

## **EXPERIENCES AMONG DOCTORS WHO HAVE AUTISTIC CHILDREN IN OBTAINING DIAGNOSIS AND THERAPY: A PHENOMENOLOGICAL STUDY**

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Submitted: 2024-12-12

Published: 2025-01-10

DOI: 10.24036/rapun.v15i2.131857

Accepted: 2024-12-12

**Abstract: Experiences Among Doctors Who Have Autistic Children in Obtaining Diagnosis and Therapy: A Phenomenological Study.** This study aims to explore the experiences of doctors who have children with autism spectrum disorder (ASD) in the process of obtaining diagnosis and therapy. The research employs a qualitative method with a phenomenological approach. Data analysis was conducted using the technique developed by Miles and Huberman. The informants in this study are three doctors who have children with ASD. In-depth interviews were conducted to investigate their experiences, challenges, and strategies for obtaining accurate diagnoses and therapies for their children. The results indicate that despite having adequate medical knowledge, their personal experiences as parents of children with ASD present numerous obstacles and challenges in securing diagnosis and therapy. The study identifies seven themes: knowledge about autism, suspicion of autism, searching for diagnosis and therapy without a formal diagnosis, coping mechanisms and resilience, sensory integration therapy (SI), occupational therapy (OT), speech therapy (TW), and their outcomes, Smart ABA and Smart BIT therapies and their outcomes, as well as regular schooling. These findings provide new and essential insights into the need for a deeper understanding of autism diagnosis and therapy among doctors. It is hoped that this research will contribute to the body of knowledge in the field of autism, particularly for medical professionals.

*Keywords: Autism, ASD Children, Doctor who has an autistic child, Smart ABA, Smart BIT*

**Abstrak: Pengalaman di Antara Dokter yang Memiliki Anak Autis dalam Mendapatkan Diagnosis dan Terapi: Sebuah Studi Fenomenologis.** Penelitian ini bertujuan untuk mengeksplorasi pengalaman dokter yang memiliki anak dengan Gangguan

Spektrum Autisme (ASD) dalam proses mendapatkan diagnosis dan terapi. Penelitian ini menggunakan metode kualitatif dengan pendekatan fenomenologis. Analisis data dilakukan dengan menggunakan teknik yang dikembangkan oleh Miles dan Huberman. Informan dalam penelitian ini adalah tiga dokter yang memiliki anak dengan ASD. Wawancara mendalam dilakukan untuk menyelidiki pengalaman, tantangan, dan strategi mereka dalam mendapatkan diagnosis dan terapi yang akurat untuk anak-anak mereka. Hasil penelitian menunjukkan bahwa meskipun memiliki pengetahuan medis yang memadai, pengalaman pribadi mereka sebagai orang tua dari anak-anak dengan ASD menghadirkan banyak hambatan dan tantangan dalam mendapatkan diagnosis dan terapi. Penelitian ini mengidentifikasi tujuh tema: pengetahuan tentang autisme, kecurigaan terhadap autisme, pencarian diagnosis dan terapi tanpa diagnosis formal, mekanisme koping dan ketahanan, terapi integrasi sensorik (SI), terapi okupasi (OT), terapi bicara (TW) dan hasilnya, terapi Smart ABA dan Smart BIT serta hasilnya, serta pendidikan reguler. Temuan ini memberikan wawasan baru dan penting tentang perlunya pemahaman yang lebih mendalam mengenai diagnosis dan terapi autisme di kalangan dokter. Diharapkan penelitian ini dapat berkontribusi pada pengetahuan di bidang autisme, khususnya bagi para profesional medis.

*Kata kunci: Autisme, Anak ASD, Dokter yang memiliki anak autis, Smart ABA, Smart BIT*

## INTRODUCTION

The increase in autism cases around the world is not followed by easy access to information and knowledge about autism, especially its diagnosis and therapy. Diagnosis and therapy are the main factors for the development of children with autism spectrum disorder (ASD). Tschida et al. (2021) Convey the importance for those caring for children with ASD to carry out therapy or intervention. Luo et al (2022) They are highlighting the importance of various policy efforts and attention so that children with ASD get the right therapy.

Access to this information should be opened as widely as possible so that parents who have children with ASD know what they should do for their child with ASD.

It has limited information and knowledge about autism, resulting in a lack of understanding of diagnosis and therapy in parents of children with ASD. This limitation is also experienced by parents who work as doctors. Limited knowledge about autism among medical professionals has been noted in several studies (Bakare et al., 2008; Bartolotta & Rizzolo, 2019;

Coughlan et al., 2020; Effatpanah et al., 2019; Hidiroglu et al., 2020; Jain et al., 2020; Mukhamedshina et al., 2022; Thomas et al., 2024) Of course, this must be a particular concern because the medical community will be the first to provide the public with information and understanding about Autism.

This limited knowledge can also increase stress for parents. Caring for children (ASD) is much more complicated than caring for children who are not ASD. Previous research has shown that parents with children (ASD) experience higher levels of stress than parents who do not have children with ASD ((Khader et al., 2020; Nunnally et al., 2023; Papanephytous, 2021; Siddiqi & Urooj, 2022). However, there has been no research that specifically discusses the experiences of doctors who have children with ASD. This high-stress level is also experienced by parents who work as doctors. This situation may be exacerbated by societal assumptions regarding the extensive knowledge that parents who are doctors possess in the field of autism. However, several studies highlight the limited knowledge among doctors concerning autism and its therapies (Bakare et al., 2009; Burki et al., 2023; Crane et al., 2019;

Effatpanah M et al., 2019; Esegbe et al., 2015; Hossein & Khalid, 2011; Imran et al., 2011; Mao et al., 2022; Mukhamedshina et al., 2022). This can cause problems in carrying out their duties as doctors.

