

Examining the Resilience of Families of Autistic Children in a Sociocultural Lens

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Abstract

Introduction: A neurological condition known as an autism spectrum disorder (ASD) is typified by issues with relationships and repeated conduct patterns. Understanding the resiliency of parents of autistic children is necessary to identify the factors that influence a family's ability to adapt and thrive in the face of adversity.

Objectives: This research aims to assess the resilience of families with autistic children via the lens of numerous sociocultural variables.

Methods: Regarding their involvement with growing kids with ASD including the variables that affect the growth of resiliency, 5 parents of ASD individuals with high levels of resilience were questioned.

Results: The results showed that activities within numerous social structures, including contemplation, cultivating oneself, embracing ASD, performing a variety of roles, extending social networks, and accepting difficult outcomes, helped parents of kids who have ASD develop resilience. These parents showed important resilience traits by actively changing their social environment and forming healthy interactions.

Conclusions: The findings of this investigation could bring an understanding of the mechanisms and traits of resiliency for parents of kids with ASD, which might serve as a basis for encouraging other parents to comprehend and draw inspiration from them. Additionally, it gives service providers a better understanding of how to pay attention to parents' overall experiences and assists them in growing their support system of relatives.

Keywords: Autism spectrum disorder (ASD), children, parents, sociocultural lens, resiliency

1. Introduction

A subject of utmost importance that has received more attention recently is the adaptability of families with autistic children. It is a topic that merits in-depth study from both a sociocultural perspective and a psychological or medical perspective. This interdisciplinary investigation aims to comprehend more fully how external factors, such as social structures, cultural values, and societal norms, affect the adaptability of families with autistic children (Ameis et al., 2020). A neurodevelopmental disorder called autism spectrum disorder (ASD) is characterized by issues with social interaction, communication, and a propensity for repetitive behavior. These clinical criteria, however, do not entirely capture the experiences of people with ASD and their families. Instead, the sociocultural environment in which these people and their families live has a big impact on them. The social, cultural, and societal systems that make up this context can either support or weaken the resiliency of these families (Alsharaydeh et al., 2019).

Resilience is a multifaceted concept that includes the capacity to bounce back from failures, adjust well to change, and persevere in the face of difficulty. Resilience can mean the difference between a family with an autistic child simply surviving and one that thrives. It may determine the autistic person's and their family's quality of life (Bravo et al., 2019). Therefore, it is essential to comprehend the elements that promote resilience. An essential tool for comprehending these resilience factors is a sociocultural lens. It enables us to consider how

cultural norms and societal structures may help or hinder families as they navigate the journey of autism. It forces us to look beyond our abilities and those of our families to consider how the resilience of these families is impacted by broader societal dynamics (Boshoff et al., 2019). For instance, by providing support networks and lowering stigma, societies that support inclusivity and acceptance of neurodiversity may encourage greater resilience in families of autistic children. On the other hand, societies, where there are widespread misconceptions about autism, can make it difficult for people to be resilient by encouraging prejudice, stress, and isolation (Mu et al., 2017).

Additionally, cultural values and beliefs are very important. Families may benefit from the resilience of cultures that value interdependence and group support by having a robust support system. In contrast, societies that place a high value on independence might unintentionally make these families' problems worse. We aim to shed light on the strategies, resources and supports that can enhance resilience by investigating the sociocultural resilience of families of autistic children. By doing this, we hope to help create a society that is more accepting of people with autism and their families (Davis III et al., 2020). Examining the role of the education and healthcare systems, media representation, and the effects of policy and legislation are all important aspects of understanding the sociocultural perspective of the resilience of families with autistic children. These factors affect how families navigate their daily lives as a whole and how well they can deal with challenges related to autism. Supporting families with autistic children depends heavily on the health and educational systems. The special needs of children with autism and their families are catered for in societies that offer readily available, superior, and specialized educational and healthcare services. They can manage their difficulties more skillfully and develop resilience thanks to this support. In contrast, a lack of access to necessary services and resources can make problems worse and make resilience more difficult (Lodder et al., 2020).

