



Stigma Experienced by Families of Children with Autism Spectrum Disorder in Urban Areas: A Phenomenological Study

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ABSTRACT

Parents of a child with Autism Spectrum Disorder (ASD) may be stigmatized as families are sometimes penalised by behaviours that are different from those displayed by usually developing children. Such stigma may be link to emotional difficulties, social isolation and experienced lower family quality of life, further emphasising the need to consider the form of stigma and the factors influencing them in their context. The purpose of this qualitative phenomenological study was to make an exploration of the types of stigma that families raising children with ASD in Urban settings experience. Participants: Qualitative data were drawn from semi-structured face-to-face interviews (N = 28) of parents, siblings and grandparent(s) at home, school and a therapy center. The analysis was carried out using qualitative content analysis and the validity of the data was established through prolonged engagement, triangulation, member checking and consultation with experts. It found 5 stigma themes: Physical, internal, public, cultural and label. In summary, urban families with children diagnosed with ASD are faced with multiple persistent forms of stigma that affect their emotional health and sense of social wellbeing. Hence, there is an imminent need for intensive public education, culturally appropriate awareness drives and increased advocacy from health care providers to reduce stigmas and change social dynamics in a favourable manner.

Keyword: Autism Spectrum Disorder, Family Stigma, Urban Population, Phenomenology



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1. Introduction

Autism Spectrum Disorder (ASD) epidemiology is characterized by significant population variability between countries, which has made difficult identifying potential factors associated with the origin of the disorder. As a society we are constantly challenged to promote health and well-being, including mental health (APA, 2013). Since each child with ASD is unique having different symptoms and levels of severity, Shaw et al. According to Jebur and colleagues, when parents have a child with ASD many aspects of life will change because of the condition the child experiences, and the impact will be felt throughout life (Jebur et al., 2022). On the other hand, even if the number of cases are increasing, causative mechanisms cannot be yet fully understood and ASD is generally thought to arise from a complex combination of genetic or environmental influences or interactions between them (Almandil et al., 2019).

The rise in the number of children diagnosed with an Autism Spectrum Disorder (ASD) has been described as one of the greatest public health threats facing the world today, and according to data published by the

Centers for Disease Control and Prevention (CDC), approximately 1 out of every 59 eight-year-old children in the US was identified with ASD in 2014 (Baio et al., 2018). And in 2020, more than 1 in 36 children aged 8 years in America were estimated to have ASD (4% of boys and <1% of girls). This makes this estimate greater than the previous ADDM Network estimate for 2000-2018, which was 1 in 44 children (Maenner et al., 2023), this then increased to 1 in 36 children in 2020 (Shaw et al., 2025). Kasus gangguan spektrum autisme (ASD) di Indonesia belum ada data pasti secara nasional seperti yang telah diperoleh di negara-negara maju seperti Amerika Serikat. But it is estimated that 5,530 cases of children with mental disorders included ASD were treated in health centers from 2020–2021 (Patiwi et al., 2023).

Despite the fact that ASD is becoming more common, it has relatively little effect on people's attitudes towards families and children with this disease. However, instead of performing a duty with dignity, there is considerable stigma for parents having to raise children with autism (Khanh et al., 2023). Likewise, parents have also been found to suffer distress from stigma and negative perceptions from their community and families as observed in research conducted (Winarianti et al., 2022). Clarke and others reiterate that stigma toward autistic individuals, as well as their families, can be exacerbated by limited knowledge and public perceptions around Autism Spectrum Disorder (Clarke et al., 2024). The only relatively small positive effects of having children with ASD in the family, such as coping adaptive and positive perception (Higgins et al., 2022), the negative impacts of having ASD children remain greater. Many studies confirmed that a child with ASD also influences the psychological distress of parents creating a significant impact on their overall quality of life and well-being as they become caretakers (Nadeem et al., 2024). It may be the physical health problems or emotional issues (depression, anxiety, and stress). The effect, too, is disparate among parents based on their coping styles and how they able to navigate the pressures brought on by recent events (Luque & Rosa, 2024). In addition, Wardany and Oktari (2021) highlight that participants with children with ASD are often stigmatized which causes increased amounts of stress affecting their well-being. This stigma arises from negative perceptions of their child's condition, often leading to feelings of shame, anxiety, and social isolation. They further emphasize that these impacts can reduce parents' quality of life, leave them feeling emotionally burdened, and diminish the level of support they receive from their social environment (Wardany & Oktari, 2025)

According to several experts, like Goffman, Harsaya, and so forth, stigma is a negative consequence arising from societal attitudes and behaviors toward individuals perceived as having attributes that tarnish their reputation (Goffman, 1963; Harsaya et al., 2021). Those experts also provide examples of various manifestations of stigma, including labeling, prejudice, alienation, negative emotional reactions, social exclusion, and discrimination, which often arise as societal responses to behaviors or communication patterns perceived as deviating from social norms (Goffman, 1963; Subu et al., 2021; Jumilah et al., 2025). One group of people who frequently face social stigma is the group of people with physical disabilities (Usman et al., 2024). Stigma not only affects individuals but also significantly influences the capacity and motivation of families to carry out their caregiving roles (Daulay et al., 2021)

