience Among Parent/s of Children with Autism in Palembang Therapy Center

Diajeng Laily Hidayati^a, Maulita Noor Aisha^b

^{ab}Magister Psikologi Universitas Muhammadiyah Surakarta, Indonesia

^aUIN Sultan Aji Muhammad Idris Samarinda, Indonesia

diajenglaily11@gmail.com

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Abstract

In the developing countries, social services for people with disability (PwD) are still limited and responsibility for the development of children with disability is often associated with their parent/s. The children with special needs, including those with autism, impacts all members of his/her family and leads to the emergence of crisis experiences in the family. The article talks the resiliency of parent/s with autistic children in Palembang Terapi Center. This paper is written with a phenomenological approach. Findings show that dominant themes emerged regarding resiliency in this paper setting are self-acceptance, self-efficacy, and adaptation. Several factors that influence the resilience of parents with autistic children are individual abilities, children's conditions, environment, and religious values. Moreover, there are three types of resiliencies according to the level of difficulty experienced by parent/s; high level of difficulty, moderate level of difficulty, and lower level of difficulty.

Di negara berkembang, keterbatasan layanan sosial bagi penyandang disabilitas dan tanggung jawab atas tumbuh kembang anak penyandang disabilitas seringkali dikaitkan dengan orang tua. Keberadaan anak berkebutuhan khusus, termasuk anak dengan autisme berdampak pada seluruh anggota keluarga dan berujung pada kemunculan pengalaman krisis keluarga. Artikel ini mengeksplorasi resiliensi orang tua yang memiliki anak dengan autisme di Pusat Terapi Palembang. Artikel ini ditulis dengan pendekatan fenomenologis. Temuan menunjukkan tema terkait resiliensi dalam penerimaan diri, efikasi diri, dan adaptasi. Temuan lain adalah faktor yang mempengaruhi resiliensi orang tua yang memiliki anak autisme dengan kemampuan individu, kondisi anak, lingkungan, dan nilai agama. Selain itu, ada tiga jenis resiliensi menurut tingkat kesulitan yang dialami orang tua; tingkat kesulitan tinggi, sedang, dan rendah.

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A. Introduction

People with disabilities often experienced discrimination in their daily lives in society (Baffoe, 2013; van Brakel et al., 2012). This is generally true because of the physical and social environment in which the person with a disability lives that is not inclusive (Rimmerman, 2013). This means that the environment in which persons with disabilities are located tends not to support and accommodate the actualization of their potential. People with disabilities, however, have needs that are not so different from those without disabilities in general. Society is often considered as an external cause of disability experienced by individuals. This assumption, although not entirely true, illustrates the efforts made by persons with disabilities to shift the general view of the causes of disability that were initially centered on the individual towards the social environment of society (Bhanushali, 2007).

According to the statistic from the Management Information System for Persons with Disabilities made by the Ministry of Social Affairs of the Republic of Indonesia, until 2021 there are 221,971 people with disabilities in Indonesia (Kementerian Sosial RI, 2021). From this figure, the variety of people with disabilities in Indonesia include people with physical disabilities, ex-leprosy/chronic disease, multiple disabilities, mental disabilities, autism, deafness, speech impairment, low vision, total blindness, slow learning, mental retardation, and Down syndrome (Kementerian Sosial RI, 2021).

Autism is one kind of disability that is experienced by 3,823 people in Indonesia. Autism can be defined as a developmental disorder that occurs in childhood and is characterized by limited communication, social interaction, imagination, and attitude (Muniroh, 2010). People with disabilities, including autism, oftentimes, need more attention from their family members. Parenting autistic children is challenging because it is related to the problem of dependence, behavior, and health of the children (Mohan & Kulkarni, 2018).

To provide education and other services for children with special needs, parents often involve external parties such as doctors, speech therapists, occupational therapists, sensory integration therapists, and behavioral therapists to help their children grow and develop. In the city of Palembang, there is a special health service that helps parents to deal with children with special needs, namely the "Palembang Therapy Center" or PTC for short.

The conditions of children treated at PTC Therapy House vary widely, ranging from children diagnosed with Autism, Down Syndrome, Dyslexia, Attention Deficit Hyperactivity Disorder (ADHD), Global Developmental Delay (GDD), and other conditions that are related or affect the stages of their development. However, the majority of cases handled by PTC Therapy House are children diagnosed with

autism spectrum disorders or what is often known as Autism. The number of autistic children in PTC is 70% of the total number of patients or as many as 150 children. The services available at PTC Therapy House include Occupational Therapy-Sensory Integration, Speech Therapy, Pediatric Physiotherapy, Applied Behavior Analysis (ABA), and basic reading and counting course for children with special needs.

