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## Psychosocial Adjustment Strategies among Typically Developing Adolescents of Siblings with Autism Spectrum Disorder

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#### **Abstract**

A neurodevelopmental disability known as Autism Spectrum Disorder (ASD) is characterised by complex neurological symptoms involving the structure and function of the individual's brain and nervous system. Since ASD in an individual lasts throughout life, it is not surprising that living with an ASD individual presents unique challenges not only to the parents but also to the siblings of the ASD individual himself, where it can leave a great impact on the typically developing individual's functioning, psychological, educational and social, or in the family economy from the beginning of the process of obtaining a diagnosis until the ASD individual steps into adulthood. Previous research findings on the experiences and perspectives of typically developing siblings growing up with individuals with ASD have been mixed. Thus, a qualitative approach with a case study design was used to explore the psychosocial adjustment strategies taken by typically developing adolescents when dealing with ASD siblings. Six participants who matched the study's criteria and were recruited through snowball and purposive sampling had semi-structured interviews with an average duration of 30 minutes. The results of semi-structured interviews were analysed using thematic analysis. Two main themes that emerged are active coping strategy and passive coping strategy. Typically developing adolescents are observed to employ both types of coping strategies depending on the situation. The results of this study offer valuable insights into how society and medical professionals can support the psychosocial development of typical adolescents who have siblings with ASD.

**Keywords:** Autism Sibling, Typical Developing Adolescent, Siblings' Relationship, Coping, Psychosocial Adjustment

#### Introduction

The Diagnostic Manual and Statistics of Mental Disorders, Fifth Edition (DSM-5), has updated the term Autism Spectrum Disorder (ASD), which further refers to a grouping of four formerly distinct disorders: autism, Asperger's syndrome, childhood disintegrative disorder,

and various other developmental disorders (American Psychiatric Association [APA], 2013). Autism Spectrum Disorder is a complex neurological developmental disorder involving brain and nervous system structure and function. A delay in language development, sensitivity to routine changes, sensitivity to smell, light, sound, and touch, unusual social interactions, nontypical play patterns, stereotyped behaviour patterns, repetition of odd behaviour, aggression, hyperactivity, and lack of concentration are among the obvious features in children diagnosed with ASD (Iannuzzi et al., 2022). This ASD is called a spectrum disorder due to its symptoms, and its severity is unique to each ASD individual (Brihadiswaran et al., 2019; Vuijk et al., 2022). This disorder is very complex, heterogeneous, and develops over time. Tanner and Dounavi (2021) state that ASD symptoms can manifest with or without a language and intellectual disability and are typically visible or detectable between the ages of 6 and 18 months (Kreysa et al., 2022). The symptoms that ASD individuals experience can lessen, especially when they receive adequate early intervention from multidisciplinary professionals, even though early detection is one of the biggest obstacles to early intervention. According to Zeidan et al (2022), while ASD is a rare type of disorder, an increasing number of children have been diagnosed with it over the past decade, with the prevalence now estimated to be one in 100, while the prevalence is one in 44 for children who are 8 years old (Maenner et al., 2021). This rise could be attributed to changes in diagnostic criteria, policies, and increased awareness of the disorder (Zeidan et al., 2022). This leads to more families being impacted. Given that ASD in an individual lasts a lifetime, it is not surprising that living with and raising an ASD child poses special challenges for the parents as well as the other typically developing family members. From the time of diagnosis, until the ASD child is an adult, the functioning of the typically developing person's psychological, educational, social, or family economy may be significantly impacted. Therefore, it is increasingly necessary to explore the impact of this diagnosis on the immediate family.