Autism is a severe neurobiological developmental disorder that occurs in children, so it causes problems in communicating and relating to their environment, starting in the first 3 years of life and continuing throughout their lives if not intervened. Autism is a generalized neurodevelopmental disorder that causes disturbances in communication problems, limited interest as well and repetitive behaviors (Hodges et al., 2019; Lord, 2020; Lu et al., 2022; Wang et al., 2018; Williams et al., 2021). The definition above can mean that autism must immediately get early, intensive, and optimal treatment.

From the author's search, no research has been found that specifically examines the experiences of doctors who have children with ASD. This research is urgent to be carried out to provide more in-depth insight into the experience of doctors who have children with ASD. This research aims to fill the gap in knowledge by exploring the experiences and challenges faced by doctors who have children with ASD in getting a diagnosis and successful therapy.

The results of this study are expected to fill the knowledge gap for doctors who have children with ASD around the world about autism. The experience of doctors who have children with ASD can provide valuable insights for their peers in understanding the challenges they face, so it is hoped that more effective solutions can be found in diagnosis and therapy. The results of this research also contribute to science, especially in autism.

## RESEARCH METHODS

This study uses a qualitative phenomenological method. This method was chosen according to the purpose of the research, which is to understand the phenomena that occur, events, social activities, attitudes, beliefs, and perceptions. Qualitative research can be applied when the research problem needs to

be studied more deeply to capture its complexity. The qualitative research approach produces descriptive data in the form of words or writings and behaviors that can be observed from the subject and object of the research itself. (Creswell, John & Poth, Cheryl, 2019) .

In this study, informants were selected through purposive techniques. The criteria are doctors who have children with ASD. Three doctors with children with ASD, two general practitioners, and one specialist doctor expressed willingness to be informants in this study. The three informants were women between the ages of 38 and 43 years. Informants in qualitative phenomenological research must be carefully selected, only those who have experienced the phenomenon firsthand. The demographic data of the informants is as shown in table 1 below.

**Table 1: Demographic Data of Informants**

<b>Informant</b>	<b>Gender</b>	<b>General Practitioner/Specialist</b>	<b>Age (years)</b>	<b>Current Age of ASD Children (years)</b>
Doctor 1	Female	General Practitioner	43	13
Doctor 2	Female	General Practitioner	41	13
Doctor 3	Female	Specialist	38	7

The data in this study were collected through in-depth interviews with

informants to obtain relevant information. In phenomenological research, this

interview technique summarizes views and perceptions of the analyzed phenomenon. (Moustakas, 1994). The interviews were conducted with a semi-structured and open approach, allowing flexibility in data collection and recording essential aspects according to the focus of the research. Before the interviews, the authors compiled an interview guide to gather information about the experiences of doctors who have children with ASD in the process of obtaining a diagnosis and therapy. This way, the writer can quickly develop additional questions based on the answers given by the informant. The interview guide and list of questions are consulted first by the expert and then approved by the expert. Interview documentation is carried out by utilizing image and sound recorders through the Zoom platform, WhatsApp voice recordings, and notes made by the author. The author has also obtained permission from all informants to use recording devices during interviews to facilitate the process of data collection and transcription for further analysis.

This study applies data analysis techniques developed by Miles and Huberman (Miles & Huberman, 1994). Which includes the stages of data collection, data reduction, data presentation, and conclusion. Data

collection is carried out to obtain information and explore experiences from informants through interviews, recordings, and authors' notes. This collection focuses on doctors' experiences with children with ASD in getting a diagnosis and therapy. The data reduction process is carried out by summarizing the information that has been collected. Information that is relevant and appropriate to the problem and focus of the research is included in the core discussion. In contrast, unnecessary information is excluded from the discussion, accompanied by essential notes. The data is presented clearly and systematically to ensure the validity of the research. The collected data is then presented as interview transcripts, followed by systematic coding and decomposition to conclude the research results. Data triangulation is carried out based on source and time.

## **RESULTS AND DISCUSSION**

### **Results**

The in-depth interview analysis of 3 informants of doctors who have children with ASD resulted in seven themes: knowledge about autism, suspicion of autism, search for a diagnosis and non-diagnostic therapy, coping mechanisms and resilience, SI, OT, TW therapy and its

results, Smart ABA & Smart BIT therapy and its results, and regular schooling. The seven themes are described as follows.

### **Theme 1 – Knowledge of Autism**

Diagnosing autism in children is a complex and often challenging process, even for medical professionals. Informants who are doctors who have children with ASD face difficulties in getting an official diagnosis for their child. Although they have knowledge and understanding in the field of medicine, for the autism part, their knowledge is minimal. The following is an excerpt from the interview:

*As far as I remember, while studying medicine, little was learned about autism, only briefly discussed, so it is minimal. In college, it was just like that, not detailed. Indeed, autism is not included in the curriculum, and there is no demand to be able to diagnose autism. So, frankly, during my studies in medicine, I had very little knowledge. So, it's not surprising that when my child was diagnosed with autism, I was confused about what the steps of therapy or treatment were (doctor 1).*

*Well, because in medical school, we were never taught autism in depth. It is just the outline. If it is like a fruit, the skin doesn't go inside. Until the consultation with the pediatrician, he, who was already a pediatrician, said that he did not know much about*

*autism. Even the discussion with me during college was only a glimpse of autism, so I did not understand it. So, he referred me to a child growth and development specialist. So, even though I am a doctor, I have little knowledge about autism (doctor 2).*

*During my medical studies, I was taught that the psychiatry department presented material about autism. However, it was very limited and minimal. At that time, when the psychiatry block covered the material on autism, the content was very sparse. From the theory presented, if I am not mistaken, there were sensory integration therapy, speech therapy, and some medications that I have forgotten. During the child health science block, there was no specific discussion about autism as there was in the psychiatry block. It was only a general overview of autism and how it is treated. Furthermore, in terms of practical experience, honestly, I have never met autistic patients directly at the growth and development clinic or during my rotation at the pediatric and adolescent clinics. So, honestly, my knowledge about autism is minimal and has never been applied (doctor 3).*

From the interview excerpt above, it can be concluded that all informants know very little about autism. This is due to their lack of knowledge about autism when studying at the Faculty of Medicine.