Most parents with children with special needs tend to be in a state of denial, angry, sad, feeling guilty (Amelasasih, 2018), and are not ready to accept their child the way she/he is, especially when it turns out that the child is diagnosed with autism. This situation is caused in part by lay assumptions that tend to give negative judgments to children with autism thus suggesting others avoid interaction and even stay away from children with autism. With these misleading assumptions, parents are often less open and objective during interview sessions with the therapist or even cover up the real condition of their child. This is a response to excessive worry and anxiety from parents about their children's future.

The presence of children with special needs, including autism, has an enormous impact on all family members. This experience can affect all aspects of family functions (McConnell & Savage, 2015). Most parents have to make adjustments to their social life and show high levels of frustration and dissatisfaction in life. Nevertheless, many of them are trying to maintain their routine (Heiman, 2002). This condition likely leads to a crisis experience in the family because the presence of autistic children puts pressure and more complex responsibilities on parents. Thus, parents with autistic children tend to be more prone to stress (Amelasasih, 2018; Muniroh, 2010; Peer & Hillman, 2014).

Emotional turmoil often appears in parents with autistic children. Several previous researchers found that families often experience physical, social, and emotional stress in the process of living together and caring for children with special needs (Whiting et al., 2019). The family's response to such emotional turmoil affects the development of the family. Families who cannot adjust to difficult conditions tend to be easily depressed (Muniroh, 2010), and vulnerable to contracting the physical disease (Woodgate et al., 2008).

In confronting crisis conditions, parents need to survive and adapt in order to be able to move on and live a good life. The resilience of parents with autistic children is very much needed to deal with pressure during the process of parenting and mentoring children's growth and development. The ability to stay afloat in the face of crisis and pressure is known as resilience. Resilience is an individual's ability to adapt even when faced with the most difficult circumstance (Amelasasih, 2018).

Resilience is a dynamic ability within an individual and can change over time (Walsh, 2016). Resilience in individuals is influenced by internal and external factors

(Garcia-Dia et al., 2013). In addition, typical problems, cultural values, and expectations also affect individual resilience. For this reason, a family that shows resilience in facing certain challenges does not necessarily have the same resilience when confronted with other challenges (Abelenda & Helfrich, 2003). In her research, Hermawati divides the factors that influence resilience into three major themes, namely "I am", "I can", and "I have" (Hermawati, 2018, p. 70).

Keye and Pidgeon revealed, that resilience can also be referred to as the ability to maintain psychological stability in overcoming stress (Keye & Pidgeon, 2013). A bit different from Keye and Pidgeon, Fernanda Rojas in Cicilia on the other hand, refers to resilience as the ability to face challenges or difficult experiences (Utami & Helmi, 2017). Other definitions of resilience include one stated by Vanbrenda. According to Vanbrenda as found on Wiwin Hendriyani, resilience is the capacity to maintain the ability to function competently to deal with various life stressors. As explained further by Reivich and Shatte in Wiwin Hendriyani, resilience is a description of an individual's ability to respond to adversity or trauma in healthy and productive ways, which is characterized by resilience in facing various kinds of difficulties (Hendriani, 2018).

Discussing resilience will certainly differ from one individual to another. Previous researchers, in general, explain that resilience of each individual of parents relates closely to the level of difficulty that they face regarding the upbringing of their children. In this research, the study is focused on explaining the different type of resiliencies among parents with autistic children in its relation with different level of difficulties of their childrearing.

Understanding resilience in-depth in parents with autistic children can help service providers to formulate appropriate interventions not only for autistic children but also for parents. Insights from understanding different form of resiliencies can serve as a valuable source of knowledge for parents with autistic children and other relevant stakeholders.

The formulation of the problem in this study is (1) how is the resilience of parents with autistic children at the Palembang Therapy Center; (2) What are the factors that influence the resilience of parents with autistic children at the Palembang Therapy Center.

B. Methodology

This paper is based on field research applying a phenomenological approach. Informants in this study were parents with autistic children who seek out therapy at PTC, and therapists who carry out therapy at PTC. The whole informants involved in this

research include five parents with autistic children and three therapists in PTC. Data were gathered through observations, interviews, and documentation.

