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Not Too Involved but Really Care: Father's Acceptance Who Have Children with Autism Spectrum Disorder (ASD)

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Abstract

ASD constitutes a persistent mental disorder that significantly impacts family dynamics, involving both parents and siblings. Limited research has delved into the dynamics of how siblings undergo the process of accepting a father with an ASD child. This study aims to investigate the unique process of paternal acceptance in the context of children with ASD. Utilizing a case study approach, in-depth interviews will be conducted with 8 fathers of ASD children. The acceptance journey for fathers in the realm of ASD differs from the stages outlined in Ross' theory. Fathers traverse a stage of confusion followed by the realistic stage, contemplating the subsequent steps and actions to optimize the development of their ASD children. While fathers may not be directly involved in day-to-day parenting tasks, they exhibit commitment by providing financial support, monitoring their children's ASD development, and realistically preparing for their future.

Keywords: acceptance, father, ASD children

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Introduction

Autism Spectrum Disorder (ASD) is classified as a neurodevelopmental disorder in the DSM-5. The diagnosis is established when an individual exhibits two types of symptoms: deficits in communication and social interaction (APA, 2013). The severity of ASD in children can range from mild to severe, encompassing impaired interaction, communication (including speech delay or inability), and comorbid disorders such as physical issues and attention-related challenges (Lee, Chen & Lin, 2016; Danuatmaja, 2003; Trevarthen, 1999; Warouw, 2003).

These conditions significantly impact the family, the closest environment for ASD children. Families with ASD children undergo various changes, as evidenced by research from Ginanjar (2002) and Witt (2005), highlighting stress disorders arising from the child's behavior, abilities, associated costs,



education, therapy, and strained relationships within the family. Physical fatigue, depression, anxiety, emotional distress, marital dissatisfaction, impaired family relations, and social withdrawal are also reported by families (Shivers, 2019; Ramelet, 2017; Yuwen, 2017; Harnum, 2015; Dewi & Wibhowo, 2014; Crai, 2014; Hartley, et al, 2016; Najmi, et al, 2018), affecting both mothers and fathers.

While previous research extensively explores mothers' experiences as primary caregivers, there is a scarcity of studies examining fathers' feelings (Barker, 2011; Frye, 2015; & Daulay, 2021), despite their crucial role in therapy outcomes and overall family well-being (Bagner, 2013; & Frye, 2015).

A pivotal stage for families to provide optimal care for ASD children is the acceptance of their condition (Fauziah, 2021; Johnson, 2020; Frye, 2015; Sommer, 2013). Acceptance enables families to offer love, attention, and realistic expectations, reducing parental stress (Indah, Zikra, & Yusri, 2013). Mother's acceptance is highlighted as a key factor in fostering positive mother-child relationships (Yavuzer, 2010), and Bekenkamp et al (2014) found a correlation between self-acceptance, self-actualization, and the physical health of parents with ASD children.

Remaining in denial and isolation impedes family adjustment and resilience. Grieving is acknowledged as a natural response to loss (Sommer, 2013), and parents should be supported in navigating these emotions towards a positive family direction (Frye, 2015). However, research on fathers' self-acceptance remains limited, underscoring the need for further investigation to ensure that self-acceptance is addressed for both mothers and fathers.

While studies abound on parenting acceptance and its effectiveness, as well as the process of mother acceptance (Han, 2020; Whittingham, 2022; Wright, 2023), there is a notable absence of research on the stages and processes of father acceptance. This gap prompts inquiry into the stages of self-acceptance among fathers with ASD children, the influencing factors, potential gender-specific experiences, and represents an intriguing avenue for future research.



The significance of fathers

The significance of fathers in the context of ASD is highlighted by Frye (2015), emphasizing positive impacts on family dynamics through their involvement in parenting. Fauziah (2021) underscores the importance of positive communication, commitment, and closeness between parents for a harmonious family with ASD children. Intact parental roles are linked to optimized ASD child care, independence, and the sexual development of ASD children (Kusumastuti, 2014; Maulana, 2014; Fleischer & Zames, 2010; Hoogsteen & Woodgate, 2013; Mackin, 2016). The heavier burden on single mothers caring for ASD children is acknowledged, emphasizing the role of fathers in supporting language development, indirectly contributing to the communication skills of ASD children (Watson & Flippin, 2008).

