

# Meltdown in Autism: Challenges and Support Needed for Parents of Children with Autism

Teassy Yalim, Suziyani Mohamed

Faculty of Education, Universiti Kebangsaan Malaysia

Email: p107066@siswa.ukm.edu.my, suziyani@ukm.edu.my

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## Abstract

Meltdown is very common to every child. However, it is more complicated and extreme among children with autism. Generally, a meltdown or a breakdown happens is caused by a situation where children with autism are in a room or place with crowds, when they hear a loud noise, or when they are in a position where it is hard to express their feelings or emotions through words. When this happens, instead of words, they will tell their feelings through loud or long cries, screams, and to the extent that they would hurt themselves. For example, bumping their head or body on the wall or even falling to the ground. This has caused many implications and challenges to the parents of children with autism. Hence, parents need support in handling meltdowns among children with autism. This study aims to investigate parents' challenges and reveal the support they require when their children with autism have meltdowns. It is critical to understand autism and how this subtopic; meltdown, challenge parents in order to understand the support that parents of children with autism require, especially when their child meltdown in a crowd where many eyes are on them, primarily to at least minimize negative perceptions towards the parents and their children with autism. A qualitative research methodology was adopted for this study, and parents of children with autism were interviewed to collect primary data. Interviews were conducted with five mothers and one father of children with autism. The findings revealed that the challenges encountered by parents during the meltdown of their children with autism include physical, mental, and emotional challenges. Emotional challenges appeared to be the most challenging for parents. Parents of children with autism require support in terms of services and skills, moral support, and societal awareness. This study also exposes to culture a minor aspect of autism, the meltdown itself, in the hope that it will help the community understand more about autism, particularly the challenges encountered and the support required by parents of children with autism. This study will help to broaden future autism research, particularly clinical explanations for meltdowns.

**Keywords:** Autism, Meltdowns, Parents, Challenges to Parents, Support to Parents

## Introduction

Autism is when a person encounters challenges in social skills and interactions, has repetitive behaviors, faces delayed speeches, and tends to be more comfortable with non-verbal communication (Autism Speaks, 2021). The United States recorded that every-one among 44

children is diagnosed with autism (Autism Speaks, 2021), and according to the Centre for Disease Control (CDC), one among 68 children are diagnosed with autism, while in Malaysia, at least 9000 children were born with autism each year (NASOM, 2021). Generally, a few types of autism are mainly influenced by genetics and environment (Autism Speaks, 2021). Although autism is closely related to spectrum disorder, every child with autism has their strength and encounters different challenges in their daily lifestyle, learning, and development (Autism Speaks, 2021).

Spectrum disorders among children with autism also involve the lifetime nerve developmental disorder, which is present and can be diagnosed as early as two years old (Early Autism Project, 2022). Autism influences the developmental disability of children, especially in their verbal and non-verbal communication and social interaction (Zainoriza et al., 2019). Usually, no physical symptoms can be seen in children with autism. However, autism influences brain development, affecting children's learning ability compared to their peers (Early Autism, 2022). Some children with autism would need extra and prominent support in their daily routines, while some children with autism need only minimal help or support, with some being able to be independent on their own just like other typical children (Autism Speaks, 2021).

Autism can be "recognized" or "assumed" based on a few traits that can be seen in a child who may be deemed to have autism, such as the child's delayed development, in addition to less visible physical signs. These traits, which would indicate delayed development relative to their peers, can be identified in a child with autism as early as 2 to 3 years old or the youngest at 18 months (Autism Speaks, 2021). Early intervention will, however, greatly aid and benefit their growth. The sensation of sensitivity, health problems like gastrointestinal (GI), convulsions, difficulty sleeping at night, and other difficulties like mental health, including anxiety, depression, and attention disturbance, are factors that typically contribute to impacting the development of a child with autism (Autism Speaks, 2021).

Tantrums are a problem that affects all children but are slightly different for children with autism. Children with ASD frequently experience tantrums for a variety of reasons, including when they do not receive enough information when they do not receive a tangible thing, when their expectations are not met, or when there is excessive stimulation in their environment. Sometimes longer temper tantrums might turn into meltdowns. Autism-related children frequently experience tantrums. Children between the ages of two months and five frequently have tantrums and meltdowns, which typically subside as they get older. According to previous research, parents of autistic children should be most concerned about their children's problems in social situations, limited interest in their surroundings, and repetitive activities (Ijaz et al., 2021). Typically, repetitive conduct is visible during meltdowns.

A meltdown is a severe reaction to an extraordinary circumstance in which a child with autism either loses control of their actions or experiences no control at all (National Autistic Society, 2021). However, this does not necessarily indicate that they are acting inappropriately. Most children with autism find it difficult to communicate their emotions, especially when they become overly anxious or overwhelmed by circumstances or environments, which can result in a meltdown.

While ordinary children typically throw tantrums to get something they want, such as toys, attention, or control over someone or something, they are nevertheless capable of self-regulation. On the other side, autistic children are acting out for no apparent cause (RDIconnect, 2021). A meltdown lasts more time than a temper tantrum. Children with autism will exhibit typical child behaviors during a meltdown, including shouting, biting, beating

themselves, and damaging things. However, due to intense discomfort, autistic children are unable to regulate themselves (RDIconnect, 2021).

Children with autism will require some time to cool off and calm themselves down during a meltdown because a meltdown cannot be turned off easily (RDIconnect, 2021). They tend to attack, injure, or break things under some circumstances. However, even though many parents and experts believe that meltdowns have an impact on a person with autism's abilities, routines, and quality of life, meltdowns are not mentioned as a diagnostic criterion for diagnosing autism.

Meltdown is unpredictable and very close to emotions (Mazefsky, 2009; Miller, 2021). Miller stated in his article *Why Do Kids Have Tantrums and Meltdowns?* That emotional overload is one of the causes of meltdowns, while Mazefsky noted that it is very crucial to understand the emotional experience of autistic children to understand them during meltdowns. Mazefsky (2009) also mentions other causes of meltdowns, such as complex or complicated situations, struggle to process a problem or specific issues, overly narrow focus, unclear or miscommunication, sudden transition, and changes in routines and anxiety will lead to an extreme meltdown for autistic children. Hence, understanding the factors and causes will help parents prepare them to face meltdowns.

Coates (2021) stated that *too many demands that are too complex will trigger* a meltdown. This can be from adults, parents, teachers, or even peers in their daily life. Sometimes, simple situations could be complicated for children with autism due to their inability to think flexibly, just like typical children (Coates, 2021). In their daily life, being exhausted from school, facing everyday challenges, and being overstimulated will lead them to an emotional overload, which primarily leads to meltdowns and sometimes could occur even with the absence of audiences (Bennie, 2022). When emotions are too much to handle, they will meltdowns (Spencer, 2022). Most of the time, typical children will need discipline enforcement during meltdowns. However, for autistic children, this is a time when they will need support from adults to handle and manage, express, and regulate their emotions, feelings, and behaviors (Spencer, 2022).

### Literature Review

Meltdown can be predicted based on how long the tantrum-meltdown happens, but this is different from situations and types of the severity of the children's autism. Generally, when a child shows extended tantrums longer than usual, it is a sign that a tantrum has transitioned to a meltdown which can happen when children with autism are frustrated or in a spread crowd with a loud noise or voice.

Previous research revealed that some of the general causes of meltdowns among children with autism include sensory overload (Watson, 2022), (RDIconnect, 2021) and (National Autistic Society, 2022), information overload, which happens when children with autism receive too much of inputs until they become unable to make decisions or take any actions Autism Charity (2020); RDIconnect (2021), an emotional overload and anxiety where children with autism challenging to express the struggle they are undergoing and asking for help Coates (2021); RDIconnect (2021); National Autistic Society (2022); dan (Miller, 2021). Meltdowns' situation caused by anxiety is more extreme and more painful, especially for children with autism who have trauma from the past and have been neglected (Simpson et al., 2019).