Children's current social and emotional development depends heavily on sibling relationships (Brewton et al., 2012; Tsao et al., 2011). With siblings who have ASD, typically developing siblings not only have fewer opportunities to experience the variety of experiences, teaching, and learning that typical fellow siblings find, but they are also more vulnerable to the wide range of complex challenges that can affect interaction, experience, mastery of socioemotional skills, as well as other aspects of psychosocial adjustment that can be attained through sibling relationships (Gan, 2017; Gorjy et al., 2017; Johnson et al., 2020). The psychosocial traits of typically developing children with siblings who have ASD are found to be more upsetting than the traits of typically developing children without siblings who have ASD (Shivers et al., 2019). Prior studies provide evidence that typically developing siblings feel isolated, lonely, confused, burdened, restless, and ashamed of how the ASD siblings displayed themselves throughout the growing process together, especially if the ASD siblings possess severe ASD, including behavioural issues and severe comorbidities (Hanvey et al., 2022; Thomas et al., 2015; Walton, 2016 in Rixon et al., 2021).

The presence of ASD children in families can cause the needs of ASD children to frequently receive the utmost attention in structuring the daily family routine (Costa & Pereira 2019), which can have an impact on the development of social skills among other typically developing siblings because of parents' reduced ability to give consistent attention to them. The role and responsibility of a typically developing child in the care of ASD siblings also no longer adheres to the traditional practice of older children assisting parents in caring for younger siblings. Instead, almost all typically developing kids, regardless of their position in the family, work with their parents to manage, care for, and safeguard their ASD siblings

together (Hanvey et al., 2022). However, some research has indicated positive findings regarding sibling relationships, adopted coping, and typically developing child psychosocial adjustment while growing up with ASD individuals, where maturity, empathy, a sense of responsibility, and higher tolerance exist in this typically developing child because their parents have exposed them to the ASD issue that their siblings have experienced since childhood (Chu et al., 2021; Gorgy et al., 2017; Costa and Pereira, 2019; Mahbot & Alias, 2022). Most respondents in Singh and colleagues' study (2021) acknowledge that it can be challenging to manage their ASD siblings' behaviour and deal with difficulties, but they also concur that they grow to be more appreciative, independent, and grateful. Due to the mixed findings of previous studies, this study was carried out to delve into the experiences of typically developing adolescents growing up with siblings who have ASD, by exploring the psychosocial adjustment strategies taken by adolescents when dealing with the challenges posed by ASD siblings.

#### **Literature Review**

Psychosocial adjustment in this study refers to how typically developing adolescents adapt and balance their mental, emotional, behavioural, and social functions when there are conflicting needs or challenges in the environment involving ASD siblings. The Transactional Theory of Stress and Coping suggests that people's stress levels are determined by their assessments of two factors: their primary appraisal (the stressors) and their secondary appraisal (the resources they must utilize to cope with the stressors) (Lazarus & Folkman, 1984). When confronted with a potentially harmful situation, people question what is at stake. The appraisals' results will have an impact on the quality and intensity of their emotions. In the secondary appraisal, the individual questions what can be done in response to the perceived threat, which is the coping option. The results of the appraisal at this level contribute to the type of response strategy that will be implemented to manage the demands of the situation.

An individual's short- and long-term outcomes are consequently influenced by their coping mechanisms, which can include emotional or problem-focused coping responses as well as personal and environmental characteristics. Coping mechanisms will be discovered through the analysis of emotional sources and cognitive processes. If social support and help are available, it is likely to encourage healthy coping strategies like problem-solving, talking about one's internal struggles, and asking for help from others. However, when under extreme stress, a lack of emotional resources and support resources is likely to result in unhealthy coping mechanisms.

Recently, the focus has begun to shift from examining ASD individuals' connections with and experiences of their parents (Ang & Loh, 2019; Cage et al., 2018; Cai et al., 2020; Efstratopoulou et al., 2022; Kutuk et al., 2021; Wang et al., 2020; Yaacob et al., 2021) to exploring the relationships and experiences of ASD individuals with their typically developing siblings. Some past studies that use a quantitative approach (Corsano et al., 2017; Dansby et al., 2018; Hanvey et al., 2022; Lovell and Wetherell, 2016) and qualitative approach (Hanvey et al., 2022; Iannuzzi et al., 2022; Leedham et al., 2020; Thomas et al., 2015; Walton, 2016 in Rixon et al., 2021) have observed difficulties in psychosocial adjustment among typically developing siblings of individuals with ASD. Typically developing siblings of ASD individuals are found to face more issues in emotional aspects (Corsano et al., 2017; Dansby et al., 2018; Lovell & Wetherell, 2016), behavioural and social (Corsano et al., 2017; Dansby et al., 2018); Selvakumar & Panicker, 2020) when compared to siblings without ASD sibling.