Method

Design

A qualitative investigation employing a single-case, multiple-participant, phenomenological approach was undertaken to illuminate the experiences of fathers raising children diagnosed with Autism Spectrum Disorder (ASD). Employing a phenomenological framework allows for a deep exploration aimed at comprehensively understanding and authentically portraying the narratives of the research subjects, facilitating a richer comprehension of the phenomenon (Munhall, 2012). Case studies serve as a suitable research design when there is limited existing information on the phenomenon under study and when the phenomenon is intricately intertwined with the lives of the participants, making it inseparable (Hentz, 2012; Yin, 2003).

Participants

Inclusion criteria for participants were as follows:

I. Fathers of children formally diagnosed with ASD (ASD: International Classification of Diseases, Ninth Revision [ICD-9] Code 299).

- 2. Voluntary consent for interviews.
- 3. Residing in the same household as their children with ASD (Buck, 2013).



Given the constraints imposed by the pandemic, data collection methods varied, with some participants engaged in direct interviews (six participants) and others participating via online platforms such as Zoom (two participants). Ethical clearance was obtained from researchers holding certificate number 2259-KEPK. To ensure a comprehensive understanding of the phenomenon within its natural context, single-case studies involving multiple participants should ideally include a minimum of four participants (Stake, 2006; Yin, 2003). However, the maximum number of participants is capped at 10 to prevent data saturation and maintain focus on the study's central objectives (Stake, 2006; Yin, 2003). In this study, eight fathers were actively involved in the single-case, multiple-participant case analysis.

Instrument

The theoretical framework guiding this study was based on Kubler Ross, with acceptance serving as the fundamental concept for acknowledging the realities of life, encompassing both positive and negative experiences. Kubler (2008) defines acceptance as the ability to confront reality instead of succumbing to hopelessness. Prior to achieving individual acceptance, individuals typically undergo various stages, including shock, denial, grief, depression, ambivalence, guilt, anger, shame, embarrassment, bargaining, adaptation, reorganization, and ultimately, acceptance and adjustment (Kubler, 2008).

Following approval from the Institutional Review Board, the recruitment of participants involved purposeful sampling, wherein individuals with extensive experience related to the phenomenon were consciously selected. Additionally, snowball sampling, involving networking to identify participants with relevant experience, was employed (Grove, Burns, & Gray, 2013). The study included eight fathers residing in the same household as their child(ren) diagnosed with ASD, selected from Semarang, Central Java (five fathers), and Madiun, East Java (three fathers). All fathers meeting the sample criteria and expressing willingness to participate were included in the study.



Procedure for Collecting and Analyzing Data

To gather data, single face-to-face interviews were conducted either in the fathers' residences or in a setting chosen by the participants. Fathers determined the time and location of the interviews to minimize disruption to their schedules and enhance their comfort. The interview questionnaire and demographic sheet can be found in Boxes I and 2. The questionnaire covered open-ended inquiries related to children with ASD, the impact of ASD on fathers' lives and families, challenges faced, reactions to the diagnosis, responses of others to their children, advice for fellow fathers of children with ASD, and strategies for overcoming ASD-related challenges. Specific questions focused on the acceptance stage, exploring when and how fathers accept their ASD children. All interviews were audio recorded to ensure data accuracy. Transcription of the interviews was carried out within 24 hours by the primary investigator (PI) and subsequently reviewed for accuracy by comparing transcriptions with the audio recordings. The demographic questions were posed by the PI, and responses were recorded on the demographic form.

Simultaneous data collection and analysis were performed to identify common themes, potential conflicting themes, and any data gaps that might necessitate adjustments to the interview questionnaire (Creswell, 2014; Creswell et al., 2007; Hentz, 2012; Yin, 2003). The PI utilized lineby-line coding to analyze each transcript, identifying both emotion and in vivo codes. Emotion coding involved discerning expressed or perceived emotions based on participants' responses to interview questions (Saldana, 2013). In vivo coding provided a nuanced understanding of participants' experiences by utilizing their own words to describe or explain phenomena (Saldana, 2013). Codes and supporting data were organized into themes using a saturation grid. NVIVO qualitative data analysis software (version 12) (n.d.) facilitated the organization of transcripts, quantification of codes, categorization of codes into themes, maintenance of the code book, and creation of an audit trail for the study.