Stigma seems to be also influenced by cultural background in families with children with ASD. Kang-yi and colleagues argue that cultural background influences families in parenting, acceptance, family reactions to the child's condition and interactions with health services (Kang-yi et al., 2018). In addition, family culture affects family perceptions of the causes of ASD such as family mistakes, curses, parental mental illness or disturbed genetic lines (Grinker et al., 2015). Reflecting on this, the Indonesian public sees good and/or bad outcomes in all that they do as results of deep cultural thoughts and sociological values or religious beliefs. Such value systems can have a powerful impact on vulnerable groups, including families of children with autism. In this sense, what society believes about the causes and treatment of any condition has huge implications for how we respond to it; which in turn directly or indirectly impacts on the lives health and well-being of autistic children and families (Subu et al., 2021). Not only does this affect children, but it also affects the parents or families who look after them. Hence, to address the higher prevalence of ASD, which is not paralleled by greater social acceptance, it is necessary that research on effects of stigma against children with ASD focuses specifically on families living in urban environments. In addition, there is still limited qualitative research that specifically focusing on the types of stigma experienced by families with children with ASD in urban areas of Indonesia. While cities have been described as providing better access to services or more open and welcoming society, research indicates that families encounter both implicit and explicit stigma. The stigma can have implications on emotional health as well, leading to poor parenting and education or access to healthcare facilities. To put it another way, the more stigma among parents of children diagnosed with Autism Spectrum Disorder (ASD), the greater the risk for anxiety and depression and lower overall family functioning

(Efe et al., 2024). As such, the objective of this qualitative study was to investigate the different types of stigma among parents with children diagnosed with autism in an urban setting.

2. Methods

2.1. Research Design

This qualitative study uses a phenomenological approach with a descriptive design to explore and interpret the essence of participants' lived experiences in depth. This approach enables researchers to understand how individuals perceive, interpret, and make meaning of their subjective experiences related to the phenomenon under investigation (Creswell & Creswell, 2018). In this approach, researchers try to get rid of personal assumptions and judgments so that they can see the experience more clearly as it is, based on how the experience is really felt by the individuals. Therefore, the aim is not only to describe what participants experienced, but also to uncover the underlying meaning embedded in those experiences. In this way, Husserlian phenomenology supports the study in developing a deeper understanding of the phenomenon, in a way that remains faithful to participants' original lived experiences (Cudjoe, 2023).

2.2. Participants

In total, developing categorical data ($n = 28$) were recruited using a purposive strategy. The participants were family members of patients with Autism Spectrum Disorder (ASD); fathers, mothers, siblings as well as grandparents that shared the same household. The number of participants in this case satisfied sampling instances for phenomenological research, and saturation of data occurred (Sarfo et al., 2021). Moreover, inclusion criteria were family members such as father, mother, siblings and grandparents who lived together with the ASD child in Pontianak and experienced stigma that directly impacted them during living with the ASD child. Participants needed to speak English, have at least one child over the age of 17 who could communicate independently and was willing to participate in the study. Inclusion of families with children over 17 years of age was to ensure participants had longer, reflective lived experiences from extensive social interactions in order to deepen the phenomenological understanding of stigma. For example, families who do not live together, families who have never received stigma about children with ASD, families living outside Pontianak and subjects reluctant or rejected to participate were exclusion criteria.

2.3. Data Collection

The data were collected between August and November 2025. Research interviews were performed face-to-face at home, special needs school and therapy center by the researcher with respondents in Pontianak. Data quality was controlled through several strategies including prolonged engagement, continuous observation, field notes, audio recording and verbatim transcription, triangulation, data saturation and member checking (Polit & Beck, 2018). Interviews were conducted face-to-face, one by one, using interview guidelines and protocol developed by researchers in consultation with psychologists as experts in the field of psychology and behavior who understand children with ASD. Until saturation of data was obtained, interviews were conducted. In this study, data saturation was reached when no new information emerged from among the 28 participants.

The interview conducted by the researchers consisted of such open-ended questions as: 1) How do you think society views families with autistic children? 2) What do people talk about when you have a child with autism? 3) What forms of community expression have you heard about your autistic son or daughter?

The interviews lasted approximately 30–45 minutes and were audio-recorded. The recordings were then transcribed into Word documents. These transcripts were subsequently compiled into manuscript form and returned to the participants for clarification and verification.

2.4. Data Analysis

To analyze the data, the researchers used a content analysis method. Qualitative content analysis is one of the established qualitative approaches used to examine data and interpret its meaning. It can be applied either inductively or deductively, depending on the purpose of the study (Im et al., 2023). Qualitative content analysis is commonly used to analyze qualitative data (Elo et al., 2014). Phases of the content analysis study consist of preparing the data, defining the unit of analysis, developing categories and a coding scheme. Afterwards, the next steps are testing your coding scheme on a sample of text, coding all the text, assessing your coding consistency, drawing conclusions from the coded data, and reporting your methods and findings (Zhang & Wildemuth, 2009; Rathore & Patwa, 2020). The coding procedure in this study followed several stages to ensure research rigor. First, open coding was conducted by repeatedly reading the interview transcripts and

assigning codes to meaningful segments of text or sentences. Next, the codes were grouped into broader categories based on similarities, relationships, or emerging patterns. Finally, these categories were developed into overarching themes that reflected the structured interpretation of the data. In the data analysis process for this study, coding was conducted by two individuals. The first coding was conducted by the researcher, and the second coding was conducted by a psychologist who acted as an expert to ensure coding consistency and avoid researcher subjectivity. Each coder independently conducted the coding process. The results were then discussed together to identify and confirm emerging themes. Findings from this cross-checking process were then consolidated and there was no disagreement among the two coders.