The researchers observed the interaction of parents with children at PTC, the interaction of parents with therapists, and the response/behavior of parents in the therapy process. Researcher asked different questions for parents and therapists. To the parents, the researcher asked about the initial response when knowing the condition of the child, parents' initial actions, and how they address the situation. To the therapist, the researcher asked about the development of the child, the therapy given to the child, and how the parents responded in the therapy process. The documents used in this study are parental demographic data and documents about the child development.

Findings were categorized according to important themes and codes that emerged during the process of analyzing the data. Researchers used Nvivo software to analyze the data. In the initial phase, researchers transcribed all the recorded interviews and put those interview transcripts onto Nvivo software. Then, researchers made several codes to represents the dominant themes regarding resilience. Researchers also used word frequency figure to see most frequent words on the transcripts and the context in which those words appear. Furthermore, researchers also made relevant classifications among informants to see whether or not there are differences among parents/caregivers regarding received supports, sources of information, and relation between emotions felt by parents and the type of autism of their child. Researchers, then, explain descriptively the essence of the phenomenon being researched.

C. Findings and Discussion

1. Resilience Among Parents with Autistic Children

This study involved five parents whose children receive therapy at the Palembang Trauma center and three therapists who do the therapy there. Researchers used the NVivo Version 12 to analyze the themes that emerged in the research data. Several dominant themes appear in this study, the most common themes are self-acceptance, adaptation, and self-efficacy.

a. Self-Acceptance

The acceptance of parents of autistic children at PTC cannot be ascertained. The psychological and emotional conditions of each parent are different. Some parents are quick to accept their child's condition and some are less accepting. For this reason, therapists at PTC always give positive affirmations to parents so that they can start

to accept the condition of their children.

Jersild, in Faradina, describes self-acceptance as a condition of individual willingness to accept physical, psychological, social conditions, self-accomplishment, as well as strengths and weaknesses. Some of the stages in self-acceptance described by Ross are rejection, anger, bargaining, depression, and acceptance (Faradina, 2016).

When parents know for the first time the condition of their children, most parents with autistic children at PTC did not take it for granted. Some of them do not dare to take their children to public places. This is because at the beginning they are still trying to regulate the emotions of regret, anger, and shame. Therefore, they tend to be afraid to take their children to public places and some still avoid mentioning that their children have autism.

In the past, I never brought A outside. Because if you take him out, it's mostly when I was busy. Sometimes I go to the market at 16.00. it's crowded there usually. The first time he was outside he threw a tantrum because he was afraid. (interview with Informant 2)

I'm more focused on fixing what can be improved, getting rid of the thought that my child is autistic. Because the word autism will only make my thoughts to be negative about the future of the child. (Interview with informant 1)

By the time, they began to accept their child's condition. They believe that every child has strengths and weaknesses. In addition, they would also gradually bring their children to public places to get them used to interact with other people.

b. Adaptation

Some forms of adaptation applied by parents with autistic children in PTC are behavioral adaptation and cognitive adaptation. Cognitive adaptation is the tendency to reassess an initially threatening situation more positively while behavioral adaptation is an adjustment to everyday life in the form of behavior (Mohan & Kulkarni, 2018).

In practice, the adaptation of behavior applied by parents with children with autism includes carrying out consistently and in highly disciplined manner tasks or guidelines given by doctors or therapists. Parents try to adapt their daily activity to daily activity of their children that contains several guidance about what the child should achieve in a given day. Parents also give more time to accompany their children to learn and to play and involve children in various activities.

Along with providing medium of learning and educational games, our children are also taken to the hospital or provate health clinic for therapy. (Interview with Informant 2)

I apply consistently and with high discipline task lists/guidances given by the doctor or therapist. (Interview with informant 4).

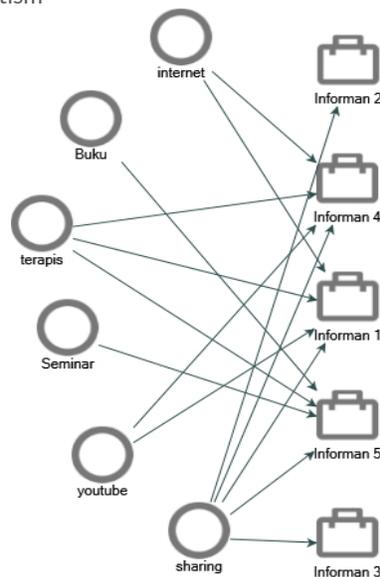
In addition, parents make more efforts to maintain their health so that they have good stamina in taking care of their children. They also think that if they got ill, no one will take care of their children which eventually leads to undermine the daily achievement of the children

No matter what, I must stay healthy and eat a lot of food (to have enough energy). (Interview with informant 1).