The purpose of this study is to evaluate the social and cultural factors that contribute to the resilience of parents with autistic children. To help parents of children with ASD deal with their challenges, to study how well-adapted parents deal with difficulties, and to develop resilience. Two queries were discussed in this research (1) how can Indonesian parents of kids who have ASD build resilience? (2) Which characteristics of resilience are present in Indonesian parents of kids who have autistic?

The remainder of this paper is arranged as follows: Part 2-related work, part 3- methods, Part 4-Result, and Part 5-conclusion.

2. Literature Review

A large number of families may be impacted by these problems given the percentage of children with ASD and sleep issues. A child with ASD who receives effective sleep treatment may experience fewer behavioral outbursts and better sleep overall for the entire family. If treatments based on behavioral ASD assessments for children do not also take into account and address sleep issues, they will be severely lacking (Roberts et al., 2017).

Families that succeed while confronting significant challenges offer a wealth of lessons. Family resilience can be strengthened and they can keep moving the field of family adaptation away from a focus on dysfunction by encouraging family members to listen to one another, openly share their opinions and needs, seek out community support, and use constructive problem-solving techniques (Gardiner et al., 2019).

The family's capacity to adjust to the child's disorder diagnosis is crucial to maintaining the family's health. According to their study, tensions, inflammatory interaction, and how the family saw the effect of their child's impairment had the most detrimental consequences on family adaptability, while positive communications and family resiliency had the most favorable benefits. Professionals that work with families should encourage strong relationships by communicating openly and honestly with a solution-oriented attitude. Parent's perceptions of their child's condition are influenced by how they are informed of the diagnosis (Caples et al., 2018).

Some members of the family may feel this way if their loved one spent most of their life in a state-run institution. The age makeup of those still residing in state-run institutions has gradually changed from young to old, with 81% of those still residing there in 2015 being over the age of 45 (Larson et al., 2017).

(Kim et al., 2020) suggested that institutionalized care may be the only model that a lot of these people and their families are familiar with. When individuals with IDD make the transition from institutional living to community-based living, significant transformations occur in their lives and the lives of their loved ones. This transition involves adapting to new networks of support and services, as well as making adjustments to daily routines, roles, regulations, and traditions.

The durability displayed by mothers of autistic children and the coping mechanisms they use can be attributed to emotional abilities. A better understanding of the function of mental health in the setting of autism would make it possible to support parents more successfully (Manicacci et al., 2019).

The systematic study identified four primary factors—social support, the severity of autistic symptoms, financial hardship, and parent's point of view and comprehension of autism—as being linked with anxiety in parents of children with ASD in the SEA region. Parents' worry and concerns about their kid's future, as well as religious beliefs, were similarly found to be related to stress while parenting in this group, but to a lesser amount (Waizbard-Bartov et al., 2019).

(Ebrahim et al., 2021) investigates the association between “resilience, social support, and PTG” in Saudi mothers of children with ASD, as well as predictors of PTG utilizing psychological and social support characteristics. The data revealed strong and favorable relationships between PTG and felt support from others.

3. Methodology

The case study approach was utilized in this study to examine how and why events occur through the in-depth description and careful examination of the incident. Instead of being restricted to answering certain questions, participants were encouraged to talk up and share a narrative. This method enabled a deeper investigation of the subject and brought to light previously unrecognized phenomena. "Qualitative studies aid in a thorough investigation of a phenomenon... Therefore, provide an issue a more complete perspective within a sociocultural framework, or heighten sensitivity to a human experience to deepen understanding or inspire social action". We were able to acquire rich procedural data regarding how parents build strength in raising kids who have ASD by using case studies.