Credibility, applicability, dependability

Credibility, applicability, dependability, and neutrality constitute the benchmarks for assessing qualitative research (Guba, 1981; Krefting, 1991). The method of triangulation, as outlined by Stake



(1995), is employed in qualitative research to ensure the provision of a realistic, accurate, and comprehensive account of the phenomenon under study. In this particular investigation, methodologic and investigator triangulation were implemented. Methodologic triangulation involved the utilization of diverse data sources, such as face-to-face interviews, observations of participants during interviews, field notes on the setting, comments on participant behavior, and additional information, to construct a comprehensive understanding of the research participants and their encounter with the phenomenon (Stake, 1995). The Principal Investigator (PI) employed each of these methods to gather data for the study. Investigator triangulation utilized NVIVO qualitative data analysis software (version 12) and line-by-line coding by the PI to discern codes and themes present in the data.

To ensure credibility, the research design, data collection, and data analysis were conducted with careful attention to appropriate methodology, simultaneous data collection and analysis, and identification of common, rival, and missing data (Gibbert, Ruigrock, & Wicki, 2008; Krefting, 1991; Yin, 2003). Applicability was addressed by adhering to inclusion criteria, maintaining a diverse sample through considerations of interview setting, data collection methods, and inclusion of fathers from different locations in Java, Indonesia. Dependability, or the ability to replicate the study with consistent results, was ensured by following the prescribed research protocol, employing suitable data collection and analysis methods, and maintaining a comprehensive research database serving as an audit trail for potential replication.

Neutrality, indicating that findings are a result of the phenomenon and not influenced by researcher bias, was maintained by adhering to interview guidelines, audio recording, accurate transcription, line-by-line coding, and using NVIVO qualitative data analysis software (version 12) (n.d.). The study adhered to the established standards for evaluating qualitative research quality, upheld rigor throughout through the application of two types of triangulation, and faithfully reported all study findings.



BOX I Interview Questionnaire

Interview Questionnaire:

- 1. How was the father's relationship with the child ASD before the diagnosis of the child with ASD (attitudes, feelings, perceptions)?
- 2. Tell me when you first learned about the condition of your child with ASD?
- 3. How did the father feel when he received the diagnosis of the child's condition with ASD?
- 4. How is the father's relationship after the diagnosis of ASD? (communicating, playing, etc.)?
- 5. What was your father's attitude after knowing the condition of your brother with ASD? (are there any changes the attitude, emotional closeness, communication pattern, etc.)?
- 6. How did the relationship change between husband and wife?
- 7. How is the relationship between ASD children and ASD children changing?
- 8. How has the relationship between parents and children changed?
- 9. How is the relationship between parents and children with ASD?
- 10. When did the father feel he could accept the condition of the child with ASD?
- 11. How did the acceptance process take place?
- 12. Tell me how fathers deal with ASD children?
- 13. Tell me how father adapted to the child with ASD?
- 14. Tell me about the most difficult time faced by ASD fathers?
- 15. How long has it been hard for you to have an ASD child?
- 16. What are the things that make a child accept the condition of a child with ASD?
- 17. Tell me about your most enjoyable time with ASD children?
- 18. What are some thing that make family members feel happy while being with an ASD child?
- 19. How do fathers become more accepting of ASD children over time?
- 20. What factors make fathers more accepting of ASD children?
- 21. Tell me how the comparison of the relationship before and after being able to accept the condition of an ASD child?
- 22. Tell how close the emotions, feelings before and after being able to accept of condition of a child with ASD?

BOX 2 Demographic Questions

| Name/Initial | : |
|------------------------------|---|
| Wife names | : |
| Gender | : |
| Age (years) | : |
| Living in the same house/ | : |
| split house | |
| Marriage | : |
| Profession | : |
| Family Income (Monthly) | : |
| Religion | : |
| Last Education | : |
| Number of Children | : |
| Age when Child Was Diagnosed | : |
| with ASD | |
| Current Age of ASD Children | : |
| Order of ASD Children | : |



| Table I |
|----------------------------------|
| Demographic Data of Participants |
| $\lambda t \rightarrow 11$ |