Even though at the beginning they were not equipped with a good deal of understanding regarding children with autism, parents at PTC tried to adapt by seeking information about their child’s condition. Some of the media they use to learn about autism are books, the internet, and YouTube. They also utilized sharing experiences with friends or family or through communities, attending seminars, and consulting with therapists or doctors.

Figure 1 shows the media and learning resources used by parents with autistic children at PTC. It can be seen that sharing with fellow parents is the most widely accessed learning resource by parents with autistic children at PTC. This shows that the experiences of people with the same experience not only provide additional knowledge but also indirectly provide strength to parents.

Figure 1: source of learning about autism



The cognitive adaptation of the parents can be seen in their belief that there is always a lesson to learn from any condition. This view motivates them to strive to provide education and therapy for their autistic children. In addition, the phrase "*Berdamai dengan diri sendiri* -at peace with yourself" is the term used by parents all the time. This shows that even though at the beginning they did not accept their child's condition, they tried to take lessons, get rid of negative thoughts about the child, and still give the best for the child.

c. Self-Efficacy

The majority of parents with autistic children at PTC believe that they become parents of autistic children because they are blessed with all the abilities to deal with it. They believe that they can live life with autistic children. "Yes, maybe, since this is what is given to me so it must be that I can handle it" (Interview with informant 1). Some parents also explained that their self-efficacy is formed after they learn and adapt. At the end of the day, they usually come to an understanding that "finally something that I think is difficult can be overcome" (Interview with informant 4).

Self-efficacy of parents with autistic children in PTC is analogue with the concept of "can do it" in the context of cognitive believe that reflect one's self-control ability. People who develop healthy self-efficacy tend to have optimistic attitude regarding their perceived ability to change the demand of their environment that challenges their own behaviour (Schwarzer & Warner, 2013). Self-efficacy is the belief that one can successfully carry out the behaviors necessary to produce results. Seeing other parents in the same situation at school or in therapy provides parents with experiences from existing social models, especially those related to children with autism (Mohan & Kulkarni, 2018). Therefore, this view reflects the resilience of individuals pertaining to their ability to address certain stressors in their life.

2. Faktors Affecting Resilience

According to the data analysis, several faktors influence the formation of resilience in parents with autistic children at PTC.

a. Individual capability

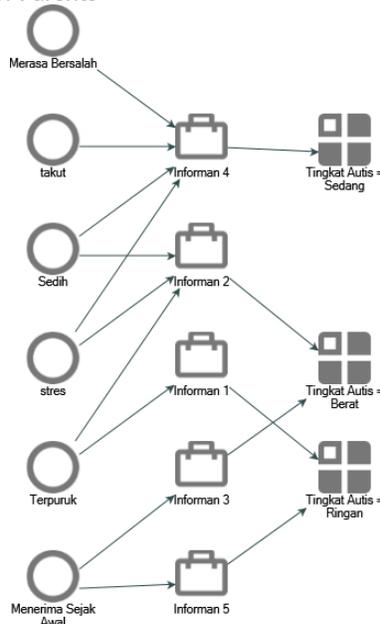
The ability of parents to establish a relationship with the therapist is one of the most important elements pertaining to individual capabilities. Parents in PTC have diverse kinds of relationships with therapists. Some of them are very cooperative in communicating with the therapist and consistently apply various stimulations at home. However, some parents are less cooperative due to their busy schedules.

All of the informants involved in this study had mixed emotions when they found out that their child is diagnosed with the syndrome of autism. Some felt guilty because they think that the autism their children have was due to improper parenting. Others felt down, stressed, and sad. Although some immediately accepted the condition of their children, all the informants were afraid and worried about the future of their children. Therefore, they hope that therapy can provide betterment in their child’s abilities.

The first impression of parents who come to PTC is that they feel worried and anxious about their child’s condition, very often parents also ask about their child’s condition to the therapists at PTC. (Interview with informant 8-Terapist).

Figure 2 illustrates the various emotions that parents feel, such as feeling guilty, afraid, sad, stressed, down, or accepting from the start. Figure 2 shows that negative emotions are not related to the type of autism experienced by children. Every parent with children diagnosed with any kind of autism has negative emotions when they first hear the news about their child’s condition.