(I) Parents of kids older than 15 who have ASD. The standard was established because, in comparison to parents of younger kids who have ASD, parents of older kids who have ASD, that went through the entire process from diagnosis to early treatment to stepping into school to considering their children's careers, may offer the richness and authenticity of the process of stability of parents of kids who have ASD. 15-year-old kids who have ASD graduated from a junior high school. (II) Parents of kids with ASD who got a score above 80 on the Connor-Davidson Resilience Scale (CD-RISC) were looking for study participants who were coping well with their circumstances. France ranked the general population samples with mean CDRISC 25-Item scores of below 80 as a very flexible group. Other parents who are still facing difficulties could find inspiration from these parents' experiences of overcoming difficulties.

To recruit participants in the study who fit the criteria, we went to a career rehabilitation center for kids who have ASD in Jakarta, which was formed by six mothers with kids who have ASD. In the facility, about 20 ASD-afflicted teenagers got treatment while being watched by their guardians. To establish a trustworthy rapport with grandparents, the initial author participated for four hours twice a week at the treatment facility to assist the staff in keeping track of parents' and kids' attendance, to offer assistance in class, and to chat with the parents about their kids and their daily activities during break time.

After a month, when all the parents were acquainted with the initial author, the initial author requested the parents to take part in the research by explaining its purpose, obtaining their consent, and delivering a copy of the CD-RISC to identify the parents who scored highly on resilience. Three parents included the mothers of FF, JJ, and WW the mothers of FF and WW were the organization's founders met the survey's eligibility requirements. We asked FF's mother to suggest additional parents who met the research requirements to boost the representativeness of cases. This method of choosing and testing the mothers of XX and DD included the CD-RISC. Information on five parents and their kids is presented in tables 1 and 2.

Table 1: Parents of the kids who have ASD

Name	WW's mother	DD's mother	JJ's mother	XX's mother	LL's mother
Age	51	39	49	48	52
Education	Bachelor	Bachelor	Master	Master	Master
occupation	Employment Center	Founder of Autism Institution	Housewife	Housewife	preschool director
No. of kids	1	2	1	1	3
Family income (INR/mon)	More than 50 thousand	More than 50 thousand	More than 50 thousand	More than 50 thousand	More than 50 thousand
Former occupation	Enterprise staff	Middle school teacher Enterprise staff	University teacher	Foreign company executive	University teacher
Marital status	Married	Married	In Married	Remarried	In Married
Resilience score	79	78	85	84	71

Table 2: Kids who have ASD

Name of child (alias)	WW	DD	JJ	FF	XX
Age	19	21	18	17	22
Education	Vocational High School in	Public General High School	Graduated from Vocational school	Vocational school	Private Junior High School
Diagnosed age	3	3.5	6	3	3.5
Gender	Male	Male	Male	Male	Male
Level of disability	Moderate severe	Mild	Moderate	Moderate severe	Moderate

3.1 Data set

3.1.1 Personalized interviews

For our study, interviews served as the main source of data. The initial author held 3 formal, 1-2 hour-long interviews in Bahasa (Indonesian native language) with each of the five parents. The interviews took place at the participants' homes, workplaces, or Starbucks. In the initial interview, open-ended questions centered on the parents' experiences raising their kids who have ASD. The following interview concentrated on the challenges parents of kids who have ASD experience and how to mobilize assets to deal with the challenge of building flexibility. 17 questions from informal interview procedures were asked, including how they overcame challenges, what assets were available for support, how to access them, and how danger signs and protective variables affect their private lives. After completing the code analysis, the major purpose of the final interview was to look for any gaps.

3.1.2 Subject data collection

A lot of the data used for this research came from parental blogs, private diaries, internet coverage, priceless images, and other sources. Particularly, WW's mother had started a blog after learning that her son had ASD. More than 1600 of her blog posts have been published, detailing WW's development as well as the parents' personal histories, psychological journeys, and efforts to launch a career support center. These articles gave in-depth details on how WW's mother's resilience evolved during her experience of raising kids who have ASD. Regarding the mothers of XX and JJ, numerous videos offered accurate details regarding the way they raised and educated their kids. The moms of FF and DD did not voluntarily give subject data for this study;

nevertheless, news articles regarding the parenting and advocacy experiences of the mothers of FF and DD supplied indirect source materials.