2.5. Trustworthiness

The validation of qualitative research truly begins with a researcher attempting to convince the reader, perhaps an evaluator, stakeholders, or funders that the results should be acknowledged. Specifically, Lincoln and Guba have established trustworthiness as a validity encompassing such criteria as credibility, transferability, dependability, and confirmability (Im et al., 2023). In this study, credibility was ensured through prolonged engagement, triangulation, and member checking. Data triangulation was achieved by collecting information from multiple sources, including fathers, mothers, siblings, and grandparents who lived in the same household as children with Autism Spectrum Disorder (ASD). In addition to interview data, site observation data was also collected through observation and fieldnotes about the lives of ASD children at home and at school. Confirmation was established through discussions with key participants. Furthermore, transferability was enhanced through consultation with external professionals, such as psychologists who were not involved in the research process.

2.6 Ethical Considerations

This research obtained ethical approval from the Research Ethics Committee of Institut Teknologi dan Kesehatan Muhammadiyah Kalimantan Barat No. 56/II.I.AU/KET.ETIK/VII/2025.

3. Results

3.1. Characteristics of Participants

This study involved 28 participants namely, 16 parents (6 fathers, 10 mothers), and siblings; the grandparents of all but one participant were also interviewed: this included grandfathers of three participants and grandmothers of four participants. Participants were mostly parents, and 16 of them hold bachelor then. The respondent descriptors are presented in Table 1 below.

Table 1 Characteristics of participants

Characteristics	Participants Role	Age (years)	Years of caregiving	Education Level
P1	Mother	40	10	Senior High School
P2	Father	45	10	Bachelor
P3	Mother	38	13	Bachelor
P4	Father	42	13	Bachelor
P5	Mother	32	3	Bachelor
P6	Mother	28	3	Bachelor
P7	Father	30	3	Bachelor
P8	Father	48	22	Bachelor
P9	Sibling	19	10	Senior High School
P10	Mother	46	22	Bachelor
P11	Grandmother	69	22	Junior School
P12	Mother	47	22	Bachelor
P13	Grandfather	72	20	Junior School
P14	Grandmother	56	4	Senior High School
P15	Sibling	18	5	Senior High School
P16	Mother	26	3	Bachelor
P17	Grandmother	50	3	Senior High School
P18	Grandfather	50	3	Senior High School
P19	Sibling	17	5	Junior School
P20	Grandfather	52	5	Bachelor

Table 1 Continued

Characteristics	Participants Role	Age (years)	Years of caregiving	Education Level
P21	Father	32	5	Bachelor
P22	Mother	30	5	Bachelor
P23	Father	45	15	Bachelor
P24	Sibling	18	8	Senior High School
P25	Mother	45	15	Bachelor
P26	Mother	44	20	Bachelor
P27	Grandmother	62	20	Junior School
P28	Sibling	17	7	Junior School

As for participant characteristics, the sample included 10 mothers, 6 fathers, 4 grandmothers, 3 grandfathers and 5 siblings of children with ASD – an overall fairly equitable representation of family roles. In summary, the participant profile displays heterogeneity in age, caregiving duration and educational background with the majority obtaining a bachelor's degree.

3.2. Themes

From the interviews are five themes surfaced. These themes show reflections of stigma ascribed to families who have children with ASD, including personal stigma, structural stigma, public stigma, cultural-mediated stigma and label-based vignettes. The diagram below presents the typological scheme of the research findings.