Changes in routines and communication difficulties, including speech and language problems such as speech delay, are common issues encountered by children with autism which also

lead to meltdowns, and are often discussed among autism experts (Special Learning, 2022) (National Autistic, 2022).

### **A. Challenges encountered by parents in dealing with meltdown situations**

Specified challenges referred to parents' difficulties faced and expressed while dealing with meltdowns based on previous research.

Dealing with a meltdown alone is challenging enough for parents and, what's more, raising children with autism in general. Siti Marziah and Shahirah (2018), in their article *The Challenges of Nurturing Autistic Children from the Mother's Perspective* stated the challenges parents face in raising their children with autism. Some challenges noted include the behavior of their children with autism which can become aggressive and hyperactive, financial challenges for therapy, transport, and travel costs, and the perceptions of certain groups of society, which often give more negative stigma towards the children with autism and their parents. This article stated that one of the most significant challenges for parents when their children with autism are in meltdowns, is an emotional challenge, which is not even new.

Parents with disabled child or children receive even more pressure compared to other parents (Afizah et al., 2020). In Malaysia, issues related to autism are still under the skin and need more digging. Hence, many people still do not understand autism because of the lack of information and experience with individuals or children with autism in general. Some of society still negatively view children with autism and their parents (Afizah et al., 2020). In addition to the traits of children with autism, such as trouble getting along with other children and a tendency to isolate themselves, these children's tantrums, stress, and meltdowns also have the impact of upsetting their parents' emotions. Parents of children with autism are also affected by severe behaviors during their child's meltdowns, such as striking or bashing their heads against a wall, slamming their bodies to the floor, injuring themselves violently, and breaking everything around them (Afizah et al., 2020).

Parents are burdened by anxieties and thoughts while they are away in addition to the impact of the meltdown problem. For instance, parents of these children with autism are terrified that something awful might happen to them when they attend school (Nor Afizah et al., 2020). The emotional strain on parents was increased when they considered how these autistic children might cope with difficulties in the future without their parents (Nor Afizah et al., 2020). When meltdowns happen, children with autism often show aggressive behavior, and this tends to cause parents to feel angry, guilty, and feel themselves failings, feel ashamed because they thought they could not control their child, or when their children with autism are not following their instructions the way typical children will do; these situations will cause significant stress, and challenge the parents' emotions.

Nor Afizah et al (2020) stated that a mother of a child with autism faces even more emotional challenges than the father. This situation is even more challenging and stressful when parents are separated (Siti Marziah & Nor Shahirah, 2018). Hence, emotional challenges are one of the challenges faced by parents of children with autism which is critically different and hardly understood by parents of typical children (Fatin Sophia, 2020).

Zainoriza et al. (2019) wrote in their article *Pengetahuan, Sikap Dan Persepsi Masyarakat Tentang Kanak-Kanak Autism Spectrum Disorder (ASD)* stated that another challenge encountered by parents of children with autism during meltdowns is when they openly receive negative perceptions from a particular layer of society, especially those who have significantly limited knowledge about children with autism. The acceptance and perceptions from the surrounding community, especially family members and loved ones, are essential to

give support to parents of children with autism as well as to have a positive influence on the growth and healthy development of children with autism (Zainoriza et al., 2019). However, not everyone will give or show positive perceptions neither toward parents or children with autism in general (Zainoriza et al., 2019). Hence, some people negatively perceive parents and their children with autism. And so when a meltdown happens, some people give them negative perceptions and opinions. This is because they do not know or do not understand the situation, especially when it is autistic meltdowns. Some people also see these children with autism as disabled people who cannot be taught. They also think these children tend to act violently, especially when they are having a tantrum, and during meltdowns (Zainoriza et al. 2019).

It is proven that in some meltdown situations, a child with autism tends to act aggressively if the situation's problems are not dealt with properly and promptly. When this happens in public, people with no knowledge of autism or have no explicit understanding of why a child with autism acted aggressively during meltdowns could have thought or probably will consider that a child with autism is dangerous. Hence, they may tend to exclude or discriminate against this child and their parents (Zainoriza et al. 2019).

Autism-affected children and their parents both struggle with this kind of view. Imagine the parents who experienced such a negative view; they would be hesitant to participate in family or neighborhood gatherings. Because of this, it is challenging for parents to fit in with the neighborhood and even to receive support from relatives and the local community. Therefore, the perception and acceptance of other people also become a challenge for parents during the meltdown situation and affects the development of children with autism. Naturally, it is difficult to raise a child who has autism. It is challenging to deal with children with autism who are having tantrums, let alone when a meltdown happens. Although parents were aware that their children would have the same pattern of meltdowns, they were unable to foresee how harmful or extreme it might be in specific situations. This is because the same meltdown pattern doesn't always result in the same responses or behaviors. To handle this scenario, parents must have a solid comprehension of it.

Repetitive and aggressive behavior are the following challenges parents of children with autism encounter when their child is experiencing a meltdown. As is well known, during meltdowns, a child with autism usually screams and cries longer. Sometimes it can be more serious, they can behave aggressively, and worse is when this behavior can be repetitive and dangerous as it involves hurting themselves and others. This worries the parents, especially when a meltdown happens in public. The possibility of a child with autism acting aggressively during a meltdown is hardly expected. This is why parents need to be constantly aware and alert to the case of meltdowns and be ready for the possible reaction and behavior of the child towards parents in the present to prepare them for the future (Siti Marziah & Nor Shahirah, 2018). Hence, the aggressive behavior of a child with autism is one of the challenges faced and worries parents the most.

How children with autism react to their parents and other adults could be different. Given that most cases may vary, parents of children with autism can still be prepared for any situation regarding meltdowns, no matter how difficult it is. However, how will the children react and behave without their parents? Hasnah et al (2010) found that special education teachers in schools, especially in Malaysia, have not yet received solid training in dealing with children with autism. The same research also found that special education teachers in Malaysia also still lack confidence in teaching children with autism. Although most of the teachers who became informants in this study stated that they have a solid general



knowledge of autism, they are still confused about the diagnosis and still have very little training in dealing with the situation of stress and an extreme meltdown in a real-life scenario involving meltdowns in autism (Hasnah et al., 2010).

Therefore, it is to be a concern for parents of children with autism if a meltdown happens at school with the possibility of having untrained or inexperienced teachers dealing with this situation because of the possibility that children with autism may have a different reaction and it could be more challenging when a meltdown happens at school. Children with autism will be hard to handle by inexperienced teachers. Therefore, the way children with autism will react and behave, which can be aggressive and repetitive, worries their parents because it can cause them to hurt themselves and others.

Autism will affect the normal development of the part of the brain that involves the interaction part social, and communication skills of children with autism (NASOM, 2021). Whether a child or an adult with autism, they usually will have problems in terms of verbal communication, which makes it difficult for them to relate to the outside world and communicate with others (NASOM, 2021). Some children with autism do not talk, have a speech delay, or have minimal verbal communication skills (NASOM, 2021). This becomes one of the challenges to parents in preparing education for their children with autism.

Feelings of worry present when parents decide whether to send their children with autism to preschool for exceptional or regular school. Therefore, providing education to children with autism also becomes a challenge to parents. NASOM (2021) reported that Malaysia has approximately 9000 children with autism born in a year which is expected to increase. This will also increase the number of parents looking for an early intervention program involving autism. Due to this increase, it will be difficult for parents to find a preferable place for education for their children with autism because of these two main reasons: most of the early intervention programs are usually run or provided by a non-government organization (NGO), and second is NGOs in Malaysia that offers intervention programs related to autism are unable to take more than 1500 children (NASOM, 2021). This is why providing appropriate education to children with autism is also one of the challenges for parents of children with autism.