Typically developing children born after the birth of ASD siblings are reported to be more at risk of experiencing maladaptive behaviour. When ASD siblings exhibit high frequency and intensity of problematic behaviours such as aggression, typically developing siblings tend to imitate and exhibit problematic behaviours such as irritability or doing forbidden things (Verté et al., 2003; Petalas et al., 2009; Tomeny et al., 2014). Typically developing children who are older than their ASD siblings are also reported to exhibit problem behaviours. They were found to ignore instructions and rules, face emotional stress such as restlessness and depression, and like to create problems, due to competition factors or avoidance factors with their ASD siblings (Longobardi et al., 2019). Difficulty with internal adjustment will usually only occur in typically developing siblings who have a high probability of having Broad Autism Phenotype (BAP) in them, which are features of autism that have never been detected and diagnosed (Dovgan et al., 2022; Petalas et al., 2012; Ruzich et al., 2016; Wheeler, 2010). The higher the level of behavioural aggression shown by ASD individuals, the more frequent the behavioural, emotional, and social adjustment problems that their typically developing siblings will show (Aparicio & Mínguez, 2015).

Aside from psychological issues, burnout can affect typically developing siblings who may be responsible for domestic tasks and the physical care of ASD individuals. Not only has this situation triggered additional responsibilities for typically developing female siblings (Cridland et al., 2016) but they are also found to be more likely to face difficulties in adapting compared to typically developing male siblings due to being often involved and held responsible by the family with additional tasks (Hamama & Gaber, 2021). When there is an increase in expectations from parents that are not in line with the allocation of time or attention parents give to this typically developing child, the situation is likely to contribute towards a form of family relationship that is not dynamic and affect the overall psychosocial adjustment of this child (Hamama & Gaber, 2021).

In the meantime, not all previous studies report negative findings related to the psychosocial adjustment of typically developing individuals towards ASD siblings. Some of these typically developing adolescents believe that the life they live with ASD siblings is normal and no different from a family where all of them are typically developing children (Gorjy et al., 2017; Mahbot & Alias, 2022). According to Walton and Ingersoll (2015), typically developing individuals who have ASD siblings do not have significant behavioural, social, or emotional adjustment problems, especially when their ASD siblings only have mild ASD symptoms, have high adaptive skills and are not exhibiting aggressive behaviour (Rixon et al., 2021). They are also reported to be more generous and have far better psychological wellbeing compared to typically developing individuals who only have typically developing siblings (Costa & Pereira, 2019; Gorjy et al., 2017; Mahbot & Alias, 2021). The study by Longobardi et al (2019) found that typically developing children who were younger than their ASD siblings, exhibited significantly more positive behaviour towards their ASD siblings. They display love and compassion towards ASD siblings (Guidotti et al., 2021; Leedham et al., 2020), can adapt with a strong self-concept (Corsano et al., 2017) and show competence in socializing (McHale et al., 2016).