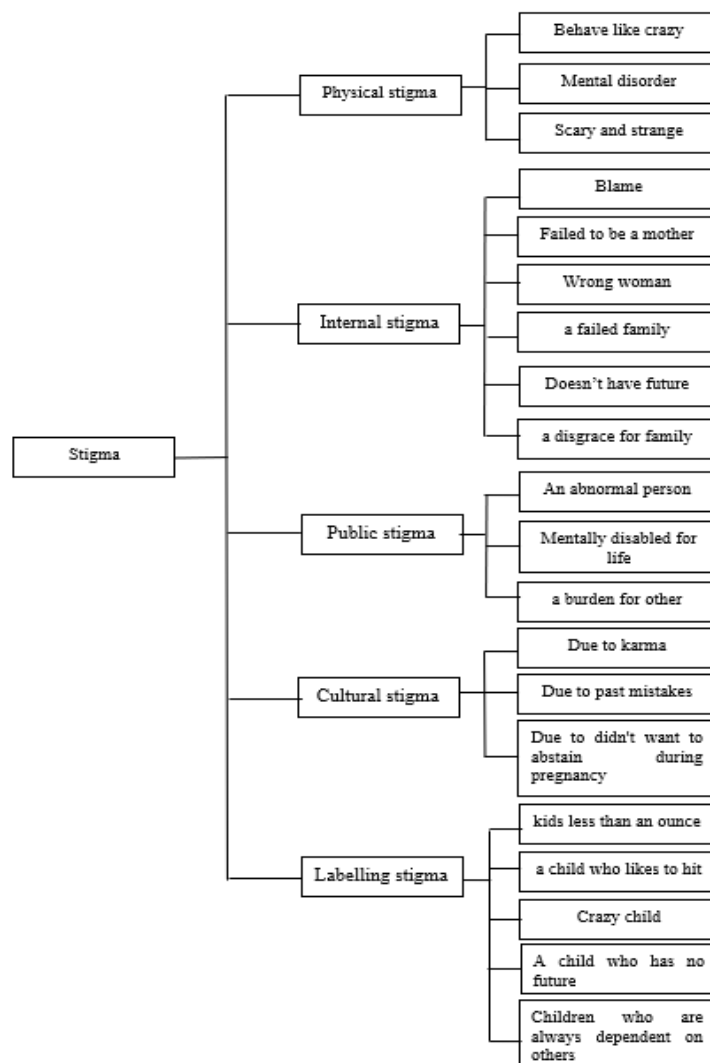


Figure 1. Theme of stigma ascribed to families who have children with ASD

Theme Theme 1: Physical stigma

The results of interviews with the families, mostly parents and grandparents, show that people out there judge ASD children as strange children, children with special needs, mentally disabled children, and children to be feared, as expressed by the following participants:

"... Sometimes my child plays outside, but neighbors often tell their children not to get close, saying things like, "You might get hurt," or "Don't go near him, he's dangerous," and even referring to him as "crazy." (P1 as mother)

"My son is said to be a child with a mental disorder..." (P3 as mother)

"When children are playing, they tend to avoid my child, saying that my child is scary and strange, and that he tends to hit people" (P5 as mother)

"Some people think of our child as a bad boy, they say he behaves like a lunatic..." (P2 as father)

Theme 2: Internal stigma

Some parents also experience stigma from their immediate family, including their nuclear family, in-laws, and relatives from either the husband's or wife's side. In this case, they believed that having a child with ASD was considered a disgrace to the family, and as a mistake made by family members, especially the mother, as shown in the following manuscripts of the participants' interviews.

"... They blame me for having a child with special needs when who wants to..." (P10 as mother)

"My in-laws said that I had failed as a mother and that my husband had chosen the wrong woman..." (P12 as mother)

"If there is another problem, for example my child has a tantrum at home or outside, I will always be blamed by my husband and in-laws" (P16 as mother)

"My in-laws see us as a failed family simply because our son is autistic" (P8 as father)

"I really wanted my first grandchild, but I didn't expect my hope to fail because my grandson was diagnosed with autism, so that I couldn't expect much with a situation like this because he doesn't have future" (P13 as grandfather)

"Having an autistic child is seen as a disgrace to my family, and my husband was told to leave the house..." (P22 as mother)

Theme 3: Public stigma

Parents experience various forms of negative societal perceptions of families with ADS children in the community, at school, and in the workplace. These forms of stigma include, for example, perceptions of autistic children as a burden to teachers at school, as "odd," or as individuals with a lifelong disability, as expressed by several participants in the manuscript below.

"My brother was called strange by my friends, like an abnormal person, they said" (P28 as sibling)

"I enrolled my child in elementary school, but as soon as the teacher observed my son's behavior and his limited language abilities, they suggested that he attend an SLB (special needs school), explaining that the school had limited resources and that they were concerned it would increase the teacher's workload in the classroom" (P4 as father)

"Sometimes people judge my child as a lacking and disabled child even though my child must have advantages, but they don't see that they know my child is mentally disabled for life" (P7 as father)

"My son became the subject of conversation among my colleagues at the office. Even when I was present, I could hear them behind me saying that my son was disabled and autistic" (P26 as mother)

Theme 4: Culture Stigma

The stigma surrounding families with autistic children relates to larger cultural beliefs and understanding of disability, but what about the stigma that comes from our societies as a whole? During the interviews, we found many stigmas of families, such as: having a child with ASD is due to taboos when pregnant and also comes from minor karma or wrongdoing of parents (as explained by these participants:

"... One of the parents told us that our child's autism was a result of our karma and past mistakes toward others..." (P25 as mother)

"My mother-in-law blamed me just because our child was born autistic, she said it was because I didn't take care of food while pregnant, and didn't want to abstain during pregnancy..." (P5 as mother)

Theme 5: Labelling Stigma

Having a sibling with ASD often leads peers to tease them with derogatory nicknames, such as calling them "the crazy little brother," "a mentally disabled sibling," or "weird kids.". Furthermore, parents also feel that some people judge their children as having no future, worthless, and dependent, as shown in the following interviews' transcripts:

"Some people call my child a child who is less than sane like a madman, even though it is a joke, but it is not justified..." (P6 as mother)

"My friends tend to avoid me and do not want to be friends because my sister is autistic. They are also afraid to come to my house to play, worried that they might be hit by my sister, and their parents forbid them from visiting" (P19 as sibling)

"Some people said my sister is crazy because she behaves like that when she is just autistic, not crazy..." (P15 as sibling)

"My grandson was told by a neighbor that he has no future..." (P11 as grandmother)

"Some people out there said that our child is a child whose lifetime will depend on his parents, and will be a burden to his parents. I have heard them say that" (P8 as mother)

4. Discussion

Five major forms of stigma faced by parents and families with children on the Autism Spectrum Disorder (ASD) was identified; these include physical stigma, internal stigma, public stigma, cultural stigma and labeling Stigma. The conclusion that could be drawn from these results is that stigma would seem to operate at the interpersonal, familial level, and societal level as a multidimensional phenomenon. Significantly, stigma came not only from the general population but also from within family members themselves so that stigmatization may be externally presented or internally consolidated.