### **B. Support needed by parents of children with autism when dealing with meltdown situations**

In general, the issue of meltdown in autism is still new, hence data or information specifically focused on meltdown issues is still very limited. Therefore, previous studies that specified meltdowns and the topic regarding support that has been received by parents dealing with children with autism, especially during meltdowns is still below the mark. However, many articles reveal the support parents need in raising children with autism. General support received by parents of children with autism is also referred to as support needed when dealing with a meltdown situation.

National Autistic Society (2022) stated that some of the general supports given to the parents of children with autism in the United Kingdom are; sharing with friends or closest friends, getting advice from other parents of children with autism who are more experienced, listening to the sharing of parents who have experience handling meltdown among children with autism, as well as self-absorbed knowledge through media or websites, such as books and blogs. In Malaysia, NASOM provides a Facebook page as a platform for parents of children with autism to find more information about autism, for asking questions, etc.

Previous studies have shown that a meltdown is different from a tantrum. There are stages in meltdowns and tantrums, and both have almost the same triggers. Stimulation that triggers meltdown can be positive, but it can cause a negative response in children with autism. This negative response becomes a challenge for parents because it can cause injury and danger to the child. In short, previous studies also have shown the challenges faced by parents of children with autism in general as parents raising children with autism, and challenges specifically when a meltdown situation occurs. Understanding the causes of meltdown situations will significantly help parents deal with this situation better, be well prepared, and be more effective.

### Research Methodology

A qualitative approach was used to understand the meltdown situation and how it challenges children with autism in general, but mainly to understand how these challenges become challenges to their parents when a meltdown happens. The same approach was also used to explore the support needed by parents to deal with meltdowns better. The qualitative approach research design is a flexible research method that uses various research techniques. Therefore, the qualitative approach with the interview as a method has been used in the implementation of this study.

### Participants

This study was conducted in Malaysia. All parents who participated in this study reside either in Peninsular Malaysia or Sabah, Malaysia. Location was not limited to one specific area because the parents who agreed to participate in this study, stayed in different places. All participants have one thing in common: experience in raising, caring for, and dealing with meltdown situations. Malaysia was in the recovery phase from the Covid-19 pandemic (post-pandemic) when this study was conducted. Hence, the chances of meeting participants were few. Interviews were done alternatively using technology through voice messages and text messaging using Whatsapp or Zoom application with parents.

Five mothers and one father (husband of participant 1) agreed to be interviewed for this study. Identity and participants' real names were kept confidential and put as samples for this study. Participants were selected based on several considerations or criteria; a parent or parents must be parents of children with autism between 3-9 years old. This study does not involve parents of adult individuals with autism since its focuses on the meltdown situation of children with autism. Table 1 shows the profile of the participants in this study.

Table 1

#### *Participations' Profile*

Participants (P)	Age of Child (With autism only)	Sex
P1 (Annie & Sun)	5	Boy
P2 (Rosie)	9	Girl
P3 (Rose)	8	Boy
P4 (Hana)	3	Boy
P5 (Doyie)	6	Boy

Source: Research Data

## Data Collection Method

### *Interview Method*

The interview was the primary method to conduct this study to collect research data. An interview is a straightforward method done in person by the researcher and participant by giving questions to the participants. Discussions in conversations between the researcher and participants are relevant in this study because, through this conversation procedure, the researcher will obtain significant and relevant information directly from participants. Data obtained from the interview was then transcribed to writing for analysis, documentation, and final report. The open-ended question was used during the interview, as suggested by Creswell (2012), to enable participants to voice out and share their answers honestly and confidently. The advantage of the interview method also allows the researcher to ask more specific questions. Therefore, this method was chosen as a prime method for data collection for this study.

Interviews with participants were conducted one to one to ensure their comfort. This is intended to enable the researcher to provide a comfortable atmosphere during the interview, ideal for the parents of children with autism to share their experiences comfortably and confidentially. With the rapidly advanced technology nowadays, coupled with the pandemic problem since the beginning of 2020, face-to-face interviews are no longer limited; virtual interviews are now possible using applications such as ZOOM, Google Meet, video calls, Telegram, and Whatsapp. Due to time constraints, researchers used the application Whatsapp either through a video call or an audio recording of a message from 4 of the participants. All participants were granted permission to record the conversation. The researcher also determines the time for the interview, whether virtual or this face-to-face, to ensure that the use of time for the interview is not disrupting the daily activities and routines of all participants, primarily mothers.

The interview time was set between 60 to 90 minutes for the researcher and participants. It took 2 to 3 days for participants who are quite busy due to work time constraints to reply via text or audio messages. Because of that, participants took several days to respond to the interview questions through audio message recording. However, the interview technique was conducted in a relaxed atmosphere and according to the flexibility and free time of the participants. The researcher also recorded the conversation through conversational voice messages made through the Whatsapp application.

### **Parents' General Knowledge of Meltdown in Autism**

Based on the interviews, parents have shown an excellent understanding of meltdowns in autism and can share its causes in detail. When asked about the causes of meltdown, some of the common reasons experienced and shared by parents is when their child (with autism) is not receiving something they want, changes in routines, daily activity that seems to be hard for them, or is not likable to them, and a situation where parents do not understand what they want or asked for, for the children with autism who has a speech delay. One of the mothers stated that other than routine changes, some daily activities that are assumed to be difficult for the children or they do not like will randomly cause a meltdown. For example, bathing time, eating time, and playing time, if not around their mood, can randomly cause a meltdown.

*"My son does not like bathing time, playing outside, and even eating time sometimes can cause him to meltdown for a short time because he does not like this..." - P5, Doyie.*



Mild meltdown like this usually lasts for a while but will happen often. The situation is controllable and is not extreme. Table 2 summarizes the causes of meltdown according to participants in this study.

Table 2

*Summary of the Causes of Meltdown*

P	Nicknames	Age of Child (with autism)	Sex (of the child) M=Male F=Female	Causes of Meltdown				
				Unfulfilled wants	Absence of either dad/mom	Changes in routines  (B) Obsession with something: route/toys	Disliked daily activities	Difficulty in expressing (speech delay)
1	Annie & Sun	5	M	/	/	/		
2	Rosie	9	F	/				/
3	Rose	8	M	/				/
4	Hana	3	M	/				/
5	Doyie	6	M	/			/	

Source: Participants

Based on Table 3 above, all participants stated that one of the causes of a meltdown for their child with autism is when their wants are not fulfilled. Annie and Sun noted that when their son was about 2-3 years old, the absence of either father or mother would also cause their son to meltdown. Annie and Sun also shared that apart from changes in routines, their son also used to have an obsession with a route that the family used to go to a park. Annie and Sun will bring their son to the park every once a week and usually will use the same route where this route will pass McDonald's on their way home.

Once, Sun took a different route back home and did not pass by McDonald's, their son started to tantrum in the car and eventually meltdown. This happened because their son, who was familiar with the original route, recognized that he did not see the McDonald's, hence his meltdown. In addition to that, whenever they come back from the park, they will always buy ice cream and porridge at McDonald's. Their son has been expecting this every time they return from the park, which is why if the father uses another route, he will meltdown.

*"Our son has set it that every time we come back from the park, we will always go to Big M just to buy ice cream or porridge for him, or sometimes will just stay there for a while before we go home; this will make him happy." P1, Annie and Sun*

They also added that to make their son happy, they would pass by McDonald's. At times, they will just stop by McDonald's without buying anything just to "fulfill" their son's routines. If

they took a different route, Annie and Sun will tell and explain to their son in advance to avoid a meltdown. That time, they decide their son had an obsession with McDonald's.

