Fathers' expectations and autism: A critical discourse analysis of paternal narratives

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Abstract

The unique characteristics of autism spectrum conditions present significant challenges for families. Existing research often focuses on mothers' experiences, leading to the underrepresentation of fathers' perspectives. This study aims to highlight the expectations and experiences of fathers raising children on the autism spectrum. Using critical discourse analysis (CDA), the research explored how power dynamics and societal ideologies shape fathers' lived experiences in raising children on the autism spectrum. The fathers' narratives reveal that inadequate support—such as lack of professionalism, limited access to services, and insufficient community involvement—indicates that society has yet to achieve true inclusivity. Additionally, fathers stress the importance of comprehensive support in managing their parenting responsibilities. The findings emphasize (1) the discourse on integrated support services and (2) addressing paternal support: insights from fathers' experiences. These results underscore the need to strengthen support systems for fathers of children on the autism spectrum.

Keywords: Autism spectrum; critical discourse analysis; father; inclusive

INTRODUCTION

Numerous studies on autism have indicated that parents of children with autism experience higher levels of stress compared to parents of neurotypical children or those with other disabilities (Piro-Gambetti et al., 2024). Receiving an autism diagnosis can be particularly overwhelming for parents, with many expressing feelings of shock and disbelief at the news regarding their child. This emotional response reflects the profound impact such a diagnosis can have on families as they begin to process the implications for their child's future (Ang & Loh, 2019). However, supporting families is essential for fostering a deeper awareness of the condition and its complexities.

Understanding the unique challenges fathers face in raising their children with autism provides valuable insights for research, as fatherhood is a field ripe for exploration, offering significant opportunities for scholars. Much of the existing literature on child development and parenting tends to concentrate on the interactions between mothers and children, often neglecting the vital role of fathers in this dynamic (Rafferty et al., 2020). This maternal-centric approach

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can give rise to specific issues within maternal research, as family studies frequently emphasize maternal experiences (Rudelli et al., 2021). However, to provide tailored and effective support, it is essential to recognize that fathers are equally important as mothers in the parenting dynamic. There is a growing awareness of the need to expand our understanding of parenting to encompass fathers and to emphasize the importance of the father-child relationship (Volling & Palkovitz, 2021).

Using critical discourse analysis, this study seeks to reveal the underrepresented voices of fathers regarding their expectations for their children with autism spectrum disorder. Conducting research through a critical discourse approach encourages deep analysis is invaluable for exploring the narratives of fathers. This method enables researchers to look beyond surface observations, uncovering implicit meanings, underlying assumptions, and societal influences that shape these fathers' experiences (Phillips, 2023). The research carries significance due to the limited literature, attention, and support addressing the challenges these fathers encounter and their efforts to enhance their meaningful roles within the family. To contribute addressing this gap, this study explores the narratives of fathers of children with autism spectrum disorder regarding their expectations for their children.

Fathers With Children On The Autism Spectrum

Following a diagnosis of autism, fathers often develop varying expectations regarding their roles. Many become increasingly concerned about their child's development and actively seek to be more involved in daily activities. However, existing literature frequently overlooks the unique needs of these fathers, while to effectively support fathers of children with autism, it is essential to recognize the distinct traits of fathers and mothers rather than generalize their experiences (Dewey & Hodgkinson, 2022). Research shows that mothers often connect with their children through social behaviors, while fathers engage more through direct interactions. For instance, mothers may feel stressed by their children's everyday behavioral challenges, whereas fathers are more likely to experience stress from externalizing behaviors displayed in public (May et al., 2022).

In addition, fathers with children on the autism spectrum face several significant challenges, including the need for additional funding for treatment and interventions, increased demands for involvement and availability, and the responsibility to participate in their child's progress. They also experience heightened stress due to their child's behaviors and potential instability in their marriages (Lichtlé et al., 2019; Perzolli et al., 2021). Recognizing these unique challenges is vital for developing tailored support that addresses their specific needs.

Insights into the experiences of fathers with autistic children in Indonesia are currently limited. Current research indicates that fathers typically provide instrumental support, such as necessary resources for their children, alongside emotional support through activities like playing, participating in therapy, and comforting their spouses (Amelia et al., 2018). A focused study on the Batak Toba tribe, which follows a patrilineal system, revealed that fathers often

initially experience feelings of shame, disappointment, and low self-esteem upon learning of their child's condition. However, they gradually realize that such negative emotions can hinder their child's development and limit access to education, love, and parental protection. As families navigate the journey of raising children with special needs, they often go through a phase of self-rejection. Eventually, many strive toward self-acceptance, a process that is facilitated by social support and gaining extensive knowledge about autism (Simanjuntak et al., 2018).