These findings are consistent with international studies reporting cumulative exposure to negative perceptions of children with Autism Spectrum Disorder (ASD), social isolation, and psychological sequelae within families as a result (Khanh et al., 2023; Turnock et al., 2022). This study adds to the literature by demonstrating the phenomenon of familial internal stigma, whereby parents especially mothers are often blamed. This indicates that stigma is influenced not only by public attitudes but also through family interactions, which exacerbates emotional suffering and overall family dynamics.

An important contribution of this study is that it explores the cultural aspect of stigma. These findings demonstrate the strong connections between stigma and local belief systems, such as autism being seen as a result of karma or bad acts in this life or a previous life or that an inability to comply with cultural norms (materialism) during pregnancy results in autism. These beliefs also point to the underlying sociocultural values where autism is situated not only as a developmental issue but more somberly, even a moral one. Thus

stigma becomes socially sanctioned and perpetuated through routine social interactions that reinforce shame, guilt, and social isolation of families.

Families responded to these experiences using a variety of coping strategies, from passive acceptance to active resistance. Some participants had internalized negative societal views, while others tried to tone stigma down by glorifying the intellectual independence and capabilities of their children. This variation implies that families experience stigma not as passive recipients but as active agents who negotiate and redefine their experiences continuously in relation to their sociocultural contexts.

Although Goffmans characterization of stigma as a socially discrediting attribute is theoretically accurate, this study indicates that stigma should be understood as an ongoing and culturally situated process. Here, stigma is characterized not simply as an external marker with a social label but also occurs through family dynamics and cultural constructions that shape meanings of identity over time as well as interpretations and responses.

This also supports Culla and co-authors argument that stigma towards children with Autism Spectrum Disorder (ASD) persists in society today as well. This ongoing stigma affects children's freedom of movement and limits their access to rights in various areas, such as education and healthcare, which have not yet been fully and optimally fulfilled (Culla et al., 2024). Likewise, the findings of this study are also in accordance with the previous investigation results by Riany and colleagues that stigma against children with ASD in Indonesia is influenced by cultural factors and beliefs such as karma, destiny, or the consequences of parents' actions in the past (Riany et al., 2016). In some countries, stigma is still present but the primary social understanding of children with ASD and their families is based on research findings. This approach will be one that can cleanse its ecosystems from sibling negative projections, and blame-shifting.

Stigma toward families of children with Autism Spectrum Disorder (ASD) can occur anywhere in the world and is driven largely by community perceptions and attitudes. This study also shows that families living in urban areas do face stigma from local workplaces, neighbours and sometimes even their own family members. Stigma is an essential part of social life, and reflects the multiplicity of ideas, values, norms and other power relations that create social categorization. It appears as a process by which societies shape and solidify their divisions between individuals or groups of people. Highly visible differences whether they be physical or non-physical often drive stigma and are a common experience for many individuals with disabilities (Nisa, 2021). In this case, the findings of this study indicate that the physical stigma experienced by families with children with autism (ASD) varies from labels or titles such as "weird," "special needs," "feared," and "less than an ounce," a common expression to describe people with mental illness." Furthermore, many parents reported that their child's condition negatively affected their family life and that they experienced various forms of stigma within their local communities (Oduyemi et al., 2021).

Furthermore, as stated by Alsamhori and colleagues that despite living in urban areas, parents and communities have different knowledge and understanding of ASD. Living in urban areas is often assumed to be associated with greater awareness of ASD and lower levels of stigma, whereas rural areas are commonly linked to more limited understanding and stronger negative judgments toward individuals with ASD (Alsamhori et al., 2024), but this is not the case. Besides what was found in this study, the study results by Oduyemi et al. (2021) show that parents' knowledge of ASD is still not good; most parents have negative experiences in parenting children with ASD caused by stigma from society and family. Knowledge, attitudes, and perceptions are positively correlated with parental understanding of ASD. Therefore, there is a need for awareness-raising programs to help parents develop a more accurate and accepting understanding of ASD, particularly in the context of ongoing stigma within both society and families (Alruwaili et al., 2024).

Accordingly, the stigma against families with autistic children becomes a widespread social problem, and is not a purely individual experience. The "failure to parent" desire can be explained in this instance as a main cause of ASD, so that individuals have negative ratings from those associated with community; supporting Turnock and colleagues staunch belief that stigma is socially constructed by the same means negative judgments against an attribute deemed undesirable (in this case however seen as more harmful so that parents were less valued than others) (Turnock et al., 2022), and discrimination becomes an obstacle to access assessment (Wilson et al., 2023).

Since children exhibit traits that are assumed not to conform with social norms or standards, they experience discrimination in social, educational and employment contexts; especially those who have special needs such as autism spectrum disorder (ASD). The stigma surrounding autism is directly related to the misunderstood nature of both autism, and autistic traits in general. Some of the factors that affect stigma include how often a person interacts with autistic people, culture, gender, and individual differences (Turnock

et al., 2022). To trisect or remove the stigma toward basic nursery care PlanChildren and Families, who have a habitually uncomplicated day life question their family dynamics seem dramatically different from what parents expect; Implement Parents of children with autism that engage in habits methods to respond with aggressive behaviors is realistic. They often feel alone, as the world around them is generally uncomprehending and unsupportive. Also the stigma that they are parents who cannot even take care of themselves weighs heavily on their mind (Swaab et al., 2025). Nevertheless, many families are still able to overcome the stigma so that it does not interfere with their children's mental health and development.