Upon realizing their son's obsession, Annie and Sun felt worried. However, they tried to see this positively. The Australian Parenting (2022) stated that it is something familiar for children with autism to have an obsession with something that can consist of a daily routine, a favorite games, television shows, favorite glasses, favorite clothes, favorite shoes, arrangement of gadgets or toys, favorite seat, etc. Although it is hard to explain the causes (causes are different for each child with autism) of this obsession itself, The Australian Parenting (2022) stated that there is a positive view on this obsession. An obsession can be related to something they are interested in. For children with autism with fewer or limited play skills, these interests or obsessions can be something they can be good at. For example, a child who loves trains tends to develop an interest in cars or transportation and can master that topic. Obsessions and routines also help some children with autism manage or deal with their stress and anxiety (The Australian Parenting, 2022). When they feel depressed because they don't understand what is happening around them, obsessions and routines will help them control their emotions in their environment (The Australian Parenting, 2022).

P2, P3, and P4 stated that their child with autism will meltdown due to their child's inability to express what they want and when parents cannot understand their wants. This is related to speech delay. Language is a significant foundation skill that should be developed in every child from an early age as it not only contributes significantly to their early development in their social interactions but also plays a vital role in ensuring success in their academic learning from an early age (Chow et al., 2022). Children who experience speech delay tend to feel less confident in their social relationships; therefore, it is essential to identify if the child has a speech delay from an early age, not only among children with autism but also among typical children (Chow et al., 2022).

Speech delay is often related to aggressive behavior, generally among all children (Chow et al., 2022). This is more obvious among children with autism. Participants also shared some aggressive behavior that often occurs during meltdowns, such as screaming, longer crying and loud, biting the wrist, and hitting or bumping their body or head on the wall or floor. This is why children with autism with speech delay tend to melt down because they struggle to express their wants or needs verbally. This will be more serious when the parents cannot understand what their children are trying to say. That is why children suspected of having speech delay are encouraged to go for speech therapy. Four out of 5 participants stated that they had sent their child to speech therapy before MCO. However, only two continued after MCO was lifted because of financial matters.

One of the participants stated that her child tends to meltdown if her child has to do chores or daily activities he dislikes. P5, Doyie also said that her son will meltdown when it's bath time and eating time. Her child has always been familiar with the exact timing for bath time, eating time, and the usual seating. Therefore, he can predict the timing of the subsequent activities. Hence, her child will start to tantrum and eventually meltdown when the timing does not go the way he expects it to be and when it is time to bathe and eat.

*"He hates taking a bath the most, and he looks forward to going outside the most. On his way, he wants everything to happen quickly. He wants the food to be ready when he sits down to eat and to cool off more quickly." -Doyie, P5.*

In another sense, this enables P5, Doyie, to forecast her son's outbursts. This enables her to anticipate meltdowns and be ready to handle them. She regularly hugs her son to calm him down when he has a meltdown. She will give her son detailed explanations, train him to wait

patiently, and teach him patience. Although teaching a child with autism to stay is difficult, she claimed that her child has begun to learn and become accustomed to waiting, eating, and taking a bath.

In conclusion, all participants had a good understanding of the meltdown scenario and could describe a few triggers and how their autistic child might meltdown. According to all of the interviews, the five most frequent reasons why autistic children have meltdowns are when their wants are not fulfilled, when one or both of their parents is not present, when routines and obsessions with particular things change, when the child dislikes their daily activities, and when the child struggles to express their wants (speech delay).

### **Actions taken by parents when their child with autism meltdown**

Despite being predictable, meltdowns can occasionally be challenging to manage. Participants discussed the actions they have taken or plan to take to soothe their kids when they experience meltdowns. Based on the causes of the meltdowns, actions are taken.

P1 Sun and Annie said they would prepare their child in advance if routine changes caused meltdowns, such as altering the route from home to the park or returning from the park. On some days, they will also explain to their child why they are going out, where they are going, and what they will do there. For instance, they might tell their son that they are going to buy vegetables instead of toys so that he won't beg for toys while they are in the store.

*"We would explain to him that when we go to the supermarket or mall for groceries, we will explain to him that we will just be going to buy vegetables, not buy toys; this will make him aware of our reason for going to the mall, for example. So when we are there, he will not ask for toys."* P1, Annie.

She added, *"...if a meltdown happens at home or in public, I will hug him; I will persuade him by giving him food. It does not always work, but he loves food so that it will shorten the meltdown period."*

When asked if they will buy any toys asked by their son, which causes their son to ask or beg to cry, Sun added, *"...it depends; if it is not so expensive, I will buy. Like, if it is just about 40 ringgit, I will buy it, but for his mother, that is expensive."*

Sun also added that sometimes their son would cool off by himself but would monitor his situation and the environment to ensure safety. *"Sometimes, I will just let him finish the meltdown. I will just let him flow it out from inside. After I see that he is ready to receive words or is calm and able to listen, then only I will talk to him and persuade him."*- P1, Sun.

P2, Rosie also shares quite the same action taken by P1, Annie, and Sun, when her daughter meltdown. Her daughter tends to hurt herself when she meltdown, so she will usually give time for her daughter to let it out from the inside.

*"My daughter tends to hurt herself during a meltdown, so the best thing I can do when it happens is to give her time to calm down on her own. Sometimes, she wants to be on her own when it happens, and she can be calmer in a quiet, empty room. We will let her stay independently in the open space or room but will still observe her from outside or from afar. I would go inside if she started to hurt herself. But now, she is calmer by herself most of the time. We provided her with a favorite pillow and made sure the space was cozy and free of furniture so she couldn't damage herself there. My spouse or I will hug her when she is calmer so that she will feel more taken care of and cherished. She will become more tranquil as a result of this. When children have meltdowns, parents should remain composed, upbeat, and emotionally neutral. While it's challenging, we parents must maintain our composure to prevent feeling pressurised at the same time."*

P1 Annie, P4 Hana, and P5 Doyie all agree that giving their kids hugs can help them calm down when they are having a meltdown.

*"I will wait for him to calm down and then persuade and hug him."* - P4 Hana.

*"When he meltdown, he will cry, angry, and is emotionally unstable. So other than waiting for him to calm down, I will hug him to help him stop crying and be calm. He also loves to be hugged."* -P5 Doyie.

Because some autistic children dislike physical interactions, such as hugs or touch, during the tantrum, P3 Rose did not suggest she would hug his son. As a result, P3 Rose will only convince her son by taking him for a stroll or taking him outside for some fresh air while he is distracted by his favorite food or toys. Table 3 shows the frequency of meltdowns in children with autism by days or minutes, taking the children of all participants as samples.

Table 3

*The frequency of meltdowns by days and minutes*

P	Age of the Child	Sex	Meltdown Frequency					
			A day	A week	A month	Mins	Remark	Frequency
1	5	M	Once	1-2 times	<10 times	20-40	On-off crying & someday, it will go the whole day on-off	Rarely
2	9	F	-Now, very seldom  (Every day at the age of 2-5 years old)	<2 times	<5 times	10-30	Now at the age of 9, she seldom meltdown	Rarely
3	8	M	3-4 times	>5 times	>10 times	5-10	It usually happens in the morning when he asks for a smartphone.	Frequent
4	3	M	3 times	>5 times	>10 times	5-10	Depending on the situation, if he's not given something he asks for, the meltdown can continue from morning to evening (on-off crying)	Frequent

5	6	M	1-2 times	>5 times	>10 times	30-60	On-off meltdown. -When he remembers what made him sad or angry, he will resume crying angrily and meltdown if not handled.	Frequent
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Source: Participants

As shared by P2 Rosie, meltdown frequency differs among children with autism.