Chart 2: Initial Emotional Condition of Parents



Despite being surrounded by feelings of sadness, stress, and anxiety at first, parents later try to implement various activities to regulate the negative emotions they feel. Some of the activities they do include playing with their cellphones, resting, eating outside, traveling by motorbike, shopping, cooking, and making cakes. These activities are chosen by parents so that they can survive in crisis conditions.

All respondents in this study have no prior understanding of autism. Thus, they develop their knowledge to understand the child's condition. They learn from various sources and share experiences with many people to be able to provide the best stimulation for children.

The economic condition of the family also has an impact on the resilience of parents, parents from lower economic stratum in this study explain that they often feel stressed about raising children. They are often caught with negative emotions when faced with the notion that they must provide for all needs of children to support their growth and development.

Sometimes I reach a turning point, especially when I have to make frequent visits (to hospital and therapist). It is economically painful for me. However, if I stop this (the therapy) then what will the future of my child be? (Interview with informant 2).

The explanation in this study supports the findings of Mohan who explained that social and economic status (SES) and social support are two important things in child care. A good SES will help parents avoid crises. Financial constraints that often prevent parents from providing proper education, decent housing, lack of transportation, and adequate facilities often put stress on parents (Mohan & Kulkarni, 2018).

b. Child Conditions

The conditions of children with autism at PTC are very diverse. Some of them have mild and moderate autism while some have severe autism. The treatments for children with autism are based on the child's ability and type of autism. The condition of children often affects the resilience of their parents. Parents with children who are not independent due to autism and are under five years old are more prone to not having good resilience. Autistic children who often have tantrums make parents even more anxious when they leave their children at PTC.

Instilling the skills needed to be independent is a huge challenge for parents of children with autism. Some children need repetition many times to become independent. Interaction with many people is also applied by some parents to build child interaction. In addition, parents often do activities together to build attachment and stimulate children's development.

All respondents in this study explained that the condition of the child in their early life was following the phase of growth and development of normal children. Parents involved in the study started to find out about their child's condition with autism at around the age of 1-3 years.

During the first 8 months, child responses are still good, his growth is also normal and did not show any symptoms of autism. At around 9-15 months, he started to become hyperactive, slept late at night, became a picky eater, sometimes he refused to eat and opted to just drink milk instead, threw tantrums, and became hyperactive. At 15-20 months, I started to feel worried since my child had not yet started speaking/babbling and his growth deteriorated. At 2 years old, I started to consult with dr. Tumbang about it. (Interview with informant 4).

According to the therapist at PTC, the developmental progress of children who have attended therapy sessions is also diverse. Some of them are experiencing rapid progress but some are not progressing. This depends on the activeness of parents in providing stimulating activities to children at home. Parenting, environment, nutrition provided, educational games and shows, and vacation to get to know the outside world also

There are children whose progress are very good, just good, and not good. (*Ada Anak yang progresnya bagus, ada yang sedang, ada yang buruk*). (Interview with informant 6-therapist).

c. Environment

The support received by parents with autistic children at PTC comes from many sources such as family, friends, therapists, doctors, and people in their neighborhood. Informants whose families live close by tend to have more helpful resources in assisting autistic children. However, some families must be informed in advance about what can and cannot be given to autistic children.

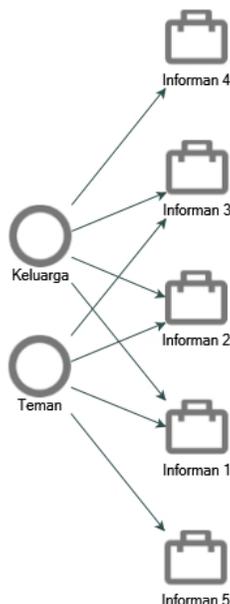
Initially, I was overwhelmed in childrearing because I am also far from my family. (Interview with informant 4).

Sharing experiences with friends who have the same situation has resulted in the formation of communities of people with common interests regarding the parenting of children with autism make parents more capable of dealing with problems in their lives.

From his grandmother, and friends. So, everyone shows supports instead of alienation. (Interview with informant 4).

It can be seen from Figure 3 that family and friends occupy a balanced position in providing support to parents with autistic children. With the support from the surrounding environment (friends and family) parents will feel more resilient and able to survive in crisis conditions.