## Theme 2 – Suspicious Autism

Early symptoms include not being able to speak, hyperactivity, sleep disturbances at night, walking on tiptoe, frequent tantrums for no reason, not being afraid of danger, not being able to play with their peers, lining up things, and several other symptoms, made all informants look for information about their children. This is as stated in the following interview excerpt:

*I suspect that when my child is 1.5 years old, why can't he talk, be quiet, jump here and there, scream, lack eye contact, and even avoid if we call him. He does not look, often gets angry, likes to see the fan, arranges and lines up toys, and his night sleep is not ordinary like other children; he wakes up a lot. From this observation, I suspect this is autism or ADHD (doctor 1)*  
*Because they are over 1 year old and cannot speak, they just mumble; At the same time, children their age have started to speak fluently. They are called not looking, there is no eye contact,*

*and they avoid eye contact with us, which makes me panic the most is the way on tiptoe like a ballet dancer, the tiptoe is tiptoe, climbing the trellis, toys are lined up, I like to see fans, wheels, rows of toy cars, Likes fine cotton, has an indistinct tantrum and has trouble sleeping at night. So, it's not a regression; yes, I was suspicious from the beginning (doctor 2)*

*I was the first to suspect that my child had ASD when he was 1.5 years old because he could not speak, was hyperactive, had tantrums for no reason, toys were lined up, made almost no eye contact if we called him, did not look and had trouble sleeping at night. However, the pediatrician who used to treat my child rejected my suspicions. By saying, "Oh, this is just a speech delay. Later, he can play alone; just talk to him often." I consulted that doctor because by the age of two, my child still could not speak or was delayed in speech. However, I still felt that there was something wrong with my child, not just a simple speech delay. (doctor 3).*

## Theme 3 – Search for Diagnosis and non-diagnostic therapy

Furthermore, all informants rely on Google and social media to find out more about the problems experienced by their children. Doctor 1 and Doctor 2 immediately took their child to therapy, where their peers and friends referred them without a diagnosis.

Meanwhile, doctor three immediately looked for a pediatrician and psychiatrist in his area, outside the province where he lived, and then went to Jakarta for certainty of diagnosis. The following is an excerpt from the interview:

*I rely on Google and call my friends to get information about autism. In 2013, I rarely found*

*seminars on autism. A friend of mine took Pediatric Specialist Education in the Philippines (PPDS). I asked him for help with the particular Nelson Pediatric Child Education guidebook photo. Ask for a photo of the autistic and how much it is explained. He only took a picture of one or two paragraphs. Then I posted on Facebook. Alhamdulillah, my younger classmate read it, and he told me that his child was also autistic. He said his son was in therapy with SI, OT, TW. So, at that time, I only knew that the problem of autism therapy was SI, OT, and TW. Finally, I discovered which SI, OT, and TW therapy place is qualified. Alhamdulillah, there is a friend of mine who is nearby here who also has a therapy place (doctor 1).*

*First, I browsed and read, finding out why with my child. After reading this, I was immediately convinced that this was autism. From there, I started looking for a place for therapy and doctors who treat autistic children. When I went to the pediatrician who usually treated my child sick, he also didn't understand much about autism and said he could not diagnose autism yet. I was confused, so I went straight to the treatment places. Psychologists and therapists handled the therapy place I went to. I was immediately treated even though there was no diagnosis. The therapy is SI OT TW, speech therapy that is massaged or done like the mouth and all sorts of things. At the therapy place, I*

*asked my child what the diagnosis was, and then they informed my child of speech delay. I wondered, autistic, isn't it? They only answered that they could not be sure, but the possibility was yes. Three months of therapy were fruitless. My son just cried during therapy. Then, several times, I moved around the places of therapy and therapy with SI OT TW, and still, there was no result at all; I was still unable to speak and only crying. In this therapy place, I heard that mothers who delivered their children to therapy had to diet. I asked what diet he was on; some said he should not drink milk or foods that contain flour and sugar. I think it does not hurt that I tried it for my son and started trying the diet (doctor 2)*

*I started looking for information from fellow doctors but did not get much information. Then I browsed, and there was a lot of info, but the info confused me. Then, immediately look for pediatricians, psychiatrists, and so on. At that time, no child growth and development specialists or pediatric neurologists were in my area. Finally, I decided to consult outside the province and then go to Jakarta to meet with a child growth and development specialist. This is to ascertain whether my child is autistic or not (doctor 3).*

Doctor 1 and Doctor 2 then get information about autism diagnosis from fellow parents whose children are treated at the same

therapy place as their child. Furthermore, while walking in therapy, they look for information about their child's diagnosis.