Previous research highlights that when fathers receive social support, such as from healthcare, society, and family, their confidence in managing the challenges of raising a child with autism spectrum disorder increases. Conversely, negative societal reactions or a lack of adequate systemic support can lead to despair and unhealthy comparisons with other families (Shave & Lashewicz, 2016; Wang et al., 2022). This is particularly relevant in Indonesia, where collectivist cultural values stress the importance of social support (Maulana et al., 2018). The influence of societal attitudes and systemic support on a father's well-being and coping mechanisms is significant, emphasizing the need for a supportive environment to help fathers navigate the complexities of raising children with autism.

Moreover, autism is a global phenomenon that impacts diverse ethnic groups and nations, with cultural background playing a crucial role in shaping how autism is understood and experienced. In Indonesia—a non-Western, developing country and the world's fourth most populous nation—cultural influences are especially pronounced. The Indonesian context, marked by collectivist, religious, and patriarchal values (Riany et al., 2017), provides a unique cultural framework that makes research on autism within this setting particularly distinctive. This context underscores the importance of examining the perspectives of fathers with children on the autism spectrum within Indonesian society.

METHOD

This research employed a critical discourse analysis (CDA) approach (text-based), utilizing qualitative methods to explore how discourse shaped, sustained, and legitimized power structures. Discourse was conceptualized as a collection of ideas that provided meaning to individual experiences and guided their actions (Fairclough, 2013; Wodak R & Meyer M, 2001).

Participants

A total of 14 fathers participated in the study, with inclusion criteria specifying fathers with children on the autism spectrum. There were no restrictions on background factors such as age, profession, number of children, or the gender of the child.

Table 1. Participants Profile

	Name	Age	Ethnicity	Religion	Profession
P1	Samsul	47	Chinese	Catholic	Entrepreneur

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P2	Gusti	39	Javanese	Islam	Entrepreneur
P3	Dika	35	Chinese	Christian	Office worker
P4	Rama	33	Padang Minang	Islam	Teacher
P5	Agung	33	Javanese	Islam	Employee
P6	Emil	39	Chinese	Catholic	Entrepreneur
P7	Jumari	52	Javanese	Catholic	Entrepreneur
P8	Risal	40	Javanese	Islam	Teacher
P9	Iwan	34	Javanese	Islam	Employee
P10	Tomi	47	Chinese-Dutch	Christian	Employee
P11	Slamet	41	Javanese	Islam	Lecturer
P12	Rosid	40	Javanese	Islam	Employee
P13	Bambang	61	Javanese Islam Retiree		Retiree
P14	Ujang	55	Javanese Islam Lecturer-I		Lecturer-Dentist

Procedures

Participants were selected through a maximum variation purposive sampling technique to gather data from individuals with a wide range of backgrounds and experiences (Palinkas et al., 2015). Primary data consists of narrative texts gathered from interviews with participants.

Data collection was carried out through in-depth interviews using a semi-structured approach, which enables the researcher to ask follow-up questions based on the informants' responses while remaining aligned with the preformulated topics (Adhabi & Anozie, 2017). The main question is, "What are your expectations as fathers of children with autism spectrum disorder?". Interviews were conducted in various formats, including face-to-face meetings, Zoom applications, and telephone to accommodate their preferences and flexibility.

Data analysis

Critical discourse analysis is an analytical approach that is not confined to a specific method, provided that the chosen methods align with a critical framework (Mullet, 2018). In this research, data analysis is conducted within a critical research paradigm, focusing on analyzing texts alongside their contextual backgrounds and situations. The data analysis technique employs thematic analysis principles, emphasizing critical theory or approaches in theme discovery and data interpretation. All names in the report have been modified to protect the identities of the individuals.

RESULTS AND DISCUSSION

To achieve the research objective of uncovering the often-overlooked perspectives of fathers, this study critically examines their expectations through an analysis of the collected narratives. The findings identify two key discursive themes:

The Discourse of Integrated Support Services Professional expert

Fathers express concern regarding the lack of professional experts who are able to provide appropriate diagnoses. As expressed below,

From my experience, if a doctor suspects something concerning, it's best if they refer us directly to a specialist, like a pediatrician who focuses on this area. That way, the child can be properly evaluated to determine if they have special needs. Delaying this can only make things more complicated and harder to address.