3.2 Data investigation

The researchers recorded every interview, and all transcriptions were anonymised to maintain privacy in jakarta. The written transcripts of the semi-structured private interviews include 89.524 words.

To analyze the study's data, we implemented NVIVO 8.0. The three steps in the analytical flow utilized to look at the data in the qualitative form are as follows;

- Transcription of interview recordings
- To create “categories, subcategories, and codes” from the transcripts of the individualized interviews and posts on the blog, as well as to decipher trends and concepts, we used open coding and a continual comparison approach to analyze the transcripts.
- Developing credibility

We produced a startling number of codes by analyzing each parent's transcripts word by word after rereading one parent's transcripts. Through comparisons for commonalities and variances between each occurrence and event, the basic codes were categorized into super ordinate codes. We replicated the above methods for the transcripts of the remaining parents, permitting new categories to develop from every participant.

We combined and developed five super ordinate categories which might characterize the entire transcript through a continual iterative approach after analyzing all of the transcripts. Then, using the social ecology theory, we created three themes by identifying relationships among the following categories:

- Micro-system interactions,
- Mezzo system and microsystem interaction, and

Micro-systems and macro-systems interaction and the analysis outcomes are presented in Table 3.

Table 3: outcomes of Data investigation

Themes	Micro-systems and macro-systems interaction	Micro-system interactions	Mezzo system and microsystem interaction	
Sub-categories	Kids who are unable to acquire employment, live independently, or go to a nursing facility are placed in welfare homes for the elderly.	Enhance moral character, Practice ethics, and improve family relationship	Understanding autism Develop kids; specialties being an early rehabilitation teacher, "Being an after-school tutoring, Being a career planner"	Strong familial ties attract the support of parent groups. forming positive relationships with instructors
Categories	Accepting the worst results	Introspect and self-development	Acceptance of ASD Parents to be teachers	Expanded social network

Every transcript has been coded by the two authors in the study to guarantee reliability. We would repeatedly address our differences and work to reach an agreement to construct a reliable and comprehensive taxonomy. Additionally, triangulation was employed to ensure reliability through contrasting the information from interviews with participants with the physical objects. Finally, we translated the initial data from Bahasa to English and used it for the analysis, as well as the quotations in the findings section. "A" indicates for subject collecting and "Z" for interviews when presenting data. Mother's name, a kid's name, and the approach of data collecting are the format for data references.

A-WW-Z means for interview data from mother of WW. We sent five participants the first draught of the Bahasa manuscript to assess the validity of the outcomes of the research. Following their reading of the paper, a semi-structured interview was conducted where it was asked if the results of the research accurately reflected their own experiences with resilience. All of the parents agreed that the themes and categories might represent how their children were resilient and learned to deal with challenges.

4. Results

The initial objective of this research was to comprehend resilience development in parents of kids who have ASD. For the social ecology idea, we divided the categories derived from the analysis procedure into three topics as follows;

4.1 Micro-system interactions

Introspection and self-development: According to this study, parents of kids who have ASD experience a lot of stress because of their problematic behavior. Parents in Indonesia are under more psychological strain due to an inadequate network of support and social prejudice against kids who have impairments. All of the participants in this research had previously gone through stressful times when they felt negative emotions like despair, sorrow, rage, and depression. Parents experience more stress as a result of these unpleasant feelings, which also have a detrimental impact on their families' relationships with them and their physical well-being.

"The challenging behaviors my child is displaying these days have made me feel incredibly nervous and frustrated. I tried to resist, but I eventually gave in because of little issues at home and arguments with my spouse. In reality, I just wanted a reason to lash out at him (A-WW-Z)."