The interview excerpt is as follows:

*Here, I asked the parents who delivered their children many questions, one of which was that I was knowledgeable about diet. So, my child had to abstain from milk, flour, and sugar; I then arranged food according to the information from the parents of other children at the treatment place. From the parents' information, this is where I took my child to one of the psychiatrists who treat ASD children. It was from this psychiatrist that the diagnosis of autism in my child was established when my child was two years old. During the consultation, I asked him if this autism could be cured, and he said that autism could be cured (doctor 1).*

*Because the diagnosis was unclear, I browsed and reread it. Meet the names of doctors who usually treat children with ASD. Then, I decided to consult a*

*psychiatrist, which I found in the browsing. During the consultation, autism was diagnosed when my child was 2 years old by the psychiatrist. Here, my child was given two types of supplements, if I am not mistaken. It was recommended that the diet and therapy be continued so far. (doctor 2).*

*After getting information from several friends about pediatric neurology in Jakarta, we left for Jakarta. At the age of three, autism was diagnosed by a neurologist in Jakarta. My child was not treated before the diagnosis (doctor 3).*

The process of finding a diagnosis for these doctors is not easy. Their peers also have the same limitations as them about Autism. As a doctor, all informants know that all therapies must be based on diagnosis. However, due to this limited knowledge, they are forced to carry out therapy on their children even though there is no diagnosis.

#### **Theme 4: Coping Mechanisms and Resilience**

Obtaining/establishing a diagnosis requires time and a long and not-easy process. This certainly has an impact on the phase of receiving autism diagnoses. Many parents experience a phase of rejection or confusion when they first receive a diagnosis of

autism. However, they finally accepted the reality. Some parents are relieved after getting an official diagnosis. Because it validates their suspicions and allows them to seek appropriate help and therapy. After receiving the diagnosis, parents try to find the proper treatment for their child. Parents show a persistent and proactive attitude in

finding the best solution for their child, although they sometimes face obstacles to accessing therapy in their area of residence. Likewise with resilience, experiencing severe things such as autism diagnosis in children, of course, requires high resilience so that parents can continue to search for the right therapy and provide therapy for their ASD children. Likewise with all the informants in this study, as conveyed in the interview excerpt below:

*Indeed, I was prepared, especially mentally. I was not emotionally affected when receiving the autism diagnosis. I just focused on what the subsequent autism therapy should be to address my child's problems, maybe because we were already strong during our time in medical school, where we were trained both physically and mentally. This includes the exhausting hours as a clerkship, which are under high work pressure. Therefore, the autism diagnosis for my child allowed me to go through that stage quickly. Next, I immediately sought to find out what should be done to help my child recover, as the psychiatrist who*

The four themes above suggest that although every family has unique experiences, there is a typical pattern in how they recognize autism symptoms, deal with diagnoses, and seek help for their child.

*diagnosed my child once said that autism can be cured (doctor 1).*

*When the diagnosis was confirmed, I was not too shocked. Previously, I had searched for information and read that I suspected my child had autism. My husband and I immediately accepted this diagnosis, and there was no denial stage. Since studying medicine, I have been trained to be mentally and physically strong and accustomed to the heavy and high burdens of learning and working. Well, I am used to being under high pressure, so this autism diagnosis was not too difficult for me (doctor 2).*

*I accept the diagnosis without any rejection. This is the destiny of Allah. Before my child was diagnosed, I had already lost a child, the younger sibling of my child, who has ASD. So, I have experienced something heavier than this autism diagnosis. Therefore, I focus on therapy. Accepting an autism diagnosis is indeed tricky. However, I am grateful because prospective doctors are trained mentally and physically while studying at medical school. When clerkships have a hefty workload, the working hours are also extraordinarily dense. (doctor 3).*

### **Theme 5: SI, OT, TW therapy and its outcomes**

The three informants, both treated before being diagnosed and treated after getting diagnosed, received the same type of therapy: SI, OT, and TW. However, all informants said that all these types of

treatment did not provide improvement/development in their children. Even though their child has been receiving SI, OT, and TW therapy for 2 years, all the informants' children still cannot speak even though they have been treated with TW or speech therapy. Improvements in their children occurred because of the diet they were taking, which fellow parents suggested at the therapy site. The following is an excerpt from the interview:

*After two years of therapy, I saw almost no progress in my son. My son's abilities are the ones I taught him before he was treated there. Whenever I ask the therapist or the owner of the therapy place when my child can speak, he always answers, "Later spontaneously if he speaks." But remember the psychiatrist who diagnosed my child that autism can be cured? I am pretty calm. However, I still keep thinking about how to recover. Meanwhile, I believe this therapy does not significantly increase the results. Because I couldn't see the therapist directly, I didn't understand anything the therapist did to my child. I had no choice but to follow because I had minimal knowledge about autism therapy. My husband always asks, "When can I talk about this? It's been a long time since I was in therapy". I answered like a therapist gave me an answer spontaneously, the therapist said. Suppose I judge that my child is improving because of his diet. After the diet has become relatively calm, he is starting to be attentive. The*

*night sleep is better, but there is still no verbal or inability to speak. I searched for therapy again. (Doctor 1).*

*I believe there has been almost no progress since the nearly 2-year SI OT TW therapy. The progress is due to the diet I applied to my child. He became a little calmer. I finally know why there is so little progress from this diet. Food should be abstained but still given to children, so progress is insignificant. Now I know that when I was given watermelon and carrots, my child immediately began to be uncondusive, such as revisiting behaviors that had been appearing for a long time; it turned out that watermelons and carrots were abstained from ASD. So, even though I felt that I had dieted my child, it turned out that it was still a virgin that I should have abstained from giving because of my ignorance as a mother. SI, OT, and TW therapy have made very little progress. It is not significant for the therapy time, which has been quite long. For about two years, my child still cannot speak. But from the diet, there is progress. So, I had to find a suitable therapy for my child (doctor 2).*

*I do not think there is any progress at all. My son still cannot speak even though he has been in therapy for 2 years with SI, OT, and TW. But I have to be patient. If I ask the doctor or therapist, they also cannot answer precisely when the child can speak. It is just that they say that each child has a different development; maybe they will be trained more often, but we do not know when. I stopped the therapy at the therapy site and then continued the same treatment in the*