| Variables | Range | Total |
|---|-------------------|-------|
| Age range of subjects | 30 – 40 | 13 |
| | 41- 50 | 7 |
| Educational background | High school | L |
| | Diploma | L |
| | Bachelor Degree | П |
| | Master Degree | 7 |
| Living together | | 20 |
| Length of marriage | 5-9 years | L |
| | 10-15 years | 13 |
| | 16-20 years | 6 |
| Religion | Islam | 20 |
| Age of children when diagnosed with autism | I – 2,5 years old | 15 |
| | 2,5 – 5 years old | 5 |
| Age of children with autism | 5-10 years old | 14 |
| | 11-15 years old | 4 |
| | 16 -20 years old | 2 |
| Children with autism is the child of the family | st | 9 |
| | 2 nd | 6 |
| | 3 rd | 4 |
| | 6 th | L |

Result

The characteristics observed in fathers and their children in this research mirror the national traits of families and children affected by ASD. All fathers participating in the study noted that it was their first encounter being questioned about their experiences with ASD. The study's fathers had six male and two female ASD children, aligning with the general population's ASD incidence of 4.5:1 male to female ratio (Baio, 2014). One father, constituting 12.5% of the respondents, identified as



the primary caregiver for their children. All participants reported cohabiting with their spouses, and the duration of marriages ranged from 9 to 20 years. The children with autism were aged 5 years (two children), 9 years (six children), 10 years (two children), 15 years (two children), and 17 years. (Table 1 presents the sample demographics.)

The survey questions were structured into quotes, which were then categorized into codes. The interviews revealed common codes leading to three major themes: (a) family life: enduring adjustments; (b) stages of confusion; and (c) Realistic: What's next?; (d) Care without excessive involvement; (e) Faith in God facilitating acceptance. "Enduring adjustments" denote the changes made by everyone in the family to confront ASD-related challenges, including fathers. Stages of confusion encompass denial, isolation, and stress. Realistic steps involve actions families take to address the challenges in ASD children. "Care without excessive involvement" describes the behavior exhibited by fathers in tending to ASD children. Believing in God signifies the pinnacle of fathers' acceptance.

Theme One: The Relationship Between Fathers and ASD Children

Primarily, fathers desire closeness with all their children, both ASD and non-ASD. However, the communication difficulties faced by ASD children hinder optimal closeness, leading fathers to develop stronger emotional bonds with non-ASD children.



Tabel 2

| The Father-ASD Children Relationship | | |
|---|--|--|
| Issue | Sampel Comments | |
| Difficulty communicating with ASD children | "Actually, at first, yes, it was with N, but with the meaning and communication that I myself am still having trouble with, right?" | |
| Wanna same but he can't | "Yes, that's all that's important, it's the same with the others, I'm not trying to differentiate it's just that with H it's different, I'm also trying to pay attention to my other children" | |
| Having closer feeling with typical children | "Closest if it's emotional, I really don't know, ma'am, actually at first it was with N, but with the meaning and communication that I'm still having trouble with, yes, it's been a while, but if I look at it now, it's more at number three. Yes number two, pay attention only when I see number three" | |

Themes Two: Confusion Stage

Almost all fathers stated that they were shocked, disappointed, confused at the early stages of hearing their child's diagnosis. Ignorance about autism, not believing that their child was diagnosed with autism was experienced by almost all participants. However, this state of uncertainty is brief, and the father promptly engages in contemplating how to enhance, remedy, and navigate the challenges presented by the child with ASD.

Theme Three: Practical Measures: What Comes Next

Following this, fathers will explore solutions and determine the next steps for enhancing the development of children with ASD. Dads, unlike mothers, might feel too overwhelmed to take action. They opt to wholeheartedly support their wives' decisions regarding the chosen solution, therapy, and care for the child with ASD.



| Confusion Stages Issue | Sample Comments |
|---------------------------|---|
| | |
| Denial | " A is OK, after a while it can be fine by its self" |
| Find out the causes | "Egh so the one who often studies is my wife, she looks for information here and there, at that time, did the internet not exist yet, but not yet, egh so finally I took this child to a psychiatrist" |
| Dissapointed | "I think from my point of view, since the beginning of F in such a way, the diagnosis was diagnosed with autism, actually what about me, yes, maybe stressed and stressed, disappointed as well as disappointed so since then, since oh F, it's autism, autism is crazy, it sucks. That's what makes me but that doesn't mean I'm stressed, but I'm disappointed" |
| Sad | "Yes, if the feeling is there, yes, ma'am, there is this, yes, there is a feeling of a little sadness, there is confusion, yes, the name is yes, children are different in general, normal children, right?" |
| Shock | "Yes, I'm shocked, I'm shocked, I'm shocked for a few days, maybe one day, two days, three days after that, I'm ready. As soon as he was born, in fact, oh yes, his birth was disrupted because the history of pregnancy since three weeks was already known" |