### Challenges Encountered by Parents When Facing Children's Meltdown

It is very different from raising a typical child to raising a child with autism. Parents of children with autism face different challenges and demands than parents of children who are typically developing. When a child with autism has meltdowns, parents confront some difficulties that are particularly different. According to Mazefsky (2009), meltdowns can occur at any time and are often unanticipated, which worries and frustrates parents. Children with autism face difficulties that subsequently affect their parents. Physical, emotional, and mental difficulties are common among parents. The issues that were shared by all participants are summarised in Table 4. Emotional challenges appear to be the most challenging.

Table 4

*Summary of Challenges faced by parents when a child meltdowns*

P	Challenges		
	Physical	Mental	Emotional
1		/	/
2	/	/	/
3		/	/
4	/	/	/
5	/		/

Source: Participants

### Physical Challenge

Challenge when the child with autism tends to hurt themselves when meltdown. P3, Rose stated that physical challenges were not so obvious when her son was younger compared to now. Now sometimes her physical body becomes more tired, especially when she needs to hold or lift her son occasionally when he meltdown because when he does, he will find any sharp things around him to hurt himself. P2, Rosie also shares the same physical challenge with P3.

*"Physically, children develop stronger and more active as they get older. Therefore, it takes more energy to settle her down and to carry my 20-kg, 9-year-old daughter." P2, Rosie.*

She continued by saying that having a breakdown in front of others is difficult for her and her husband, but she also needed to be emotionally composed and psychologically strong.

**Communication difficulty.** P1 Sun stated that communication is also one of the significant challenges where he could not understand what his son tries to communicate to him. This made him unsatisfied with himself, and he felt terrible for his son for not understanding his words or being late in helping him. His son's communication however had improved since they sent him for speech therapy at University Malaya Medical Centre (PPUM) when he was three.

P2 Rosie also stated that she would feel bad for her daughter when she cannot understand what she is trying to say during the meltdown.

*"I feel so depressed mentally and emotionally since I was unable to understand my daughter. I also find it saddening to watch her when she is under pressure and threatens to harm herself during a meltdown."* - P2 Rosie.

P3, Rose also shared that communicating with his son during a meltdown is the hardest because of his speech delay. It is mentally and emotionally challenging to communicate with his son when he cannot say his wants or if she is not able to understand her son. In addition to that, she also finds it hard to bring her son out due to this exact reason to avoid sudden extreme meltdowns outside.

*"It is hard to bring him outside, in public, because he can be active and hardly listen, so we need to be firm and ensure he is under control. To do this, however, is a great emotional and mental struggle, especially to communicate with him in a way he would understand when a meltdown happens."* P3 Rose.

**Challenge when a child with autism acts aggressively during the meltdown.** P4 Hana shared that sometimes, her son tends to act aggressively during meltdowns, especially when the meltdown happens for a longer time. She also stated that when an on-off meltdown happens, aggressive behavior tends to repeat when her son remembers an event or what causes him to be upset, angry, dissatisfied, or stressed.

*"Mother is mentally tired of dealing with tantrums and then moving on to meltdowns, and then if he acts aggressively such as shouting, throwing things, crying continuously, hitting head..."* P4, Hana.

This is one thing unpredictable when a meltdown happens in public. Even when parents have made preparations for the worst, it is still impossible to know how severe a meltdown might be. Therefore, a physical challenge is one of the most difficult things for parents of children with autism, particularly when their child meltdown.

### **Mental and Emotional Challenges**

**Perceptions** of people in the surrounding, especially when a child with autism meltdown, is a challenge that often happens to parents of children with autism. Perceptions are uncontrollable, undetermined, and difficult to be explained. Sometimes, some people tend to show negative perceptions toward parents of children with autism and the children themselves. P4 Hana said that even though she is always ready for any possibility of her child to meltdown, especially in public, as well as trying to avoid situations that could lead to meltdowns, she cannot hide the facts that there could be negative perceptions from this local community, not only when the meltdown happens but as simple as when the child started to tantrum.

*"It is most challenging if my child throws a tantrum in a public place because I may appear fierce or some people may think I was too fierce or too strict towards my child...especially when my son meltdown in public"* P4 Hana.



P4, Hana also stated that mental and emotional challenges are the most challenging for her. She added how thinking about an individual, other people, or local communities, especially those who do not know or do not understand the situation of a child with autism, tend to make her overthink. Hence, she added that all mothers must be physically, mentally, and emotionally intense for their children.

**Challenge to remain patient.** Parents of children on the spectrum of autism needs need to be more loving and more patient. Patience is one of the values one needs to have as a parent and it needs time to learn, expand, and grow, and is a process all parents shall go through in parenting. Being patient is a process that can be exhausting and draining emotionally, mentally, and physically. This is very real for all parents, including parents of typical children. All participants stated that patience is challenging when their child meltdown. P4 Hana noted that it is one of the challenging times for her to be patient and remain calm when her child is undergoing a meltdown. Sometimes she will do nothing but wait for her son to calm himself from the meltdown.

*"I will wait until he calms down, and at the same time, I will calm myself before slowly distracting him from the cause of the meltdown to things he likes to help him move on from the cause of his meltdown..." P4 Hana.*

When a child with autism exhibits aggressive behavior and attempts to harm themselves, things become more complicated. P5 Doyie admitted that she occasionally finds it difficult to maintain her composure while her child is having a meltdown. She finds it difficult to control her emotions while her child is having a meltdown. When she tries to calm her son down, she will feel guilty and blame herself, but it will be difficult for her to keep her emotions in check in front of her tantrum-throwing son, who will then have a meltdown. As a result, even though it's challenging most of the time, she must exercise patience while also maintaining composure when dealing with her son's tantrums.

*"My issue as a mother is what to do to regulate my emotions instead of becoming furious with my child when they're having a meltdown...when my child is having a meltdown, I need to be more and more tolerant. To prevent losing my temper with my son, I will take some time to cool down. I usually will take a deep breath and drink some cool water to help me relax. - Doyie, P5.*

When asked which challenge is the most challenging, P5 Doyie answered that challenges involving emotions and the mind are the most difficult.

*"Mental and emotional challenges are the hardest. It is tough for us, mom or dad, to control our emotions from not wanting to be angry with our son when he has a meltdown. Hence, there is no use of being strong physically if we are mentally and emotionally unstable."- P5 Doyie.*

P5 Doyie also shared how she always makes sure she is patient and healthy from a physical point of view by regularly exercising to maintain and make sure her physical body is always strong enough to hold or confront her son when he has a meltdown. *"Physical health is very influential to the emotional and mental stability of a mother,"* she added, who is also a fan of aerobics and Zumba exercise at home, which she often does with her son at home.

Other than that, P2 Rosie added that support from a spouse is essential to help mothers to remain patient and calm during the meltdown of their child. Additional support from family members and friends is also equally important in this matter.

*"The most important thing for parents is moral support. Support from spouse and family is critical. Apart from that, parents should make every effort to understand children's emotions. Suppose we know something that can trigger a meltdown in a child, try to avoid that. For*

*example, avoid being in crowded and noisy places if the child has acute senses that can disturb his emotional stability. Understanding children is significant, so it is easy to anticipate things that can trigger a meltdown." P2 Rosie.*

P3 Rosie added that from all three aspects, physical, mental and emotional are equally challenging during her daughter's meltdown.

**Challenge to reverse or manipulate the child's (with autism) obsession.** This is related to the situation shared by P1, Annie, and Sun, where, if they go to the park, they always visit McDonald's because their son predicts his parents will take him there to buy ice cream or stop for a while. If this is not met, their son starts tantrums and meltdowns in the car. On a particular when either mother or father has planned and promised to play in the swimming pool garden at their residence, canceling at the last minute, which means not filled, will cause their son to have a meltdown. Annie and Sun found that their child will tend to be obsessed with places, routes, and games if that catches his eye.