*area where I lived. It is the same as no result. I stopped at the therapy place and said goodbye. So, after approximately two years and 3 months of therapy with SI, OT, and TW, almost nothing progressed, even*

### **Theme 6: Smart ABA & Smart BIT Therapy and its results**

The journey was long and tiring, but all the informants had to continue their search for therapy for their children. Again, browsing the internet brought together all informants at the KID-ABA Autism Center. The process winds like the following interview excerpt:

*Because I was not satisfied with the results of this therapy, even after two years of treatment, I continued my search for autism therapy. One time, my son was sick, and at that time, it was starting to get good; it was calm, his sleep at night was also good, his eye contact was good, and he was beginning to be aware of the environment because of the diet I applied. The doctor who treated my son gave me paracetamol. After I was healthy, I was surprised that his ability disappeared; he started to be ignorant again, lost eye contact, and began to be disturbed again at night. I know that only paracetamol is given when treated in the hospital. Then, I found out about paracetamol and autism. I found a post by Doctor Rudy Sutadi about the effects of paracetamol on children with ASD. I read it thoroughly and thought, whose doctor is this? How did he know the relationship between paracetamol and regression or*

*though I had followed all the rules conveyed by the therapy place. This may be a way for Allah for me to try again for my son's recovery (doctor 3).*

*deterioration in my child? When I went to the doctor who diagnosed me with no this information, I got it. I searched the website and found [www.kidaba.com](http://www.kidaba.com). I saw on the website a lot of information about autism that I had been needing. I was surprised that I did not find this website before. I read all the information from the web. It turns out that the diet I run for my son has many faults. It is a pity that my son has been eating the wrong diet. In short, my child was treated at the KID ABA Autism Center using the Smart ABA and Smart BIT methods. The difference is evident from the improvement of the diet provided by Kidaba. I observed that my child understood that he was given instructions and began to make eye contact with others. Although economically, the cost is not reasonable. Alhamdulillah, my husband agreed. Alhamdulillah, after 2 months of therapy with Smart aba and Smart BIT, my child began to be able to speak and have many more abilities. Everything is evident here, including the stages children go through to be able to talk to others. CCTV is also provided so that parents can see the therapy session. My dad said, "Lose pay, win use," one of the minang proverbs, which means that despite the high cost, the result is very satisfying. Smart ABA therapists also have competence in teaching children with ASD, and their*

*resilience is also high, in my terms. (Doctor 1).*

*Even though it has been almost 2 years of therapy and has moved from place to place, there is almost no progress. I remembered information about Dr. Rudy from one of the therapists. Then I browsed and found [www.kidaba.com](http://www.kidaba.com) website. I read all the content on the website, ahaaa I know why my son has made very little progress so far. I was immersed in reading all the very complete information. I know that the diet I give to my child has many faults. That is where I connected with the KID ABA Autism Center. In short, I was given a consultation schedule with a doctor there whose child also had ASD. From the information I got, the child was in good condition. Then, during the consultation, I did a second opinion for diagnosis. As a result, my son has ASD. Then, she explained the therapy in detail, which was very clear and detailed. I thought, how come I have only found a therapist who knows the ins and outs of autism and its therapy, and it makes sense from everything that is explained? However, I must not regret it. Allah has arranged well for the good of my son and me. I am grateful; maybe this is God's way for me to correct my mistakes so far. Next, I was guided to make a daily menu. When I consulted, a child doctor, Y, was beside him. I am very happy to see that his child is very smart, even though he used to be more or less the same as my child. In my heart, I asked Allah that my child would also be allowed to heal like Dr. Y's son. Because I have been tired of several years of wrong therapy. Finally, I saw the hope I had been*

*seeking from Dr. Y. Alhamdulillah. I finally accepted everything and increased my enthusiasm because I wanted this. Smart ABA and Smart BIT therapy started for my child. As a result, entering the third month, my son began to be able to speak, which I had been waiting for. This Smart ABA therapist has excellent cognitive abilities and skills in treating children with ASD. Moreover, they are patient and diligent in treating my child. There are many programs, but we parents can see through the CCTV monitor provided for each parent. It is a bit expensive, but the results are worth it (doctor 2).*

*Before going to Jakarta for consultation and therapy, I already had information about Dr. Rudy, one of the autism experts in Indonesia. However, other doctors have already consulted about it. God's destiny may determine the best time to see Doctor Rudy for Smart ABA and Smart BIT therapy. Because of my son's lack of progress, I began to explore the world of social media to find out what was wrong and why my child had so little progress. Even after 2 years of therapy, I have not been able to speak, leading me to meet the Instagram of Doctor DD in 2022. On his Instagram, I saw him talking about his son. I opened it and saw the content of his Instagram. The DD doctor told the story of smart aba and smart bit therapy, in which he ran on his child and showed significant progress quickly. Even though with the previous therapy, there was almost no progress. I got an education from Instagram. At that time, her son was already in school and excelling. After I looked again, I saw that Doctor DD's therapy in Kid*

*Aba belongs to Doctor Rudy. I remembered my journey two years ago, even though I already knew about Dr. Rudy. However, I cannot regret this incident; I have taken the lesson. Through the DD doctor's Instagram, I connected with the KID ABA Autism Center and consulted with the team of doctors. My son then underwent Smart ABA & Smart BIT therapy under the guidance of KID ABA Autism Center. Entering the*

*fourth month, my son began to be able to speak, feeling relieved after a long and tiring wait. I can see through the CCTV monitor what and how Smart ABA therapy is implemented. Smart ABA therapists do have competence so that they can teach children with ASD to be able to speak and many more skills that were previously difficult for my child (doctor 3).*

These similarities show that Smart ABA and Smart BIT therapy provide positive outcomes for children with ASD, supported by parental commitment and a systematic and practical therapeutic approach.