Table 4

| Steps | Sample Comments | |
|---|---|--|
| Find out all about autism | "We going to the doctor, asking our friends, dukun, to find out, what happen on my child?" | |
| Making new commitment with spouse to ASD children development | "Because our child cannot communicate like other children in general, but we try to give our best and make our child feel loved by their families". | |
| Giving Full support to the wife decision about ASD children | "So the problem with this kind of initiative, yes, there are many who play a role, the wife, I just support maybe that's what it was" | |
| Role sharing | "Yes, of course if there is a change, with him like this, I appreciate my wife even more, who used to be in an ordinary, flat, now my husband and wife are working, I am the one looking for food for my wife, who is at home with the children". | |
| Realistic Hope | "Yes, especially when it is hoped that there will be independence, especially when you are an adult, you will be able to be like other normal people and be independent". | |



Fathers have modest expectations for their children with ASD, primarily valuing their independence and basic self-care skills. They do not necessarily prioritize higher education or formal schooling for them. Additionally, fathers are open to sharing parental responsibilities, such as assisting with therapy sessions, accompanying them to medical appointments, or occasionally caring for them at home when time permits.

Themes Four: Not too involved but really care

Under the theme of "Not too involved but genuinely caring," fathers are less engaged in day-to-day parenting tasks like bathing, feeding, or implementing therapy center teachings at home. However, they demonstrate support for their children with ASD through endorsing the efforts of mothers and entrusting them with primary caregiving responsibilities. Fathers mainly focus on providing financial support, recognizing the substantial costs associated with ASD-related needs such as developmental specialists, diagnostic evaluations, travel expenses to specialty centers, private tutors, communication aids, therapy sessions like Applied Behavior Analysis, and potential loss of income for one parent. Many of these services are expensive and not covered by insurance, necessitating additional efforts from the family to secure funding.



Tabel 5Not Too Involved but Really Care

| Action | Sample Comments |
|--|---|
| Work hardly (Bearing the family financial) | " I did what was best for this child at the same time I was working on a career, it took too long to work, right, if I left work too long, it could be confusing and indeed, with my first child with special needs, some of my income is for treatment this child" |
| Future preparation for ASD | "Yes, I might be more prepared to do business for him, if he is still able to go to school, if he can afford it, then yes, it's okay, it's okay it's just that later he has to be able to find his own money, which in the future must be prepared". |
| | "Yes, if the world of work is suitable for him, it means something online or something" |
| | |
| Monitoring child developmental | "I also see how the child is developing, now I can do anything, I also see it every day" |

Participants in this research, including three parents with children aged 18 years and above diagnosed with ASD, express concerns about future plans, particularly the financial challenges associated with caring for children with ASD. Fathers are particularly sensitive to the social differentiation faced by their ASD children in school and various services, often experiencing



frustration. Additionally, fathers take an active role in monitoring their child's therapy progress and engage in discussions with their spouses for advice when needed.

Themes Five: Believing in God make acceptance

Embracing faith fosters acceptance in the initial stages of their child's ASD diagnosis, fathers commonly embrace the perspective of surrendering to the gift from God. When asked about their response to the ASD diagnosis, all participants conveyed this sentiment.

"At times, circumstances may vary, and distances may be significant. The key is to approach everything with positive thinking, avoiding dwelling on the challenges posed by situations like 'N.' We channel our energy positively, hoping that, God willing, there will be a day when things improve. This is contingent on Allah's guidance, and ultimately, He will be the one providing utmost attention to parents."

Discussion

The well-being of families with children experiencing ASD-related challenges is significantly impacted across various dimensions, including parenting dynamics, daily routines, family goals, and interpersonal relationships. These outcomes align with the findings of Kim (2015), who demonstrated that a child's condition significantly influences the overall family dynamic. Hartley (2016) further emphasized that the heightened stress levels faced by parents dealing with ASD children can detrimentally affect family cohesion.