The findings of this study also align with the suggestion by Riany and colleagues (2016) that cultural beliefs about parenting significantly influence parenting practices, including perceptions of appropriate care for children with Autism Spectrum Disorder (ASD). As in Indonesia itself, as a large and diverse country which is home to various cultures and ethnicities, each has its own perspective on children with ASD. Prior to this study, Jiu and Rungreangkulkij, (2019) conducted a study on the views of families who have children with ASD based on the views of Malay culture. The study findings show that having a child with ASD is often viewed as a test or destiny from God, with ASD children perceived as different from other children and in need of intensive support. From a societal perspective, families with children with ASD are seen as being tested in terms of caregiving responsibilities, while children with ASD are sometimes regarded as “pure” or “innocent” individuals who are free from sin due to their mental limitations. Despite the stigma attached to families with children with ASD, as found in this study, previous research suggests that not everyone views children and ASD negatively, depending on individual perceptions. Some families and communities view children with ASD positively as a gift received from God for the family. Consequently, one recommendation stemming from the present results is for improved public and parental awareness to mitigate stigmatizing behaviors toward children with ASD (Ransley, 2020). Positive support from various parties can help reduce the stigma experienced by families.

This study has several strengths. The phenomenological approach enabled me to delve deeply into the experiences of participants, and including multiple family roles parents, siblings, and grandparents offered a richer account of stigma among varied perspectives. Moreover, strategies to enhance rigor (eg, triangulation, member checking, expert consultation) increased the credibility and trustworthiness of findings.

Even so, there are a few limitations that must be considered. Data were collected in a single urban setting Pontianak and this could mean that the findings may not be transferable both within and beyond Indonesia as such stigma adopts uniquely different cultural interpretations among the many ethnic groups across this diverse country. Additionally, the majority of participants had higher level education and this may lead to an over-representation from high socio-economic groups and result in bias towards educated views. Moreover, face-to-face interviews may have caused social desirability bias as the respondents might have changed their responses based on what they believed would be publicly acceptable.

The findings indicate that our results can inform research and nursing practice. Studies in the future should involve even more different variables including social economic status and geographical locations to reflect the diversity of stigma experiences. Studies comparing urban and rural settings, as well as longitudinal designs to help explain how stigma evolves over time, are also recommended. The results underline the need for culturally appropriate and family-centered care in practice. Nurses have a vital role in providing psychosocial support, implementing school-based stigma-reduction programs and participating in community-based awareness-raising to help increase acceptance of children with Autism Spectrum Disorder (ASD) and their families.

5. Conclusion

Furthermore, as per the results five themes were identified which reflect types of stigma (physical stigma, internal stigma, public stigmas Cultural stigmas and labeling stigmas) Families being experiencing stigma according to these latent thoughts. The new emerging stigma is not solely based on the child's behavior being viewed as abnormal but by existing social biases and cultural perceptions. In this case, the stigma experienced by most parents comes from both local communities and their own families. And for families, stigma remains a major emotional burden even in urban areas where they are relatively well connected to facilities providing up-to-date information and services. This stigma leads to shame, anxiety and social isolation which in turn decreases the quality of life of not just parents but the whole family unit.

Thus, addressing stigma and reducing it among children with autism and their families will necessitate a holistic approach that combines community education, social inclusion, and family psychosocial support. In addition, long-term campaigns that increase knowledge around autism and the benefits of diversity can convert

negative perceptions into acceptance. The critical functions of community nurses in supporting families with autistic children and their parents include health education, assisting access to medical services and helping the parent manage long-term care for autistic children. Additionally, schools and places of work should implement inclusion programs and provide training for educators and healthcare professionals. These measures are intended to ensure that children with autism are not treated unfairly, that children with autism receive equal opportunities for thriving lives, and that their families continue to be supported alongside them in daily challenges.