(Samsul, 47 years old)

Mr. Samsul expressed concern over the lack of professionalism among doctors in making a diagnosis, noting that time is crucial for enabling timely intervention for the child. This concern was also expressed by Mr. Iwan, 34 years old, who stated, "When we first took him to the doctor, there was no clear diagnosis, but now the symptoms have become increasingly evident". Similarly, Mr. Ujang, 55 years old, experienced a lengthy process before obtaining a precise diagnosis for his child at the age of 12. Fortunately, through extensive information-seeking and his instincts as a father, he enrolled his child in an inclusive school, even though the diagnosis had not yet been accurately established at that time.

Finally we started to invite consultation to various experts for child psychologists, child development doctors, child psychiatrists that they all did not give a definite diagnosis that my child is autistic, even the growth who at that time said that it was not autistic, he was indeed speech delayed, but at that time we did not remain silent, we had already put my son into specialty schools because it led to autism. (Ujang, 55 years old)

Based on narratives' above, it appears that professionals hold a decisive authority over assessing their child's condition, making it crucial for these experts to work with the utmost professionalism. This dynamic reveals a power relation, as professionals such as doctors, psychologists, and psychiatrists—who are granted authority to make diagnoses—play a critical role in shaping the family's understanding and approach to their child's needs. As Foucault suggests, society consists of complex power relations, where power is everywhere—not because it controls everything, but because it arises from all directions (Bhattarai, 2020). In this context, doctors hold a form of power in their ability to make diagnoses, influencing how individuals are classified and understood within the healthcare system. Fathers emphasize the need for accountability and empathy from these professionals, given their significant impact on both the child's treatment plan and the family's overall well-being.

Accessibility of therapy

Moreover, fathers express the need for accessible therapeutic support for their children, emphasizing the importance of affordability to align with the availability of nearby facilities. This issue is particularly prominent in rural areas compared to major urban centers. As Mr. Samsul strives to relocate his family to a larger city in order to access better therapy services, he stated "After therapy, we went to the developmental pediatrician, who said, 'Oh, if the therapy is only this much, it won't be enough.' So, after some consideration, we decided to move to Surabaya. That way, the therapy sessions could be longer, held daily, and more

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intensive." This is also experienced by Mr. Iwan and Mr. Risal, who have limited access in terms of distance and the availability of therapists in their area.

Unfortunately, in this province, there is only one therapist available, so we have to take turns.

(Risal, 40 years old)

The first thing is, in terms of government support, access to therapists is really crucial, ma'am, because the therapy location is an hour away from home, which is very far, and I feel bad.

(Iwan, 34 years old)

The narratives highlights that awareness and understanding of autism within our culture remain insufficient, leading to a lack of familiarity with autism-related issues. As a result, therapeutic services—which are essential components of a systematic support system for individuals on the autism spectrum—are still not well established or consistently available. This shortfall is particularly pronounced in both private and public sectors, especially in smaller towns and rural areas, where access to such services may be significantly limited compared to larger urban centers.

Educational services

Besides therapy, fathers seek inclusive education for their children, as several have expressed feelings of rejection by regular schools. As articulated by Mr. Iwan, a 34-year-old private employee, "School is a significant issue because many environments refuse to accept my child, particularly since he should be in early childhood education (PAUD). They assert that the teachers are unable to manage children with special needs due to the requirement for specialized training."

Mr. Agung expresses his wish for his child with autism spectrum to be accepted in a regular school. He hopes that mainstream educational institutions will be open to enrolling children with diverse health conditions, which reflects his desire for inclusivity in education. Furthermore, Agung critiques the current education system, pointing out the lack of adequate support for diversity within educational settings. He suggests that while some schools may accept children with special needs, the quality of education and the attention provided to these students may be insufficient.

I hope for educational support because, from what I observe, there may be a few schools that are willing to accept children, meaning not special schools, but rather regular schools that can accommodate healthy children. However, in my opinion, there are still very few of these, and even when they do exist, they can still be categorized in a certain way.

(Agung, 33 years old)

The limited attention and challenges in accessing appropriate inclusive education lead fathers to hope their children can be accepted in regular schools. This reflects a cultural inclination toward collectivism, where having children included in the same educational environment as others is viewed as ideal. Moreover, choosing a commonly accepted educational path is seen as important for easing the child's social acceptance and integration within the broader community.

Addressing Paternal Support: Insights from Father's Narratives Moral support

Fathers express a significant need for support, especially in the form of moral support manifested through positive attitudes and behaviors from the community toward their children. They frequently experience discomfort and a sense of marginalization when individuals in society direct disapproving glances that indicate negative perceptions of their children. This response highlights the persistent negative views surrounding autism within the community and the broader stigma related to disabilities. Tucker's (2013) research on parents of autistic children in Javanese culture found that certain cultural beliefs contribute to this stigma. Studies have shown that beliefs about the causes of autism in Indonesia include factors like complications during pregnancy or infancy, breaking pregnancy taboos, ideas of karma or divine fate, and family size (Daulay, 2018; Handayani & Paramita, 2020).