The parental acceptance of an ASD diagnosis plays a pivotal role in shaping the future development of children with autism. Parents who struggle to accept their child's autism may inadvertently contribute to feelings of isolation and rejection in the child, potentially manifesting in undesirable behaviors (Marijani, 2003). Despite the challenges, it is crucial to recognize that children with autism still require affection, attention, and love from their families (Safaria, 2005).



Research by Işikhan (2005) in Zembat & Yildiz (2010) revealed that a significant portion of mothers faced difficulties accepting their children's disabilities, leading to various psychological struggles in caregiving. This aligns with the broader consensus that rejecting a child's diagnosis leaves mothers feeling hopeless and more pessimistic compared to those who accept their child's condition (Ceylan, 2004 in Zembat & Yildiz, 2010).

Examining the unique journey of fathers in accepting their children's condition, Kubler Ross's acceptance theory (1969) posits that acceptance occurs when individuals confront reality rather than succumb to hopelessness. Contrary to the theoretical stages outlined by Kubler Ross, fathers of ASD children often bypass these phases, swiftly moving to what can be termed as the realistic stage—adapting and reorganizing without lingering in despair (Kubler, 1970, in Tomb, 2003).

The financial responsibilities of fathers in the context of ASD children occur concurrently with their acceptance process. Despite not being extensively involved in daily caregiving, fathers contribute significantly to the therapy process through financial support, energy, and logistical assistance. Traditional gender roles persist to some extent, with fathers often being the primary breadwinners while mothers undertake caregiving responsibilities. However, there are instances, reflecting a shift in gender roles, where fathers take on a more active caregiving role, challenging traditional norms (Gray, 2003).

The spiritual perspective adopted by parents, particularly fathers, significantly influences their acceptance journey. When fathers perceive ASD children as a divine gift and embrace a realistic outlook, the acceptance process is expedited. Fauziah (2021) highlights that the perceived meaning of ASD children profoundly affects the acceptance and care processes, emphasizing the importance of positive spiritual values.

Differences in stress management between fathers and mothers in the context of ASD children are rooted in their distinct problem-solving approaches. Fathers, characterized by logical



reasoning and problem-focused coping, experience higher stress levels compared to mothers. Mother's stress is closely tied to the child's behavior and the partner's actions, while fathers' stress is more dependent on the mother's mental well-being (Hastings et al., 2005; Olsson & Hwang, 2001).

The role of fathers in providing social support is crucial for mothers dealing with the stress of caring for ASD children. Husband's support, as observed by Fauziah (2021), significantly alleviates parenting stress. Interactions between spouses also play a vital role in optimal parenting outcomes for ASD children (Hartley, 2016). Support systems positively impact mothers' emotional regulation and reduce worry, contributing to a happier caregiving experience (Pottie, 2008; Goets, 2019).

Observations of fathers actively engaging in caregiving tasks, learning from mothers' methods, and developing their communication skills with ASD children indicate a positive impact on the child's development. Recognizing different stressors for fathers (e.g., child tantrums) and mothers (e.g., daily caregiving activities) provides insights into tailored strategies for enhancing family dynamics and improving the overall condition of ASD children (Davis & Carter, 2008).

Conclusion

The research concludes by addressing key inquiries. Initially, fathers of children with ASD typically navigate two distinct phases of acceptance: confusion and realism. Acceptance, for fathers, signifies a dedicated commitment to prioritizing the child's well-being through their parenting approach.

Various factors influence paternal acceptance, including the father's initial hopes during the child's pregnancy, cognitive reasoning, and spiritual beliefs, such as the conviction that divine trials are manageable within one's capabilities.



It is challenging for fathers to fully embrace their child's condition akin to mothers, as per acceptance theory's framework. However, this does not imply a lack of affection or involvement; rather, fathers strive to engage logically and realistically, taking appropriate actions and providing support when needed, while also considering their spouse's perspective and diligently preparing for their ASD child's future.

Implications

Recognizing variations in the stages of acceptance between fathers and mothers enables both parents to foster mutual understanding, avoiding blame and fostering collaboration. This collaborative effort ensures optimal care for children with ASD.

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