References

- Almandil, N. B., Alkuroud, D. N., Abdulazeez, S., & Alsulaiman, A. (2019). Environmental and Genetic Factors in Autism Spectrum Disorders : Special Emphasis on Data from Arabian Studies. *International Journal of Environmental Research and Public Health*. <https://doi.org/10.3390/ijerph16040658>
- Alruwaili, B. F., Alrashdi, B. A. T., Mallick, A., Alshami, T., Alruwaili, M., Alanazi, M. F., Alruwaili, H. F. S., Alanazi, W. F., Alanazi, W. M., Fehaid, A., & Altaymani, M. (2024). Knowledge , Attitude , and Perception towards Autism Spectrum Disorders among Parents in Sakaka , Al-Jouf Region , Saudi Arabia : A Cross-Sectional Study. *Healthcare*, 12(1596), 1–16. <https://doi.org/10.3390/healthcare12161596>
- APA. (2013). *Diagnostic and Statistical Manual of Mental Disorders*. In *Encyclopedia of Applied Psychology, Three-Volume Set (5th ed)*. Arlington, VA: American Psychiatric Publishing. <https://doi.org/10.1016/B0-12-657410-3/00457-8>
- Baio, J., Wiggins, L., Christensen, D. L., Maenner, M. J., & Daniels, J. (2018). Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network , 11 Sites , United States , 2014. *MMWR Surveill Summ*. U.S. Department of Health and Human Services Centers for Disease Control and Prevention, 67(6). <https://doi.org/10.15585/mmwr.ss6706a1>
- Clarke, E. B., Mccauley, J. B., Lutz, A., Gotelli, M., Sheinkopf, S. J., Lord, C., & Caldwell-harris, C. (2024). Understanding profound autism : implications for stigma and supports. *Front. Psychiatry*, 15(January). <https://doi.org/10.3389/fpsyt.2024.1287096>
- Creswell, J. W., & Creswell, J. D. (2018). *Research design qualitative, quantitative, and mixed methods approaches*. In *Clinical and translational science (Fifth Edit)*. SAGE Publications, Inc.
- Cudjoe, E. (2023). Making Sense of Husserlian Phenomenological Philosophy in Empirical Research. *International Journal of Qualitative Methods*, 22, 1–9. <https://doi.org/10.1177/16094069231171099>
- Culla, A. S., Lawi, A. F., Cangara, A. R., Puspita, A., & Pendidikan, D. (2024). The Implementation of CRPD in Indonesia to Ensure Education Rights for Autistic Children (Case Study: Makassar). *Intermetic: Journal of International Studies*, 8(2), 553–574. <https://doi.org/10.24198/intermetic.v8n2.8>
- Daulay, W., Wahyuni, S. E., & Nasution, M. L. (2021). Family Behavior in Caring for People with Mental Disorders During Covid-19. *CARING: Indonesian Journal of Nursing Science (IJNS)*, 3(1), 1–9. <https://doi.org/10.32734/ijns.v3i1.5797>
- Efe, F., Aksoy, H., Ok, F., Kocak, E., & Gunes, S. (2024). Perception of Internalized Stigma in Parents of Children With Autism Spectrum Disorder : Investigating the Effects of Depression , Anxiety , and Family Functioning. *Cureus*, 16(11). <https://doi.org/10.7759/cureus.73860>
- Elo, S., Kääriäinen, M., Kanste, O., & Pölkki, T. (2014). Qualitative Content Analysis : A Focus on Trustworthiness. *SAGE Open*, 1–10. <https://doi.org/10.1177/2158244014522633>
- Goffman, E. (1963). *Stigma: Notes on the Management of Spoiled Identity*. Penguin Books, United States of America by Prentice- Hall Inc.
- Grinker, R. R., Kang-yi, C. D., Ahmann, C., Beidas, R. S., Lagman, A., & Mandell, D. S. (2015). Cultural Adaptation and Translation of Outreach Materials on Autism Spectrum Disorder. *J Autism Dev Disord*, 45(8), 2329–2336. <https://doi.org/10.1007/s10803-015-2397-6>
- Harsaya, I., Fitrikasari, A., & Yusuf, I. (2021). Stigma , Discrimination , and Public Perception : A Relationship between Screening for Mental Emotional Disorders and Public Perception of Mental Disorders. *Unnes Law Journal: Jurnal Hukum Universitas Negeri Semarang*, 7(2), 405–418. <https://doi.org/10.15294/ulj.v7i2.52696.405>
- Higgins, L., Mannion, A., Chen, J. L., & Leader, G. (2022). Adaptation of Parents Raising a Child with ASD : The Role of Positive Perceptions , Coping , Self - efficacy , and Social Support. *Journal of Autism and Developmental Disorders*, 53, 1224–1242. <https://doi.org/10.1007/s10803-022-05537-8>