#### **Theme 7: Regular school**

Regular schools are the primary goal of the Smart ABA approach. This systematic, structured, and measurable method of teaching helps children with ASD develop skills that were previously difficult for them. The three informants revealed that when their children started talking after undergoing Smart ABA and Smart BIT therapy, their stress and anxiety levels decreased. They were initially worried that this therapy would not be different from the previous one. The peak moment occurred when their children were allowed to attend regular schools after reaching 80% of the Smart ABA curriculum. Although the three informants still doubted their son's

eligibility to be tested in regular school, their happiness increased. Here is an excerpt from their interview:

*My son started school after 2 years of Smart ABA and Smart BIT therapy. Entering Kindergarten B. Before school, there is a replication program. The therapy room is made like a regular school classroom. There is my son and another child who is not ASD. The therapist becomes a teacher and a shadow, so it is a transition to school. I then became a shadow for my son. When I entered kindergarten, the school carried out a test, and my child passed. At that time, I thought the demands of the lessons were not too high. However, it turns out that the lesson is quite difficult. I see that the lag is quite far. This kindergarten is an Islamic kindergarten. The lessons include memorization of verses from the Quran and others, while my child's Quran memorization ability is still limited. Director Program of KID ABA Autism Center then created a program to help my child catch up with his friends. Drilling was carried out after school. Moreover, Alhamdulillah was able to catch up with his friends. Moreover, my son is*

*in the 2nd grade of junior high school. Alhamdulillah, the development is good. There may be a problem, but it is not related to his autism. Interaction with the environment is good. Maybe people who do not know me do not know that my child used to be autistic. Only for difficult lessons such as mathematics, I have to help remedially at home (doctor 1)*

*Alhamdulillah, after 14 months of therapy with Smart ABA and Smart BIT, my child can be accepted into a regular school. Previously, replication was done by making the therapy room a regular school classroom; other children were not autistic, and therapists and therapist assistants were used as teachers and shadows. This struggle is not easy, but be sure of God's help. For us, this is indeed difficult, changing our routine as a family and sacrificing for my son's recovery. When I wanted to enter kindergarten, all of the six schools refused. Alhamdulillah, the seventh school accepted my child after the test, but there must be a companion. Alhamdulillah, my son's therapist has also been trained by KID ABA as a shadow companion at school. My son is in the 1st grade of junior high school, and*

*communication with the environment is good. Some of my friends did not even expect that my child was autistic. He is perfect; sometimes, he likes to be sad if his grades are not good and his friends have better grades. He is sad if his science score is not 100 (doctor 2).*

*After 2 years of therapy with Smart ABA and Smart BIT, Alhamdulillah, my child was tested to go to a regular school. Previously, replication was carried out by changing the therapy room to be similar to a classroom in a regular school. In it, some children are not autistic, and therapists and therapist assistants play the role of teachers and shadows. Accepted into one of the kindergartens in my area. Communication with the environment is still limited. My struggle is still long and hard, but I am sure that Allah will not let me in trouble. I believe in God's help. The proof is from being unable to speak, Alhamdulillah. Now, my child is at school, and I am moved to the point that my child is starting to be able to read the Arabic alphabet or Iqro. I am grateful for the blessings that Allah has given me, and I feel that my burden is lighter than when my child cannot speak (doctor 3).*

## **Discussion**

### **Theme 1 – Knowledge of Autism**

From table 2 we can understand the similarities in opinions among informants

regarding their knowledge of autism and the signs that may indicate autism in children.

Table 2: Points of similarity/similarity of opinion among informants about knowledge Autism and suspected autism

Aspects	Similarities/Similarities
Knowledge of Autism	The informant's knowledge of autism is limited because of the limited acquisition of this knowledge when studying at the Faculty of Medicine.
Suspicious of Autism	<ul style="list-style-type: none"> <li>• Parents suspect autism after observing the child's behavior and comparing it with their peers.</li> <li>• Early symptoms between 1 and 1.5 years.</li> <li>• Not being able to speak, hyperactive, minimal eye contact, not looking when called, frequent tantrums, lining up toys, often screaming, and sleep disturbances at night.</li> <li>• In Doctor 2, coupled with a knot like a ballet dancer.</li> </ul>

In terms of knowledge of autism, informants have limited understanding, primarily due to insufficient exposure to this topic during their medical education. Regarding the suspicion of autism, parents often become suspicious after noticing their child's behavior and comparing it to that of their peers. Signs of autism can appear as early as 1 to 1.5 years of age. Common behaviors that raise concerns include the inability to speak, hyperactivity, minimal eye contact, not responding when called, frequent tantrums, lining up toys, excessive screaming, and sleep disturbances at night. Additionally, one informant (Doctor 2) noted a specific behavior described as a "knot like a ballet dancer," possibly indicating a unique or unusual way of movement. Overall, the table highlights a

general lack of knowledge about autism among informants and identifies key behaviors that can lead to suspicion of autism in children.

### Theme 2 – Suspicious Autism

All participants expressed concerns about the possibility of autism spectrum disorder (ASD) or attention-deficit/hyperactivity disorder (ADHD) in children. Common signs mentioned include the inability to speak at 1.5 years old, lack of eye contact, hyperactivity, unusual sleep patterns, and behaviors such as arranging toys and tiptoe walking. One parent felt dismissed by a pediatrician who attributed these signs to simple speech delay, yet this parent remained convinced that there was a more serious issue with their child. Overall, the

excerpts highlight parents' challenges in recognizing developmental disorders and

the skepticism they often encounter from healthcare professionals.