Socioeconomic and cultural factors also have a direct influence on the psychosocial adjustment of an adolescent. The more socioeconomic resources that families of children with ASD have and the more social policies that can be obtained from their environment, the less the issue of self-control of typically developing siblings (Aparicio and Minguez, 2015). The role that parents play in the family turns out to have a positive effect on the experiences that siblings go through. The findings of Aparicio and Minguez (2015); Kovshoff et al (2017); Selçuk

and Aytaç (2020) found that there is less maladaptive behaviour among typically developing adolescents if they have other typically developing siblings in the family other than siblings who suffer from ASD. Furthermore, an increase in awareness, knowledge, and acceptance as well as support by teachers or counsellors at school towards these typically developing adolescents, can contribute towards a more positive psychosocial adjustment of typically developing adolescents (Hayden et al., 2019). This is due to the presence of outsiders from the family context who take the initiative to understand the challenges that these typically developing adolescents go through, especially if the typically developing adolescent does not have other typically developing siblings other than ASD individuals to share the burden of feelings or stress.

Different research approaches and designs taken by past researchers play a role in the diversity of research findings regarding the psychosocial adjustment of these typically developing adolescents. The results of the meta-analysis of Shivers et al (2019) on 69 studies found that previous researchers had used questionnaire data collected from the perspective of parents or teachers rather than from the typically developing siblings themselves. Therefore, psychosocial adjustment from the perspective of typically developing adolescent siblings deserves to be explored and known further.

#### Methodology

This study was designed based on a qualitative approach that is exploratory, descriptive, and interpretative (Maxwell, 2018). A case study was chosen as the research design. The limited consensus on the psychosocial experiences and adjustments of typically developing siblings coupled with the importance and need of this study for the local community parallels Yin's first condition that "Case studies must be significant" (Yin, 2009). In-depth interviews were conducted on typically developing female adolescents who have younger brothers with ASD to explore as deeply as possible the perspectives of the participant on the issues under study. This is in line with previous researchers' statements that in-depth interviews can reveal more accurate details, understand more deeply, and have a better relationship with the participant (Jamshed, 2014 in Zulkefli & Rabi, 2021).

Lincoln and Guba (1985) in Vasileiou et al (2018) suggested the determination of sample size in qualitative studies based on the criterion of overlapping information, that is, sampling can be terminated when no new information is obtained even by taking more samples. This study has reached a level of thematic saturation on six participants recruited through purposive sampling and snowball sampling. Among the participant eligibility criteria for this study are

- (i). Have at least one sibling diagnosed with Autism Spectrum Disorder (ASD)
- (ii). No mental health issues or other disabilities.
- (iii). Aged between 10 and 13 years old

All the participants come from different families living around Selangor, a state on the west coast of Peninsular Malaysia. They are typically developing adolescent females who are older than their siblings with ASD. It was not intended to recruit all female participants but a recommendation by the first participant and the rest led to the recruitment of the female siblings. One of them is Indian while the rest are Malays. Five of them have at least one other typically developing sibling in the family. They live with both parents except for one participant who stays in a boarding school. The findings also found that only one of them had both parents working, but all families had a stable economic status where no family belonged to the lowest 40% household income category in the country (B40). Table 1 summarizes the

demographics of the participants as well as siblings with ASD where the pseudonym "A" as an abbreviation for adolescent, followed by a number, was assigned to the participant.

Table 1
Demographics of the participant and siblings with ASD

Parti	cipant					Sibling with ASD				
Pseu.	Ethnicity	Gender	Age (in years)	Sibling per family	Birth Order	to	tionship siblings ASD	Age (in years)	Gender	ASD Severity
A 1	Malay	Female	11	3	1	Elde	r Sister	9	Male	Mild
A 2	Malay	Female	12	5	3	Elde	r Sister	10	Male	Mild
A 3	Indian	Female	13	3	2	Elde	r Sister	7	Male	Mild
A 4	Malay	Female	10	2	1	Elde	r Sister	7	Female	Mild
A 5	Malay	Female	11	3	1	Elde	r Sister	10	Male	Mild
A 6	Malay	Female	10	4	1	Elde	r Sister	4	Male	Moderate