As conveyed by Mr. Dika, 35 years old-office worker, moral support is essential, "For example, when we're out together, people should not look at or regard my child with disdain or as if there is something unusual about him. Sometimes, I feel frustrated when I notice that", additionally, "I hope that we can be heard more, stand up for ourselves, and speak up more". Mr. Dika's comments reveal his need for moral support from society, especially in accepting and understanding his child. He feels frustrated by the disdain and negative looks his child receives in public, highlighting a wider issue of stigma. He also wishes for greater visibility and advocacy for fathers like him, emphasizing the need for their voices to be heard and for a more supportive community. This shows how important it is to create an inclusive environment that recognizes and helps families with children who have special needs. Strengthened by the statements from Mr. Rosid and Mr. Ujang as well.

That's right, because we could say that the neighborhood environment is okay, but as I mentioned, when she was younger, people found her cute. However, now that she is getting older, perhaps people are hesitant to ask why, but from the way they look at her, they already know.

(Rosid, 40 years old)

In fact, they (fathers) also need support; they need to have their specific needs heard.

(Ujang, 55 years old)

Fathers' experiences indicate that societal attitudes and stigma can hinder the acceptance and inclusion of children with autism, underscoring the critical need for heightened awareness and a deeper understanding to foster inclusivity.

Community support

The fathers' narratives also highlight the importance of forming connections with others who have similar experiences, emphasizing the necessity of a supportive community. As stated by Mr. Tomi, 47 years old, "Don't give up on joining a community." Zimmerman and Rappaport's (1988) findings on the close

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relationship between psychological empowerment and community involvement resonate with the experiences shared by these fathers.

Fathers highlight the advantages of being part of a community, noting that as social beings, they cannot face their challenges in isolation. They emphasize the necessity of a support system from both family and their surroundings, particularly given the existence of online and offline communities that facilitate the sharing of experiences and emotions. These communities serve as a communication platform for parents, acknowledging the various needs and parenting approaches associated with children on the autism spectrum. Such forums are especially beneficial for young families, assisting them in managing the realities of raising a child with autism spectrum. Ultimately, these communities provide mutual support and encouragement, promoting psychological well-being by creating a safe environment for self-expression.

From society's perspective, there should be more communities like this, which can serve as a platform for communication among parents since children with special needs are diverse, and their parenting styles vary. The more forums there are like this, the better it will be, especially for young mothers or young families who may not be prepared to accept the reality that their child has special needs.

(Slamet, 41 years old)

At least if there is a unit or community that can be described as mutually supportive or motivating, that can uplift them, at least it can help them psychologically by providing a space for expression. (Bambang, 61 years old)

Fathers recognize the importance of joining a community as a form of support; however, they also feel there is a challenge due to the limited availability of communities for fathers, as stated by Mr. Tomi, "Maybe most of those who want to socialize and share are mothers; it seems I rarely see communities that involve fathers." and Mr. Rosid, "Perhaps most of those who want to socialize and share experiences are mothers, as I rarely see communities of fathers." This phenomenon emerges from traditional cultural roles in parenting, which designate mothers as the main caregivers. As a result, most support and attention in child-rearing practices tend to focus on mothers. Additionally, prevailing gender stereotypes reinforce the notion that men should be strong, less expressive, and less engaged in parenting, further entrenching these dynamics (Kuo et al., 2018).

Table 2. Themes, Subthemes, and Key Insights of The Findings

Theme	Subtheme	Key Insights
The discourse of integrated support services	Professional expert	The lack of professionalism within the support services for children with autism highlights systemic issues in the provision of expert guidance.
		The authoritative professional role in autism care often reinforces a power dynamic where professionals are seen as the primary decision-makers

	Accessibility of therapy	Challenges and opportunities in accessing various therapeutic services for children with autism.
		Barriers like location, cost, or availability affecting fathers' ability to secure necessary therapies.
		Fathers' satisfaction or frustrations with the current therapy options available.
	Educational services	Structural gaps in the education system highlight societal challenges in addressing the educational rights of children with autism, limiting their inclusion.
		Fathers' aspirations for equitable education highlight the need to address systemic biases and create a more inclusive educational framework.
Addressing paternal support:	Moral Support	Moral support enhances fathers' confidence in their parenting role, shaping their sense of support or isolation in the process.
insights from father's narratives		Fathers need their voices to be heard, advocating for recognition and a greater role in decisions regarding their children's care and development.
	Community support	Fathers emphasize the necessity of joining a community, as psychological empowerment is closely linked to community engagement.
		Fathers recognize the value of community for support and well-being, yet struggle with the limited availability of father-specific communities.