Figure 3: Social Support among Parents



This is in line with the results of some previous studies that have shown that social support is a variable that is significantly related to mental health problems such as depression, stress, anxiety, and suicidal ideation (Bulkhaini & Purwandari, 2015; Djuwitawati & Djalali, 2015; Nurfatimah & Entoh, 2018; Salsabhilla & Panjaitan, 2019). Family attachments contribute to good coping. Families with good coping will be able to have good resilience as well (Krstić & Oros, 2012; Skinner et al., 2001).

Quoting Gottlieb, Ernawati & Rusmawati explained that social support consists of real help, verbal and non-verbal advice, and actions from others that have a positive emotional or behavioral effect on the recipient. In line with this, Sarafno explains social support as an individual's perception of the support received from others such as a sense of comfort, attention, and assistance given when needed (Ernawati & Rusmawati, 2015).

d. Religious values

For a country where the majority consider themselves religious, religious values play an important role in building resilience. With the religious values they profess, they view the problems they are experiencing more positively. The values and practices of religion that many parents apply are gratitude, believing in prayers. Surrendering to God Almighty is the Action they choose after praying and trying.

Religious values such as gratitude are one (theme/coding/what) that often appear in interviews. Kurniawan explained that gratitude can be realized through four things, namely being grateful with the heart, grateful verbally to Allah, being grateful verbally to humans, and grateful with actions (Kurniawan et al., 2012).

Parents give it all to God after they are sure they have done the best they can. It is one way to give them inner peace. This is done to relieve feelings of anxiety, especially regarding the child's future. The results of this study support the results of several previous studies showing that people who practice Gratitude increase their enjoyment of life, and significantly reduce the impact of the difficult circumstances they experience. People describe feelings of gratitude as a warm, friendly experience, and make difficult conditions easier (Amjad, 2013). In addition to that, religious affiliation is another faktor that helps reduce stress and improve coping (Krstić & Oros, 2012; Skinner et al., 2001).

According to interviews with all informants, gratitude is the most used way by respondents to keep up their level of resilience. This is reflected in the following excerpts of interviews with informants 4, 3, dan 2.

Yes, praise Allah, I alwast try to be gratefull. (interview with informant 4).

I am gratefull because taking care of my child A is easy. (Interview with informan 3).

I return all (my problem) to Allah, surrender it all to Allah and belief I can do it. (Interview with informant 2).

3. Patterns of Resilience Among parents with Autistic Children in PTC

According to results of this research, three patterns of resilience can be formulated which can be classified based on the level of difficulty. The first group is parents with a high level of difficulty which is characterized by a low level of education, less well-established economic conditions, living far from family, and the level of autism in children. Parents at a high level of difficulty tend to have to try harder in increasing self-resilience.

The second group is parents with moderate difficulty level. Even though the second group is economically more established, they need to optimally divide their time to balance between their children's activities and their own routines. Without optimal support and acceptance from family and friends, the second group are also vulnerable to get mental health problems. The first and second groups tend to have a longer time to shake off feelings of shock and accept their child's condition.

The third group is parents with low difficulty level. They are parents with college education backgrounds who are able to understand the condition of children and have access doctors, therapists, and schools. Parents who are in the third group tend to be more accepting of their children's conditions and calmer in crisis situations and are able to optimize efforts to help achieve their children's optimal potential.

The result of this research supports the results of some previous studies about resilience. Resilience has been defined in various ways, but the two most important elements that appear in all definitions include threats to healthy development and positive adaptation (Mawarpury & Mirza, 2017). Furthermore, Farkaz and Orosz describe two constructs that build resilience. First, the function is to keep the personality system stable and intact, and second, to adjust the personality system adaptively to a dynamically changing environment (Farkas & Orosz, 2015).

Walsh explains three foundations that make family resilience, namely belief systems, organizational processes, and communication processes (Walsh, 2016). These three things are inextricably linked and serve a continuous role in building resilience in the family. Therefore, practitioners who work with families can pay attention to these three foundations to be able to see the resilience of the family.

D. Conclusion

The resilience of the parents involved in this study is diverse. This diversity is related to the type of burden that parents bear in raising children. The dominant themes that emerged related to parental resilience in this study were self-acceptance, self-efficacy, and adaptation. Factors that affect the resilience of parents with autistic children are individual abilities, children's conditions, environment, and religious values. Based on the above mentioned explanation, this study explained how different level of difficulty (high difficulty, medium difficulty, and low difficulty) pertaining to the upbringing of children with autism leads to different types of resilience among parents or caregivers.

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