#### **Research Instruments**

Referring to Creswell and Poth (2018), the primary tool for gathering and analysing data for a qualitative study is the researcher because the researcher obtains information directly from the participant. The interview protocol adapted from the study of lannuzzi et al (2022), was used to obtain the necessary information from the participant because the researcher used a semi-structured interview method whose scope had been determined in advance. A total of 3 constructs in the interview protocol consisted of an introductory question construct, a question construct that answers the research question and a closing question construct. Among the questions presented are (i) What do you do when [mention the main difficulty when dealing with an ASD sibling] happens?; (ii) How did you feel during or immediately after [name the main difficulty when dealing witan ASD siblings] happened?; and (iii) What can you learn from observing parents when faced with [the situation mentioned above]?. The questions target a typically developing adolescent's memory of events and situations that have given rise to certain emotions and interactions. This approach maximizes the content of the interview without having to deal with long interview times, which may put an additional burden on the participant (Creswell & Poth, 2018).

A pilot study was carried out on one sample who met the research eligibility criteria. The results of the pilot study found that the sample could understand and be able to answer each question, the duration of the sample giving a response could be estimated, and the quality of the voice recorder used was clear. According to Chua (2011), the findings of the pilot study can prove the feasibility of this study to be carried out.

#### **Data Collection Procedures and Data Analysis**

Ethical approval to conduct the study was first obtained from the Faculty of Education of Universiti Kebangsaan Malaysia before the parents of the potential participants were contacted. The purpose of the study and the interview procedure was explained in detail while permission to be interviewed and recorded was asked before written consent was given by both parents and their children.

Interview sessions either via phone calls or video conferences were conducted separately between participants to build a friendly relationship between the researcher and the participant in addition to preserving the privacy and comfort of the participant in sharing the experience of growing up with their ASD siblings. It is important to ensure that their

privacy is respected, their needs are met, and children's data is protected (Bichard et al., 2022). To ensure the accuracy of the data, each interview was recorded in writing and audio using an Oppo CPH 2375 smartphone. The interview conducted lasted an average of 30 minutes.

The audio recordings were verbatim transcribed, and the transcript was sent back to the participant via Whatsapp Messenger for member check. This member check was used to obtain feedback from the participant on the accuracy of their shared experiences in the interview transcripts. Maxwell (2018) sees this descriptive verification as an agreement between both the researcher and the interviewee.

The interview transcripts were then analysed using a thematic analysis approach based on Braun and Clarke's six-phase framework (Braun & Clarke, 2006). This process included engagement with the data (all interviews were conducted and transcribed by the first author), generation of preliminary codes, categorisation of codes into initial themes with corresponding quotes, review of themes with credibility checks, and final coding of themes. According to Braun and Clarke (2006), the frequency of occurrence in the data should not be used to build themes, therefore the frequency of themes is not reported. Emerged themes that answered the research question also went through the process of researcher triangulation. Researcher triangulation is one of the triangulation types recommended to increase the validity and reliability of research data (Denzin, 1978). Since these themes are large and complex, the researcher has identified several sub-themes to aid with their construction. Table 2 shows the sub-themes that make up the themes that highlight the psychosocial adjustment of the participant while growing up with an ASD sibling.

Table 2
Theme and sub-themes

No.	Themes	Sub-themes					
1	Active Coping Strategy	Emotion control; Problem-focused coping; Seeking understanding behind the incident; Seeking outside support and help; Empathy					
2	Passive Coping Strategy	Avoidance; Diversion; Showing negative emotions; Wishful thinking					

#### Results

This section discusses each main theme and sub-theme that answers the research question. Excerpts of verbatim comments from participants that refer to themes are also provided as evidence of participant statements that describe themes and subthemes, and to give the reader a better understanding of how meaning is constructed (Corden and Sainsbury 2006).

#### **Theme 1: Active Coping Strategy**

This theme describes how a person adapts directly in dealing with stressful events. The subthemes that were found consisted of problem-focused coping, seeking understanding behind the incident, empathy, controlling emotions and efforts to seek external support and help. Further explanation of the sub-themes is as follows.