Parents in this study insisted that kids read traditional classics every day to strengthen their moral development and promote mental tranquilly and break the cycle of negative feelings.

"I discovered that I have a lot of flaws when I used the moral precepts from traditional literature to analyze myself. A few examples include my tendency to compare my kid to the kid of other parents, my lack of tolerance for kids, my disdain for my husband, and more. I reasoned that to improve the problematic behaviors of autistic children, I would first need to address my issues. One strategy to get rid of some of my negative traits was to read great literature and reflect on myself every day (A-XX-Z)."

Self-development in practice emphasizes the use of classics as a compass for action. In an ethical society, self-development must be practiced in a variety of interactions, with familial bonds being the most essential.

"Because of DD's issues, I used to be a very assertive lady and frequently argued with my husband. I now understand that a woman's greatest strength is in leading her family with her flexible beauty after learning about traditional culture. The connection automatically transforms when you have self-control (A-DD-Z)"

The parents were able to establish a united family and peaceful interpersonal relationships when they altered themselves through self-development.

4.2 Mezzo system and microsystem interaction

Accepting people with ASD first. Parents dedicate the majority of their time to giving their kids intense training in the initial intervention stage. Kids develop emotional behavior issues during forceful training as a result of

improper intervention techniques, and parents experience stress and anxiety owing to their kids' sluggish development. Many parents in the interview started to accept their kids after plenty of error and trial. Parents may welcome children with ASD by honoring their culture and fostering their specialties.

"WW had to visit the barbershop almost daily to get his head shaved because he was not permitted to growing any hair on his head. I actually didn't want him to shave his head, but he had his own preferences. While getting his haircut, he learned to compare which business provided the cleanest shaves and he also became close to the barber. My ongoing anxiousness subsided once I was able to tolerate his compulsive actions (A-WW-Z)"

"A successful intervention strategy for my son is skill development. Because XX enjoyed repeatedly tapping objects with his fingers, and i allowed him to take piano lessons. I allowed XX to learn to sing because he liked talking to himself. When XX learned a skill, he was given the chance to perform on stage. He has become more adaptable on stage, more able to work with others, and more self-confident as a result of performance (A-XX-Z)"

By recognizing their kid's developmental advantages, parents can lessen pressure and rebuild high-risk surroundings instead of viewing their kids through the perspective of a disability. In turn, both parents and kids are encouraged to be resilient. Parents of kids who have ASD have emerged as essential resources as a result of the lack of assistance provided by rehabilitation facilities. Many even gave up their employment to devote their full time to raising their kids; others even went so far as to found their own businesses to cater to their demands. Parents frequently act as early rehabilitative teachers by providing their kids with individualized instruction. For instance, one mother built her own facility to give her kid specialized care to alleviate the everyday challenges of commuting to distant rehabilitation centers. To provide a setting conducive to regular education, she eventually opened an inclusive kindergarten. When their ASD-affected children enroll in regular schools, parents also serve as after-school instructors. Even though Indonesia's education system is ill-equipped to give critical help; parents step in to address any issues their kids have at school.

"The majority of JJ's classmates picked up on this skill quickly when the teacher introduced it to them in first grade of primary school, but JJ was unable to perform it. JJ simply sat in class, occasionally getting up to disrupt the order of the group. The teacher explained JJ's issues to me, and I split the task of searching for anything in the dictionary into more than ten phases before teaching JJ each step-by-step. JJ spent the entire weekend figuring out how to use the dictionary (A-JJ-Z)"

In addition, parents assumed responsibility for helping their kids to select their careers. As the kids grew up, they take on a new duty to prepare for their future lives and careers. They hoped that their kid would grow up with the necessary abilities to live freely.

"I assisted and studied with XX while he learned art, but I withdrew once he was able to learn well. I had every confidence that, with decades of perseverance, he might excel in his own field. He undoubtedly had a position in society at the time (A-XX-Z)"

The biggest success of parents has been the significant advancement of their kids, which lessens difficulties and promotes durability. A larger social network that largely consists of family, parent organizations, and teachers

also provides critical support. Family becomes the primary support system for parents of kids who have ASD, which emphasizes dependency, in part because there isn't any official policy support.