This table presents key themes, subthemes, and insights regarding the discourse on integrated support services and paternal support for fathers of children with autism. The findings highlight systematic challenges and social dynamics that shape their experiences. The first theme, "The discourse of integrated support services" underscores the structural barriers and power dynamics within professional autism care. The "Professional expert" subtheme reveals concerns about professionalism and the authoritative role of experts, which may limit parental involvement in decision-making. "Accessibility of therapy" highlights both opportunities and barriers in obtaining necessary services, such as location, cost, and availability, which impact fathers' ability to secure therapies. Additionally, fathers express varied levels of satisfaction with current therapy options. The "Educational services" subtheme identifies systemic gaps in education that hinder inclusive learning opportunities for children with autism. Fathers advocate for equitable education and challenge biases that limit their children's academic development.

The second theme, "Addressing paternal support: insights from fathers' narratives," emphasizes the emotional and social dimensions of support. The "Moral support" subtheme illustrates how fathers' confidence in their parenting role is shaped by the level of emotional support they receive. Fathers express a need for their voices to be acknowledged and for greater involvement in their children's care. The "Community

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support" subtheme highlights the importance of peer networks in providing psychological empowerment. While fathers recognize the value of community engagement, they also struggle with the limited availability of support networks tailored specifically to them. This approach creates a sense of belonging and mutual respect, celebrating diversity as a core strength of the community (Fikri et al., 2021). Overall, the findings indicate that systemic challenges in professional services, therapy accessibility, and education significantly affect fathers' experiences in raising children with autism. Additionally, the need for emotional and community support is crucial in shaping their confidence and involvement. (Shave & Lashewicz, 2016) identify several important factors in their research on support groups for fathers. These insights suggest the importance of policy improvements and the development of more inclusive and father-specific support structures.

CONCLUSION

Based on the findings from the fathers' narratives, it shows that they have voices that express their hopes, emotions, and perceptions as fathers of children on the autism spectrum. The discussion highlights the experiences of fathers navigating challenges within a cultural context shaped by power relations and ideologies that is slowly progressing toward inclusivity. While there are areas for improvement in both formal and informal forms of support, fathers express a cautious hope for advancements in these areas. Currently, formal support—such as access to professional services, educational resources, and community group—remains limited, indicating a need for further development. On the other hand, informal support, acknowledged by the fathers as moral support, plays a crucial role in their lives. This moral support includes positive attitudes and behaviors that affirm their children's condition, contributing to the overall well-being of the fathers and their families.

Inclusivity means embracing diversity, addressing inequalities in areas like education, employment, and healthcare, and fostering a social environment where people feel welcomed and respected. An inclusive society values everyone equally and ensures fair access to opportunities, regardless of background, ability, or identity. The aspiration for more inclusive environments underscores the necessity for ongoing efforts to enhance support systems for families with children on the autism spectrum. To strengthen support systems for fathers and families raising children with autism, several key actions can be undertaken. First, fostering community education and awareness to promote understanding and acceptance of autism, helping to reduce stigma and misconceptions. Second, improving access to professional services and support groups can provide families with the resources and guidance needed to navigate their unique challenges. Lastly, advocating for inclusive policies ensures that families receive the necessary support from governmental and institutional frameworks, fostering a more accommodating environment for children with autism and their families.

Fathers recognize the significance of having a supportive community group to improve their parenting of children with ASD. However, an ideal model for autism father community groups has yet to be established in Indonesia. Generally, fathers prefer non-traditional support approaches that focus on

shared experiences rather than formal discussions of emotions. They value both providing and receiving information, finding fulfilment in sharing their experiences while also gaining practical insights from others.

For future research, it would be beneficial to explore effective models of inclusive culture and identify actionable steps toward achieving them. Additionally, examining how communities of fathers with children on the autism spectrum can be beneficial, as well as strategies for creating and developing these communities within our cultural context, would provide valuable insights.

AUTHORS' STATEMENTS

Elvi Yunianti was responsible for developing the study, collecting and analyzing data, drafting the manuscript, and making final revisions. **Teguh Wijaya Mulya** contributed by supervising the research, refining the theoretical framework, providing critical insights, and approving the final version. **Nanik Nanik** assisted in guiding the research process, contributing to the study's direction, ensuring the overall research procedures were appropriately conducted, and approving the final version. All authors have read and approved the final version of the manuscript and agree to be accountable for its content.

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