Their son also seems to think that what he wants will be fulfilled or should be fulfilled. These needs can still be met when their son is 2-3. However, they find it difficult and time-consuming to change routines and reduce their child's obsessions when their son is four years old and has already started attending school. Sun and Annie are attempting to lessen their child's obsession or fixation with things like parks, walking paths to parks, and toys like dinosaurs, cars, and other things rather than trying to modify their child's interests. He is no longer interested in things that could cause a breakdown now that he is five years old. A meltdown is therefore unlikely to occur. He has, however, shifted to other hobbies, which, occasionally, if not satisfied, may result in a meltdown. As a result, an obsession in an autistic child might result in a meltdown and is difficult to reverse or influence. Obsessions may still be diminished or altered, but doing so will likely take time. It is when parents have to alter or try to manipulate the child's obsessions that challenge them emotionally because doing so will take time, will trigger great tantrums, will put the child in great distress, and possibly lead to an extreme meltdown. Hence, it is one of the emotionally challenging.

However, parents can use this obsession to distract their children during the meltdown. If parents can use preoccupation to divert their autistic children during meltdowns, it can be a strategy to lessen meltdowns even though it is one of the challenges. Table 5 outlines the specific challenges parents encounter when their children have meltdowns.

Table 5

*Physical, Mental, and Emotional Challenges*

Physical Challenge	Mental and Emotional Challenges
<ul style="list-style-type: none"> <li>• Communication difficulty</li> <li>• Aggressive behavior</li> </ul>	<ul style="list-style-type: none"> <li>• Perceptions</li> <li>• Challenge to remain patient and calm</li> <li>• Challenge to manipulate the child's obsessions</li> </ul>

### **Support Needed by Parents in Facing the Situation of a Child with Autism During A Meltdown**

#### **Supports Received**

The researcher enquired as to whether the parents had ever received assistance from the government or an NGO in addition to moral support from family members. P2, Rosie claimed

that she never got particular support or assistance from the government or NGOs for handling the meltdown. She however has a Whatsapp Group Chat with parents of children with autism. *"There is no specific support, but we do have a special WhatsApp group for parents as a platform to exchange opinions and encourage each other. Apart from that, spirituality/religion is also important as our basis of strength & patience."* -P2 Rosie.

She also added sharing advice and spiritual encouragement from family members and close friends encouraged her to be patient as a mother when dealing with the various behavior and challenges of a child with autism, including when her child meltdown.

P1, Annie and Sun stated that in addition to moral support from one another, they also get help and guidance from therapists and their son's doctor, who have become a close friend of their family. Sun added that in addition to this moral support, they also equipped themselves by searching for knowledge and information related to autism through suitable reading materials from local and Western countries through social media and websites. He added that he had joined the Malaysian Autism Parents Group on **Facebook**, where he and his wife can read articles, get information, exchange opinions, and share tips with other parents of children with autism in Malaysia.

P3 Rose, on the other hand, states that besides the support from family, she also receives support from the school and her son's teacher, who shared knowledge and tips on how to handle the emotion of her son during the meltdown.

*"The support we received was from the family, who helped me coax our son during a meltdown. Other support, from school teachers, because they are special education teachers and have experience, they share and guide me on how to deal with a meltdown..."* P3 Rose.

Meanwhile, P4, Hana, and P5, Doyie each added that the place where they used to send their child for therapy also provided guidance, especially on how to deal with meltdowns. P5 Doyie stated that his son is currently receiving treatment at Bukit Padang Hospital, Department of CIEC, and Speech Therapy at Queen Elizabeth I Hospital, Kota Kinabalu.

### **The support parents need in coping with a child with autism during a meltdown.**

In general, raising a child with autism presents several difficult situations for parents. There's no denying that since 2016, the proportion of kids with autism diagnoses has increased (Fatin Sophia, 2020). In the upcoming year, it is likewise anticipated that this would rise. According to CodeBlue (2022), 589 children under the age of 18 were found to have ASD (autism spectrum disorder) in 2021, up from just 99 in 2010.

According to data from 2021, there were 5% more children with ASD diagnoses than there were in 2020 (CodeBlue, 2022). This suggests that there are also more parents of autistic children today. As a result, this group of parents requires assistance in coping with the difficulties of raising autistic children, particularly when their kids are having meltdowns. This is because the assistance and services parents of autistic children require are frequently deemed essential but frequently fall short of meeting those needs.

P3 Rose, P4 Hana, and P5 Doyie mention the necessity for skills linked to meltdown avoidance or handling as well as parents being exposed to the knowledge about the meltdown when asked what kind of support parents need while dealing with their autistic children who are having one. This kind of help refers to assistance in the form of abilities and services.

*"Besides needing mental support, I hope to add more knowledge about more effective ways to deal with meltdowns..."* P3 Rose.

*"...more organizations will **provide talks or knowledge as well as training** on how to handle meltdown among children with autism, other than being patient..."* - P4 Hana.

*"Parents need to get support from organizations involved or work with organizations related to children with autism or community-related to autism so that parents can learn other skills when dealing with their child's meltdown. Person in charge of the **right procedure for, delicate procedure with strong privacy and confidentiality**, such as in or through a media application such as WhatsApp to make it easier for parents with autistic children in general."* - P5 Doyie.

In addition, P2 Rosie also added on the support parents need from moral support from society.

*"Parents also need 'understanding' from outside. Apart from that, knowledge about Autism is essential to parents because that it is one of the basis of all conclusions about special children. Send the child to a therapy center if the parents can afford it because this is also helping support overcome a meltdown. However, if the parents are not able, knowledge can be sought. Everything comes from the parents themselves to want to dig for knowledge which can be gained through reading, learn from other parents' experiences and on the internet."* – P2 Rosie.

In this regard, the government should take an active role, particularly through departments like the Ministry of Health (MOH), the Social Welfare Department (JKM), and the Ministry of Women's Development. Additionally, the community should work together with organizations like Autism Malaysia, media outlets like Berita Harian, advertising firms, and other groups to raise local awareness of autism, autism meltdowns, and other crucial issues related to autism.

It will be illuminating for society to learn more about autism and to become more conscious of oneself. If autism is more well-known and understood, more people will be able to learn about it. With it, we can lessen the unfavorable opinions of parents of children with autism. For parents of children with autism, this kind of support is essential.

P1, Annie, and Sun also agreed that there is a need for comprehensive awareness among people about the issue of autism in general and the meltdown issue in autism.

*"I think one thing the government can help us, parents of children with autism, is to display awareness about autism as a whole and specify in meltdown. Our people need to know about this; they need to be educated about autism. If this can be done, this will help to prevent negative perspectives towards parents of children with autism, as well as the child itself."*- P1 Annie and Sun.

He believes that it is not only the parents of children with autism who need awareness of the importance of knowledge of autism, but it is also crucial for the public to know and understand autism.

He added, *"...when our people are aware of this (autism), and when meltdown involving autism child happens in public, they will be able to help or at least understand what is happening."*-P1 Sun.

The researcher concurs with this suggestion because it is undeniable that not only should the general public be aware of more about autism, but there may also be young parents out there who may have children with autism but aren't aware of it due to a lack of information and awareness from the government in particular. As a result, the child and their parents may miss out on services they should have received at a young age, receive them much later, or not at all. This is why there is a significant need for an increased public understanding of autism.

Table 6

*Summary of the Supports needed by Parents when facing their child with autism meltdown*

Support Needed by Parents
<ol style="list-style-type: none"> <li>1. Support in terms of services and skills</li> <li>2. Easy procedure to contact the organization that provides help or training</li> <li>3. Moral Support</li> <li>4. Preparation of awareness or comprehensive awareness of autism among the locals</li> </ol>

### **Sharing for parents of children with autism when dealing with meltdowns and as parents of children with autism in general**

P1, Annie, and Sun reported that their son benefited from early counseling. When this couple learned that their child had autism, they at first experienced anxiety, fear, and worry. They accepted it and made an effort to learn as much as they could about autism. Finally, they decided to send their child to some therapy. They ultimately chose to send their child to treatment. A speech therapist was chosen to treat their son. Their son's speech therapy has been beneficial. As a result, they advise parents of autistic children to seek treatment for their child if they can afford it. But if they can't, they should try to learn as much as they can to support their autistic child. Spend time with the child outside and expose them to the environment more because this fosters the growth of their inquisitiveness and interest.