- Im, D., Pyo, J., Lee, H., Jung, H., & Ock, M. (2023). Qualitative Research in Healthcare : Data Analysis. *J Prev Med Public Health*, 56, 100–110. <https://doi.org/10.3961/jpmph.22.471>
- Jebur, H. G., Sahib, M. M. S., & Kadhim, A. K. (2022). Learning problems regarding children with autism spectrum disorders. *International Journal of Health Sciences*, 6(S3), 8572–8579. <https://doi.org/10.53730/ijhs.v6nS3.8071>
- Jiu, C. K., & Rungreangkulkij, S. (2019). The Meaning of Having An Autistic Child in Malay Family Indonesia. *Unnes Journal of Public Health*, 8(2), 73–80. <https://doi.org/doi.org/10.15294/ujph.v0i0.29527>
- Jumilah, B. S., Wahyuni, S., & Warayana, M. Y. (2025). Dampak Stigma Sosial Terhadap Eksistensi Diri Penyandang Disabilitas. *Jurnal Moral Kemasyarakatan*, 10(1), 294–305. <https://doi.org/https://doi.org/10.21067/jmk.v10i1.11005>
- Kang-yi, C. D., Grinker, R. R., Russell, R., & Shea, K. (2018). Influence of Community-Level Cultural Beliefs about Autism on Families' and Professionals' Care for Children. *Transcult Psychiatry*, 55(5), 623–647. <https://doi.org/10.1177/1363461518779831>
- Khanh, T. L., Mai, T. L. A., & Hoang, P. A. (2023). Stigma among Parents of Children with Autism: An Integrative Review. *Pacific Rim Int J Nurs Res*, 27(3), 530–548. <https://doi.org/10.60099/prjnr.2023.261650>
- Luque, A., & Rosa, D. (2024). The Effect of Autism Spectrum Disorder on Family Mental Health : Challenges , Emotional Impact , and Coping Strategies. *Brain Sciences*. <https://doi.org/10.3390/brainsci14111116>
- Maenner, M. J., Warren, Z., Williams, A. R., & Esther Amoakohene. (2023). Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network , 11 Sites , United States , 2020. *Centers for Disease Control and Prevention Morbidity and Mortality Weekly Report*, 72(2). <https://doi.org/10.15585/mmwr.ss7202a1>
- Nadeem, N. J., Afzal, S., Dogar, I. A., Smith, J. G., Shah, T., Noreen, M., & Ali, A. (2024). Research in Autism Spectrum Disorders The impact of having an autistic child on parental mental health and wellbeing in pakistan. *Research in Autism Spectrum Disorders*, 115(January), 102423. <https://doi.org/10.1016/j.rasd.2024.102423>
- Nisa, U. (2021). Stigma Disabilitas di Mata Orang Tua Anak Difabel di Yogyakarta. *INKLUSI Journal of Disability Studies*, 8(1). <https://doi.org/10.14421/ijds.080106>
- Oduyemi, A. Y., Okafor, I. P., Eze, U. T., Akodu, B. A., & Roberts, A. A. (2021). Internalization of stigma among parents of children with autism spectrum disorder in Nigeria : a mixed method study. *BMC Psychology*, 9(182), 1–12. <https://doi.org/10.1186/s40359-021-00687-3>
- Patiwi, R. D., Pranata, A. D., Ayuningtyas, G., & Azzahra, P. (2023). Determinan Kejadian Anak Autis Based on Systematic Review. *Nursing Science Journal (NSJ)*, 4(2), 183–197. <https://doi.org/10.53510/nsj.v4i2.212>
- Polit, D. F., & Beck, C. T. (2018). *Essentials of nursing research : appraising evidence for nursing practice* (Ninth Edit). Philadelphia : Wolters Kluwer Health.
- Rathore, M., & Patwa, A. (2020). Content Analysis and Uses in Research. *SDES-International Journal of Interdisciplinary Reseach*, 1(3). <https://doi.org/10.47997/sdes-ijir/1.3.2020.92-98>
- Riany, Y. E., Meredith, P., & Cuskelly, M. (2016). Understanding the influence of traditional cultural values on Indonesian parenting. *Marriage & Family Review*, 0(0), 1–20. <https://doi.org/10.1080/01494929.2016.1157561>
- Sarfo, J. O., Debrah, T. P., Gbordzoe, N. I., & Afful, W. T. (2021). Qualitative Research Designs , Sample Size and Saturation : Is Enough Always Enough ? *Journal of Advocacy, Research and Education*, 8(3). <https://doi.org/10.13187/jare.2021.3.60>
- Shaw, K. A., Williams, S., Patrick, M. E., Valencia-Prado, M., & Durkin, M. S. (2025). Prevalence and Early Identification of Autism Spectrum Disorder Among Children Aged 4 and 8 Years — Autism and Developmental Disabilities Monitoring Network , 16 Sites , United States , 2022 (Vol. 74, Issue 2). <https://doi.org/10.15585/mmwr.ss7402a1>
- Subu, M. A., Wati, D. F., Netrida, N., Priscilla, V., Dias, J. M., Abraham, M. S., Younan, S. S., & Yateem, N. Al. (2021). Types of stigma experienced by patients with mental illness and mental health nurses in Indonesia : a qualitative content analysis. *International Journal of Mental Health Systems*, 15(77), 1–12. <https://doi.org/10.1186/s13033-021-00502-x>
- Swaab, L., Campbell, L. E., Tavener, M., & Goodwin, J. (2025). “ People Thought I Was a Dreadful Mother ”: Stigma Experienced by Parents with an Autistic Child Who Exhibits Aggressive Behaviour. *Advances*

- in Neurodevelopmental Disorders, 0123456789. <https://doi.org/10.1007/s41252-025-00460-2>
- Turnock, A., Langley, K., & Jones, C. R. G. (2022). Understanding Stigma in Autism : A Narrative Review and Theoretical Model. *Autism In Adulthood*, 4(1), 76–91. <https://doi.org/10.1089/aut.2021.0005>
- Wardany, O. F., & Oktari, S. S. (2025). Stigma experienced by parents of children with autism spectrum disorder Spektrum Autis. *Jurnal Unik: Pendidikan Luar Biasa*, 10(2), 107–117. <https://doi.org/10.30870/unik.v10i2.34771>
- Wilson, R. B., Thompson, A. R., Rowse, G., & Freeth, M. (2023). Research in Autism Spectrum Disorders The experience of seeking , receiving , and reflecting upon a diagnosis of autism in the UK : A meta-synthesis of qualitative studies conducted with autistic individuals. *Research in Autism Spectrum Disorders*, 103(March), 102135. <https://doi.org/10.1016/j.rasd.2023.102135>
- Winarianti, Jiu, C. K., Kardiatur, T., & Bhakti, W. K. (2022). Family Management on Children with Autism : A Phenomenological Study. *Indonesian Journal of Disability Studies*, 9(2), 265–281. <https://doi.org/10.21776/ub.ijds.2022.009.02.10>
- Zhang, Y., & Wildemuth, B. M. (2009). Qualitative analysis of content. In B. M. Wildemuth (Ed.), *Applications of Social Research Methods to Questions in Information and Library Science*. In Libraries Unlimited.