#### **Subtheme: Emotion Control**

This subtheme details the ability of typically developing adolescents to regulate their emotions when they are in certain situations. A younger brother with ASD to one of the participants was found to be quite impatient and easily angry by displaying negative emotions

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and behaviour due to not being able or slow in getting what he wanted. Participant A1 was found to try to be patient and take quick action to comply with the will of his brother when such a situation occurs to alleviate the issues that arise. An interview excerpt that exemplifies this situation is as follows.

"When I was late to give him the requested food, he got angry or when I helped him select his cartoons on the television ...when I selected them wrongly, he got angry too, sometimes he even hits me or something like that. (But) I know I must be patient because he doesn't understand. I will quickly give (him) what he wants".

(A 1)

On the other hand, A 4 was aware of her ASD younger sister's habit of taking other people's things without permission. She once wanted to scold her sister but decided to be patient and reprimanded the act several times because she knows that ASD individuals do not know the meaning of the limits of belonging.

"My sister is naughty. She is mischievous and likes to take people's things. Always takes my pencil, book, eraser, and sharpener. She always brings her (school) friends' belongings home. She likes to draw (in) people's books, so she brings (those) books back. I want to scold her, but I must be patient. Every time my sister does that, I reprimand her nicely". (A 4)

#### **Subtheme: Problem-focused Coping**

Attempts to modify or eliminate the sources of stress in stressful situations are included in problem-focused coping. The participant, A 3 who has an ASD younger brother who suffers from sensorial sensitivity issues, is said to have a phobia of darkness. Therefore, at night, A 3 took the effort to install a dim sleeping lamp in her brother's room and accompany her brother until he fell asleep.

"He's afraid of dark places and he's afraid of being alone....for example, when he wants to go to sleep and it's time to turn off the light, he'll be afraid. So, at that time, I will try to persuade him, and after that, turn on the night light. If he is afraid of being alone, I will try to be by his side, not leave him. (Because) if he is left alone, he will cry".

(A 3)

For ASD siblings who have sensorial sensitivity issues to loud noises such as the sound of vacuum cleaners and firecracker explosions, typically developing siblings are found to immediately bring the ASD sibling away from the source of the loud noise. This situation is explained by A 4 as quoted below.

"He is afraid of firecrackers. I quickly bring him inside the house". (A 4)

In addition, when typically developing siblings were in an unexpected situation, among the actions taken by them to deal with the situation was to take certain actions and reprimand the ASD siblings well. This is what happened when the ASD younger brother of participant A 1 unabashedly greeted and waved at anyone when in public places. An excerpt from the interview that describes the situation is as follows.

"Like in a public place, there are times when he can say "hi" to people he doesn't know. If at our house area, if bumps into other people like the security guard, he can wave and say "hi"

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right in front of that person's face. (So what I did was that) I pulled his hand, I told him not to say hi to that person". (A 1)

In different situations, a few ASD siblings easily display aggressive behaviour towards people sitting nearby regardless of whether the person is a family member or a stranger. ASD's younger brother of participant A 6 reportedly hit other children nearby when he was frustrated that the cartoon, he was watching on his electronic device was interrupted. Participant A 6 felt upset and depressed by the incident and she took the initiative to immediately apologize to the child and the child's family.

"If something wrong happens to his smartphone, he will (beat) other children nearby. (When he hit people) I felt sad, I was stressed sometimes (especially) when he hits small kids. I would think the kids' parents must be angry, then think about why he did that. (So) I will apologize to the person he did (hit), to that person's parents he did (hit)".

(A 6)

#### **Subtheme: Seeking Outside Support and Help**

This subtheme details the mechanism of adapting to stress by getting help and support from other people. Under this subtheme, it was found that half of the participants often seek help and advice from their parents when out-of-control situations involving siblings occur.

"My parents are the ones who would apologize to anybody (when there is an unpleasant situation occurs), saying that my brother has autism". (A 1)

The situation that happened to A 3 and her family was when her hyperactive ASD younger brother lost patience while waiting for the food, they had ordered at a restaurant to be ready. Participant, A 3's brother not only felt frustrated and agitated but also ran out of that place. In such a situation, her mother both helped her supervise and persuaded her brother to be more patient.