Table 3: Points of similarity of opinion among informants about the search for a diagnosis and therapy without diagnosis

Aspects	Similarities in doctors 1 and 2
Diagnostic search	<ul style="list-style-type: none"> <li>• Find a doctor who treats children with ASD from fellow parents at the therapy site.</li> </ul>
Therapy without diagnosis	<ul style="list-style-type: none"> <li>• Carry out therapy without a diagnosis/before getting a diagnosis.</li> <li>• With SI, OT, and TW therapies.</li> </ul>

Table 4: Points of similarity of opinion among informants about the search for a diagnosis and therapy without diagnosis

Aspects	Difference (doctor 3)
Diagnostic search	<ul style="list-style-type: none"> <li>• Finding a doctor who treats children with ASD through the internet</li> <li>• Directly consult out of the area, then to Jakarta</li> </ul>
Therapy without diagnosis	Not taking therapy before getting a diagnosis

**Theme 3 – Search for Diagnosis and non-diagnostic therapy.** In the diagnostic search, Doctors 1 and 2 emphasize the importance of finding a specialist for children with autism spectrum disorder (ASD) through recommendations from fellow parents who are already engaged in therapy. This suggests a community-based approach where parents support each other by sharing resources and experiences. In contrast, Doctor 3 takes a different approach by suggesting that parents utilize

the internet to find specialists, indicating a more independent and possibly less community-focused method. Additionally, this doctor advises seeking consultations outside the local area, specifically directing parents to Jakarta, which may imply a belief that better resources or specialists are available there.

Regarding therapy without a diagnosis, Doctors 1 and 2 had to start therapy even before a formal diagnosis was made due to difficulties in obtaining a diagnosis. They

were unaware of the appropriate therapies for autism because of their limited knowledge, so they simply followed the advice provided by the clinic where their children received therapy services, such as Sensory Integration (SI), Occupational Therapy (OT), and Speech Therapy (TW). Doctor 3 believes that therapy should not commence until a diagnosis is established. This indicates a more cautious stance, prioritizing a clear understanding of the child's condition before initiating any therapeutic interventions.

Overall, the opinions reveal a spectrum of approaches among the doctors regarding the diagnostic process and therapy initiation for children suspected of having ASD. Doctors 1 and 2 promote community engagement and early therapeutic intervention, while Doctor 3 favors a more independent search for specialists and a conservative approach to therapy, emphasizing the need for a formal diagnosis first.

Table 5: Points of agreement among informants about coping mechanisms and resilience

Aspects	Similarities/similarities
Coping mechanism	<ul style="list-style-type: none"> <li>• The three informants immediately received a diagnosis</li> <li>• Because you already suspect autism</li> </ul>
Resilience	<ul style="list-style-type: none"> <li>• I have been trained to be mentally and physically strong since studying medicine.</li> <li>• Especially during clerkship, they are used to the heavy and heavy workload of studying and work. Which, of course, requires high resilience.</li> </ul>

**Theme 4 –coping mechanisms and resilience.** In terms of coping mechanisms, all three informants were able to receive a diagnosis promptly because they already suspected autism. When it comes to resilience, they each expressed that their

training in medicine has equipped them to be mentally and physically strong. This strength was particularly developed during their clerkship, where they became accustomed to the demanding workload of their studies and professional

responsibilities, which naturally necessitated a high level of resilience.

Table 6: Points of similarity/similarity of opinion among informants about the search autism therapy and its results

Aspects	Similarities/Similarities
Autism therapy	<ul style="list-style-type: none"> <li>• All informants only know that the therapies for autism are SI, OT, and TW.</li> <li>• Not getting clarity on what is done during therapy because the informant cannot see the progress of therapy.</li> <li>• There is no clarity on when their child can speak and what the problem is</li> </ul>
Therapy outcomes	<ul style="list-style-type: none"> <li>• It has been 2 years of running SI, OT, and TW therapy, and the informant's children still cannot speak</li> <li>• Even though they are dissatisfied with SI, OT, and TW therapy results, parents still hope to find an effective solution.</li> </ul>

**Theme 5: SI, OT, TW therapy and its outcomes.** Table 6 highlights the points of similarity in opinions among informants regarding the search for autism therapy and its outcomes. All informants are aware that the therapies for autism include Sensory Integration (SI), Occupational Therapy (OT), and Speech Therapy (TW). However, they express dissatisfaction due to a lack of clarity about what occurs during therapy

sessions, as they are unable to observe any noticeable progress. Additionally, there is uncertainty regarding when their children will begin to speak and the nature of the underlying issues. Despite two years of undergoing SI, OT, and TW therapy, the informants' children still cannot speak. While they are dissatisfied with the results of these therapies, the parents maintain hope of finding an effective solution.

Table 7: Common points of opinion among informants about Smart ABA therapy &amp; Smart BIT