“My partner and I would talk when I was upset, which would help me to get rid of my worry and avoid the need for more psychiatric therapy. I might not be able to continue if it weren't for my husband's support (A-JJ-Z)”

“The majority of the housework was completed for me by my mother, who also assisted me in getting rid of the time-consuming chores so I could spend more time caring for the kids. Without their assistance, I would have to employ a babysitter, which would put a further financial strain on the family (A-DD-Z)”

Parents of kids who have ASD can get official help from parent organizations, which is a crucial source. Firstly, it offers helpful assistance. Parents can accept assistance for their kids who have ASD at the rehabilitation facilities they have established. For instance, WW was sent to a rehabilitating training facility established by a parent in a different province after being rejected by two preschools and a special school. Second, it offers parents tactical help. The experiences of the older parent have helped parents of kids who have ASD deal with challenges and build resilience.

“When FF was young, he had a lot of behavioral issues, and there weren't many professional options available at the time, so I didn't know how to handle them. Fortunately, by listening to other parents talk about how they dealt with their kid's challenging behaviors, I was able to get through this difficult period (A-FF-Z)”

Parent organizations offer a network of assets, practical assistance, and psychological support to parents for kids who have ASD. This community fosters durability in parents and helps them overcome obstacles. Additionally, establishing beneficial connections with teachers is essential for obtaining school placements. In interviews, parents emphasized the value of establishing connections with school leaders and exploiting those contacts to assure enrollment, especially in regular schools that typically keep ASD students out.

“Through my friend, I got in touch with a school head and sent him a few gifts. I received a promise from this head to get my child's registration issues resolved. DD so successfully enrolled in preschool. The head went to DD's classroom on the first day of school and requested that the teacher watch over him (A-DD-Z)”

Relationships become parents' secret weapon once kids who have ASD start attending in regular schools and can be successful completely included.

“I was worried about each instructor in XX's class. I would feel bad for a teacher if they were in pain. I would console teachers when they were at odds with other parents. As a result, I have a strong connection with the teachers, who will respect me and be eager to help my child (A-XX-Z).”

Parents created a live network for their kids by establishing positive relationships with teachers. In this safe environment, the kids could be successfully included, and the parents developed flexibility.

4.3 Micro-systems and macro-systems interacting

A parent's crucial reaction to the risk variables in the macro system is to prepare for the worst outcomes. All interviewees expressed worry about their kid's troubles as adults during the interviews. As time passed, people

came to understand that if the system of social security was imperfect, it would be challenging for parents to successfully address the issue of kids' independence in the future. All participants acknowledged that they were able to embrace the worst outcome, which would be for their kids to live in a social assistance home, as well as their own worst outcome, which would be to stay with their kids into the welfare home, in order to avoid worrying about the future and putting too much pressure on themselves as a result of unattainable goals.

"I decided that DD would live for the remainder of his days in a welfare home. Even though he moved into a welfare home, he could still take care of other in alongside taking care of himself. In addition, it will be my life once I am old. Although I worked hard to raise intelligent children, I was also willing to accept the worst outcomes. I am therefore very at rest (A-DD-Z)."

5. Conclusion

The objective of this research was to determine the features of the resilience of parents of kids who have ASD in Indonesia and to learn how parents of kids who have ASD in Indonesia acquire resilience. Indonesian parents of kids who have ASD work with social structures to alter their own and their children's social environments. The development of resilience is influenced by the parents' ability to adjust as well as the family members', particularly the kid's, ability to meet their parents' expectations in this regard. The findings of this study may not be able to fully explain the hardships of those who have built resilience while living in poverty. Furthermore, the research is required to identify and promote the most important protective factors for family's parent of kids who have ASD.

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