"...when we went to a restaurant, the food was late, so [the ASD sibling] got angry. He's frustrated so he's restless, crying, and then he tried to run away from the table. Usually, it's mom who helps control and persuades [the ASD sibling]". (A 3)

Participant, A 6 once expressed her disappointment to both parents and questioned the reason behind her ASD younger brother's aggressive behaviour towards others. Nevertheless, she accepted what has happened with an open heart and tried to understand her younger brother's situation which is not the same as other typically developing children, soon after it was well explained by her parents.

"(I) once (told mom and dad about how I feel when my brother hits people) I said, "Why is he always like that?" (Mother and father will say) "Your brother is not the same as other kids, we have to understand that". So, I try to understand the best that I could."

(A 6)

ASD individuals are known to have comorbidities such as Attention Deficit and Hyperactivity Disorder (ADHD) or Epilepsy. Participant, A 6's ASD younger brother is reported to be frequently attacked by epilepsy. During the first incident encountered by the

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participant, she became panicked as not know how to deal with it, but she acted quickly by asking for help from his father who happened to be at home.

"I recalled that time was the first time, he had a severe seizure. I was studying in the living room...he was sleeping near the living room near the sofa. I called my father. (I felt) anxious, scared. Now he seems to be less affected".

(A 6)

#### **Subtheme: Seeking Understanding behind the Incident**

This subtheme details the typically developing adolescent's efforts to think positively. This type of coping may help when the stressful situation is something they cannot change or control. Two participants namely A 5 and A 6 were found to build their understanding in translating the meaning behind challenging behaviour or impulsive behaviour shown by their ASD siblings. Participant, A 5, for example, assumed that the hitting behaviour of her ASD brother was one of the forms of communication considering his brother's limited speaking ability.

"I know why he hit (me) because he wanted to get my attention (to get what he wanted). That's his way of telling me what he wants because he can't speak". (A 5)

Participant A 6, on the other hand, thinks that her ASD younger brother acts impulsively and aggressively whenever a stranger is nearby his family because he feels jealous and feels that the person is trying to steal the attention of his family members. What A 6 was able to do at that time was to calm her brother down.

"..my brother, he can't (be close) to people he doesn't know. If there are people he doesn't know, he'll suddenly attack. Because (I believe) he thought that people would steal attention from the one he loves. (So) I tried to calm him down".

(A 6)

Participant A6 also just think positively about his younger brother's act of hitting people. An interview excerpt that explains this situation is as follows.

"He also does beat other people, he also does beat his family. To me, he doesn't know (hitting) is right or wrong". (A 6)

#### **Subtheme: Empathy**

The next subtheme explains the typically developing adolescent's ability to also feel the emotions that ASD siblings are feeling. The participant, A 4, recalled a moment in which her ASD younger sister felt frustrated when she was marginalized by her peers because she was not good at socializing and playing like other typically developing children. Feeling sympathy for the situation, A 4 acted persuasively and ask her ASD sister to just play with her. Their parents also joined their play.

"(ASD's younger sister) is angry because her friends did not want to be friends with her. She likes to make friends, but people exclude her. (So, I ask) her to befriend me. Ummi (mother) played with her, abi (father), and I (even) played with her. (we) took her to cycle, took her to the park. (Because) she likes running (and) playing slides". (A 4)

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On a different occasion, A 4 once again realized and understood her sister's discomfort when they were at a party. Her younger sister, who has issues with sensorial sensitivity to noises and crowded places, exhibits unstable emotional and behavioural changes once she was in such a situation. She used a persuasive approach until her sister stopped crying and calmed down.