*"...if you can afford, go for therapy, but if you can't afford, find knowledge. Reach out for help, and expose your kid to nature as much as you can, spend time with them..."*. P1 Annie & Sun.

Annie and Sun also emphasize the importance of spiritual aspects to encourage each other.

*"...spiritual foundation is fundamental to remain stronger, and as parents, it is warm to share with church members about our struggles and pray for one another, it strengthens us both..."*.

*-P1 Annie & Sun.*

One of the most important components of parenting and the institution of the family is the spiritual component. Every person should have a good community and healthy environment to share, encourage, and provide moral support to one another, regardless of religion or creed. All of the participants emphasized the value of spiritual elements in empowering their children.

*"To all parents of children with autism, do not keep it all to yourself, especially moms; find a friend and community to share and encourage one another, and take turns to take care of the child with your partner. It is okay if our child is a little bit different from our typical child, be honest, do not hide the fact that your child has autism, and explain in advance if needed. Because not all people are ignorant if they know the facts..."* - PK 1 Annie and Sun.

For their entire families to comprehend the minor differences that will be visible in their children when they gather at kampong, Annie and Sun recounted their experience in discussing their son's situation—who has been diagnosed with autism—to their relatives before they returned home. They were appreciative that their family accepted their child for who they are and did not take criticism from inside their own family.

Therefore, if a meltdown occurs while they are in the village, at least members of their families understand their child's condition. PK 2, Rosie stated that even though it was not easy to raise her daughter who has autism and another daughter who has a speech delay (but not autism), he sees this as an opportunity to love both of her daughters equally. She learned to



see this from a positive perspective. She also learns to be more patient, especially when her child has tantrums and meltdowns.

*"If a child has a meltdown, the first thing we need to have is patience and calmness. If these two things are not present, we as parents can be stressed and tired. We shall keep in mind that when a child is going through an autism meltdown, it is our opportunity to help our child because this is when they need us emotionally, hence we shall be more understanding and pay attention to their needs."* - P2 Rosie.

PK3, Rose described how she always takes her sons on walks and nature outings in the village's hills, including her son who has autism. Some parents do not want their autistic child to leave the house because they will probably do things that 'trouble' others, but to her, making her son stays at home all day is a struggle. Her son must experience nature because it is what will benefit him the most.

*"...don't set aside or keep autistic children from other people. They may have difficulty getting used to being in a crowd, but parents can slowly bring them together with others to get them used to getting along and can slowly develop their social development. Encourage them to explore, get them used to socializing or making friends, and help them in their social development, even though it will take a long time..."* P3, Rose.

They must be taken outside with parental supervision. While each autistic child's circumstances and environment will be different, exposing them to nature and giving them positive outdoor experiences will certainly have a positive effect on them. This will also help them develop their social skills. As a result, P3 Rose, highly recommends taking a child with autism outside to experience nature.

Coming back to the perspective of a society that individuals cannot control, it is a fact that there is always a possibility of negative perception from people when they see a meltdown situation, especially during an extreme meltdown. Hence, P3 Rose added, *"...our heart and mind as a mom must be strong to face the child's behavior during a meltdown. The same goes while expecting people's views. Not all will be positive. But, calm down, don't be quick to anger, and if possible, avoid raising your voice when communicating with your child with autism. Try to understand all the attitudes and behaviors of our children, their hearts and their feelings, because when we understand our child, it will be easier to face a meltdown situation."* - P3, Rose.

P3 Rose then added that reading a lot is one way for her to gain information related to autism and meltdowns. *"As parent, mental & physical preparation is essential if a child has a meltdown. Learn not to care what others may say about us because not everyone will understand what we are going through. Look for support from a close **community** that is especially a community that understands autism well or from a group of parents who has experience raising special children. Find a positive & understanding environment or friends. Above all, never forget God, because no matter how deep the difficulties we face, true strength can only be found in God. Parents, **read** more, be more resourceful, and be patient all the time..."* -P3, Rose.

P5 Doyle also agrees that self-learning and self-equipped understanding and knowledge of autism are important for parents, which helps her enhance her parenting experience and skills.

*"Do not hesitate to ask for help from parents with more experience raising children with autism. Grab every opportunity to ask questions from a nurse or doctor who is giving therapy to children with autism..."* P5.



She added that apart from moral support from her family and people around, as a mother of a child with autism, she is also ready to give support to other parents of children with autism. The research data explained was obtained from the interviews with all participants.

### Findings and Discussion

This research aims to explore the challenges faced by parents of children with autism when their child (autism) is experiencing meltdowns, including physical, emotional, and mental challenges. In addition, this research also aims to explore the support needed by parents of children with autism when encountering meltdowns. Based on the obtained research data through interviews, one of the most common challenges stated by all participants is an emotional challenge. Emotional challenges could lead to significant stress, distress, and worst, depression. Previous research found that mothers of a child or teens with autism are expected to face a greater tendency to face stress, anxiety, and depression compared to mothers of typical children or none - ASD spectrum (Nicholas et al., 2015).

Findings showed that all participants, five mothers and one father (spouse of P1), stated that facing their child during a meltdown challenges their emotions. However, their feelings are still under control and stable. Nicholas et al (2015) said that in line with a mother of a child with autism tends to have depression and extreme anxiety more than compared to fathers, mothers also tend to face deterioration of self-skills and self-efficacy. This, however, was not mentioned by any of the participants. Hence, this shows their strength as they go through all the challenges mentioned. It could have been complicated had they not had a right and strong community as a support system to share and lean on. Therefore, support from spouses other than close friends and the community plays a vital role in ensuring the emotional stability of either mother or father. This is also supported by spiritual support from friends, their own family, and the religious community.

The physical challenge follows the second challenge. Physical challenges include when the child with autism tends to hurt themselves during the meltdown when the child struggles to communicate when the child behaves aggressively during a meltdown, challenges to communicating are related to speech delay. All participants stated that their children with autism experienced speech delay, making it difficult for them to express their desires verbally. Children with speech delay could use a word or a particular phrase to express their ideas but are challenging to understand (Harnett, 2022). P3, P4, and P5 mentioned this. When autistic children want to ask their mothers for something, they will act because they can't speak correctly yet or will hold their mother's hand and lead them to where they want to go. Some children with autism may also express what they wish to do aggressively during meltdowns because it is hard for them to communicate verbally. Gorlin (2018) revealed that; *"They will not understand signals, cues, or body language during the meltdown. With these challenges during meltdowns, it will be verbally difficult for them to ask for bits of help. Since it is difficult for them to communicate for help during meltdowns, this will confuse parents or adults who want to help. Difficulty to communicate will then lead to unpredictable behaviors..."*.