Aspects	Similarities/Similarities
Search for Information about KID ABA	<ul style="list-style-type: none"> <li>• Parents can learn about KID ABA through searches on the internet or social media, such as Instagram.</li> <li>• After finding the information, they call the number listed to get more details.</li> </ul>
Parental Commitment Despite High Costs	<ul style="list-style-type: none"> <li>• Although the cost of therapy is relatively high, parents decide to continue treatment because they realize the importance of investment in their child's development.</li> <li>• This decision shows a strong commitment of parents to provide the best care despite financial challenges.</li> </ul>
Rapid and Significant Therapy Progress	<ul style="list-style-type: none"> <li>• After undergoing Smart ABA therapy, children show significant progress quickly, such as starting to talk or reducing hyperactive behavior.</li> <li>• Systematic and effective therapy gives positive results, with children beginning to show verbal abilities after a few months.</li> </ul>
Emotional Experience	<ul style="list-style-type: none"> <li>• Parents feel very moved and grateful for the quick and effective progress of Smart ABA &amp; Smart BIT therapy.</li> </ul>
Satisfying and Sustainable Therapy Results	<ul style="list-style-type: none"> <li>• Despite the challenges, the results of Smart ABA and Smart BIT therapy were very satisfactory, with children showing significant progress in verbal and behavioral development.</li> <li>• Parents remain committed to continuing therapy, seeing its positive impact on their child's development.</li> </ul>
Experience and Support from Therapists and Professionals	<ul style="list-style-type: none"> <li>• Parents appreciate the approach of the professional Kid ABA team and therapists, who are highly resilient and competent in teaching children with ASD.</li> <li>• Support from a reliable therapist and effective communication help the therapy run smoothly and produce the desired progress.</li> </ul>

**Theme 6: Smart ABA & Smart BIT Therapy and its results.** Table above outlines the common points of opinion

among informants regarding Smart ABA therapy and Smart BIT. Parents report learning about KID ABA through internet

searches or social media platforms like Instagram. After gathering information, they typically call the provided number for further details. Despite the relatively high costs associated with therapy, parents are committed to continuing treatment, recognizing the importance of investing in their child's development. This decision reflects their strong commitment to providing the best care, even in the face of financial challenges. Informants note that after undergoing Smart ABA therapy, children exhibit rapid and significant progress, such as beginning to talk or showing reduced hyperactivity.

The systematic and effective nature of the therapy leads to positive outcomes, with children demonstrating verbal abilities after just a few months. Parents express feeling

deeply moved and grateful for the quick and effective advancements made through Smart ABA and Smart BIT therapy. The results of these therapies are reported to be very satisfactory, with children showing significant improvements in both verbal and behavioral development. As a result, parents remain dedicated to continuing therapy, recognizing its positive impact on their child's growth. Additionally, parents appreciate the approach taken by the professional Kid ABA team and therapists, who are seen as resilient and competent in working with children with ASD. The support from reliable therapists and effective communication contributes to the smooth implementation of therapy and helps achieve the desired progress.

Table 8: Common points of opinion among informants about Regular School

Aspects	Description
Replication	<ul style="list-style-type: none"> <li>• Before entering the regular school, replication is carried out.</li> <li>• Some children are not ASD in the replication class, and the therapist plays the role of teacher and shadow.</li> </ul>
Regular school process	<ul style="list-style-type: none"> <li>• Pass the test like any other child.</li> <li>• Children's social interaction is good, except for doctor 3, whose child's interaction with the environment is still limited.</li> </ul>

Aspects	Description
High Standards in the school curriculum	<ul style="list-style-type: none"> <li>The high standards in academic achievement, especially in certain subjects, highlight the development of these children.</li> </ul>

**Theme 7: Regular school.** From the table above, common points of opinion among informants regarding regular school can be observed. Before children enter regular school, a replication process is conducted. In this replication class, some children who are not diagnosed with ASD are included to learn alongside children with ASD. The therapy space is transformed to resemble a classroom. Two therapists take on the roles of both teacher and Smart ABA Shadow. The admission process for children with

ASD in regular schools is the same as for those without ASD; they must pass tests just like any other students. Generally, children's social interactions are good; however, one informant noted that their child's interaction with the environment remains limited. Additionally, the high standards in the school curriculum, particularly in certain subjects, emphasize the academic development of these children.

**Table 9: Summary points**

Points	Description
The Importance of Receiving a Diagnosis and Starting Therapy Quickly	All informants emphasized the importance of receiving a diagnosis of autism quickly and not procrastinating in starting therapy.
Advice for Parents in Running Therapy	The advice for parents, whether doctors or non-doctors, is to carry out therapy with dedication, family support, prayer, and patience.
Integration of Knowledge about Autism into the Educational Curriculum	Integrating knowledge about autism into the educational curriculum, including the curriculum of medical faculties, is essential to improve understanding and treatment of autism.
The Importance of Continuing to Learn and Never Giving Up in Accompanying Children with Autism	Each informant highlighted the importance of continuing to learn and never giving up in accompanying children with autism to recovery, with confidence in the best destiny of Allah.

**Advice from all informants:**

All the informants emphasized the importance of receiving a diagnosis of autism quickly and not procrastinating in starting therapy. Whether you are a doctor or not, it is to carry out therapy with dedication, family support, prayer, and patience. Integrating knowledge about autism into educational curricula, including the curriculum of medical faculties, is essential to improve understanding and treatment of autism. The importance of continuing to learn and never giving up in accompanying children with autism to recovery, with confidence in the best destiny of Allah.

**CONCLUSION AND SUGGESTIONS****Conclusion**

This study reveals the experiences of doctors who have children with ASD in the process of getting a diagnosis and therapy. Despite having a medical background, they face significant challenges in obtaining the correct diagnosis for their children. The limited knowledge acquired during medical

education about autism is the main obstacle. As a result, they often rely on information from the internet and peers, which is often inadequate. Despite experiencing high levels of stress, all informants showed resilience and proactivity in seeking appropriate therapy. The therapies, such as SI, OT, and TW, did not show significant results. However, some informants reported progress through the diet applied.

**Suggestions**

This study also highlights the potential of Smart ABA and Smart BIT therapies as more effective methods in helping children with ASD. After undergoing this therapy, the three informants' children could speak and develop various other skills. Currently, all the informants' children are in regular schools. It is hoped that these findings can contribute to increased understanding and support for parents and medical personnel in facing the challenges of autism, especially in effective diagnosis and therapy.

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