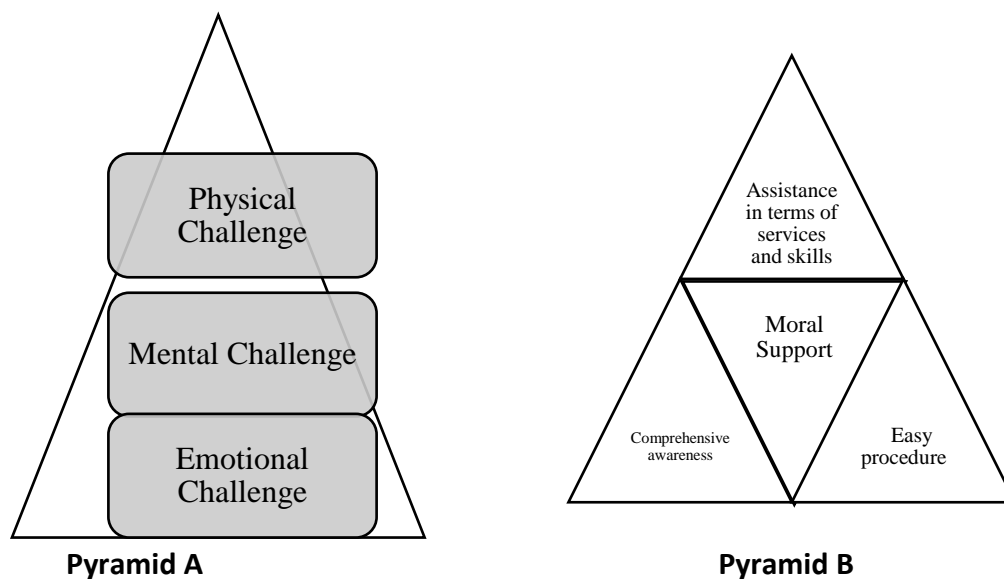
This is also mentioned by P1, Sun, who feels terrible for his son when he cannot understand and is confused with what his son is trying to say, especially during the meltdown. This is why communication is one of the challenges during the meltdown. Sometimes, this also leads to a child with autism behaving aggressively when meltdowns. Aggressive behavior also tends to repeat. This aggressive behavior becomes parents' worry since it tends to lead the child to hurt themselves. Patnam (2017) stated that children with autism tend to self-harm physically during a meltdown, and Bernard (2015) also noted that these aggressive actions are

repetitive. *“Common behaviors during meltdown such as rocking, wrist biting, self-scratching, kicking, banging their heads, or even lashing out violently have been identified as a self-harm to most children with autism show during meltdown”* (Patnam, 2017). However, Bernard (2015) added *the association between self-injurious behavior and the severity of autism, where meltdowns tend to happen frequently in a child with severe autism*. In light of this, the aforementioned behavior will not frequently occur if the child's autism is not severe.

Therefore, even while some participants claim that their children tend to hurt themselves occasionally, it may be claimed that the likelihood that their child has a moderate form of autism. The relationship between the severity of the meltdown and the autistic child's impact should be understood by parents and educators, thus they must take this information seriously.

Mental challenges consist of perception challenges, challenges to remain patient, and control emotions toward the child during meltdowns. Therefore, support needed by parents in dealing with an autistic child whom meltdown is supported in terms of services and skills, more talks or workshops from NGOs, especially on the spread of knowledge and training, moral support from various parties, and the need for NGOs, government or specific organizations in providing awareness to the community local related to the topic of autism and meltdown specifically. Awareness of autism and meltdown in autism is vital because many parents may not realize that their child could be within the spectrum of autism. Schelly et al. (2019), in their article *Barriers to an Information Effect on Diagnostic Disparities of Autism Spectrum Disorder in Young Children*, found that there are families in the minority within the low socioeconomic circle in Costa Rica who have less access to awareness of autism. The researcher believes that Malaysia may see a similar situation, where some families may have a child or children with autism but have not received a diagnosis since there has been little government or nongovernmental organization (NGO) awareness, information, or exposure to autism.

Parents are unaware of this and are not attentive to it as a result of the appropriate parties' lack of awareness. These children are not given the proper care, thus they are viewed as aggressive, naughty, and other types of hostile children. As a result, efforts to inform parents about the traits of autism should be made seriously and with prompt action so that the community is not ignorant of information about autism. Additionally, the researcher concurs that organizations like Jabatan Kebajikan Masyarakat (JKM), the Ministry of Health, specific institutions, and NGOs should be more proactive in promoting and disseminating information about autism through all channels so that parents, educators, and institutions related to autism would be able to search for institutions to communicate with as well as for parents to seek assistance when necessary. It should be simple to get in touch with and free from lengthy procedures to receive special assistance for children with autism and their parents.



Pyramid A depicts a summary of the challenges faced by parents of children with autism, with emotional challenges appearing to be the most difficult for parents, as previously explained. Pyramid B, on the other hand, depicts the assistance or support that parents require, which are equally important and must be addressed by all parties, including the government, non-governmental organizations (NGOs), schools, educators, and society itself.

### Conclusions

In general, this study intends to examine the challenges parents encounter when their autistic children have meltdowns and the support or help parents require in such a situation. Despite this, some of the results of this study's participant interviews are consistent with what the researchers discovered in the previous literature evaluation. This study made a revelation about an obsession in autistic children that can trigger meltdowns. Because an obsession is difficult to change, this preoccupation presents a difficulty for parents. This is due to the intimate connection between autistic children's obsessions and their everyday routines. Researchers may use this as a reference in the future to look into more in-depth features of preoccupation in autistic youngsters. Even though the word obsession can have a little negative connotation, it can also be a strength that aids autistic children's growth in several ways.

Previous research has identified several major factors that can set off an autistic meltdown. Emotional factors, senses, surroundings, bodily, thoughts, and minds are among the things that frequently cause meltdowns in people with autism. Parents of autistic children and their children may experience significant repercussions as a result of the issues that have been addressed. Even though the effects of meltdowns vary for each autistic child, they are nonetheless incredibly difficult for parents. Based on the discussion above, the challenges parents of autistic children face when their child has a meltdown include emotional challenges, difficulties managing their child's response or behavior during the meltdown, and difficulties managing the perception or acceptance of the neighborhood.

Parents of children with autism require a variety of supports as they deal with their child's meltdowns, particularly training on how to deal with an autistic child's emotions during a meltdown. Parents will feel more comfortable handling real meltdown situations, particularly severe meltdowns, with the support of realistic simulations or practical exercises. Therefore,

according to the study's findings, numerous organizations and groups should pay attention to the help that parents of children with autism need.

Taking care of and parenting a child with autism is not an easy task. Parents of children with autism should be knowledgeable about and skilled in a variety of areas. Naturally, autistic children have rights and are entitled to the same treatment as other typical children. The greatest obstacle for parents is not just when their child has a meltdown, but also when they have to cope with the surrounding community, which could stigmatize them and their autistic children.

As a result, autism-affected children themselves need support in addition from their parents. They ought to develop in the same way as typical children and receive the support they require at a young age. Again, moral support from their families and the neighborhood community is crucial in fostering an atmosphere where children with autism can thrive.

Society's ignorance of autism, particularly its symptoms like meltdowns, tension, tantrums, hyperactivity, and more, contributes to its negative reputation. This needs to be put out by raising awareness through social media, especially by educating people about autism, which should have been done a long time ago.

As a result, not only parents and family members but also educators, preschool teachers, special education teachers, and society at large should be exposed to information on autism. The school must prepare preschool teachers and exceptional education teachers who will instruct special needs children and children with autism, particularly the strategies for handling meltdowns, to support parents of children with autism. Parents of children with autism will find it easier to send their children with autism to school if the teachers are knowledgeable about children's autism, especially sub-issues like this meltdown.

Future research support is still required to fully understand the factors that lead to meltdowns and the difficulties parents have while handling these meltdowns in children with autism. Therefore, further research can be expanded by examining the meltdown phase in greater detail and how it affects the autistic child's mental and physical health in addition to the challenge it poses for parents of children with autism; study methods or techniques involving clinical methods, whether on autism in general or about meltdowns in particular; studies in terms of the therapy support parents receive when dealing with the meltdowns issue.

These topics are appropriate and pertinent for further study to provide parents of children with autism with more information and knowledge, as well as for the general public, including special education teachers and the individuals who will work with children with autism in schools.

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