"If (go to) a crowded place, (like) a party, she doesn't like it at all. She (would) covers her ears, she rages, and she cries. (So) I would always persuade and persuade her until she stops (crying) until she is happy. Like saying, it's ok sister". (A 4)

In the other situation, when the researcher asked about the happy moments that happened between both siblings, A 4 described the feeling of happiness when her sister, who has limited communication skills, was able to have fun and joke in her way. This happens when her ASD sister who likes to take family photos using a smartphone, turns their family photo into a funny photo using software capable of altering pictures.

"She took a picture of mother, father and me. She transformed it into a picture she liked, a funny one". (A 4)

Other than that, participant A 3 expressed a feeling of relief when the ASD condition experienced by her younger brother was understood and well-accepted not only by her family but also by her friends. She has no problem inviting her school friends to spend time at home to study and chat because her friends already know and understand what ASD is. They also treat her younger brother like an ordinary child.

"(I) feel comfortable inviting friends to come, eat, and study at home because people understand the condition [of the ASD brother]. People already know (what Autism is) when they look at [ASD sibling]. I feel satisfied because my family members and friends, everyone understands about Autism [ASD sibling] and people don't easily judge him. So, when he jumps around or screams, people understand, didn't say anything, and people will have fun with him. People will still call him cute and play with him. So, I feel happy when I see that people can understand him having this condition". (A 3)

#### **Theme 2: Passive Coping Strategy**

This theme explains a series of strategies that allow a person to tolerate, reduce or escape from the stress faced by avoiding, denying, or withdrawing from the situation. This strategy can involve behavioural or cognitive aspects and usually results in the individual relinquishing control to other people or situations. The sub-themes that emerged were found to include coping in the form of avoidance, diversion, displaying negative emotions as well as putting on hope. Further explanation of the sub-themes is as follows.

#### **Subtheme: Showing Negative Emotions**

This subtheme details the negative emotional response among typically developing adolescents such as feeling sad, feeling disturbed, frustrated, angry, stressed and near to giving up when unable to control the stress caused by their ASD siblings. Four participants in the study were found to be emotionally affected. Among them, participant A1 felt uncomfortable and disturbed whenever her ASD younger brother behaved oddly by often greeting and waving at strangers or showing sudden anger in public places.

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"...there are times when it feels annoying, there are times when it feels very uncomfortable or strange. That's how I felt (because) he always says "hi" (to strangers) or (suddenly) gets into meltdown when he goes to public places".

(A 1)

Participant A 2, who studied at the same school as her ASD younger brother, admitted to feeling pressured when it was difficult to calm the feelings of her ASD younger brother who felt restless and impatient every time their mother fetched them home late from school.

"It's like at school, when it's time to go back, (I felt) it's hard to control him especially when my mother was late in fetching us home. I felt a bit stressful". (A 2)

In addition, participant A 3 expressed her frustration and feelings of hopelessness when all efforts to control the movements of her hyperactive ASD younger brother from running and jumping uncontrollably in public places, did not work. She also felt ashamed when her younger brother's behaviour caused a collision with people around him and became a public spectacle and attention. The quote below explains the situation.

"..especially at a public place, so (when) many people were looking, he couldn't control his sense of happiness, he will run around until he incidentally bumps into people. If that happens, it's a little difficult to control. Sometimes I feel frustrated because I couldn't control him. Because no matter what we try, he still won't sit still, he wants to run, jump around, so I feel frustrated".

(A 3)

In addition, A 5 admitted that she lost her patience and vented her anger towards her ASD brother who often behaved aggressively and impulsively towards her. This unprovoked and unpredictable aggressive nature is very difficult for the participants of this study to face, especially when she is the only one among family members who become the target of ASD siblings. The participant that experienced this situation considered that the act put a lot of pressure on their emotions. This can be shown through the results of an interview with him as follows.

"I can lose my patience when he hits me or wants things quickly. I can get angry quickly, get angry too at him, (because) he always hits me when I didn't get him straight away things that he wanted. He didn't even hit my other brother ". (A 5)

#### **Subtheme: Avoidance**

This subtheme details individual efforts to take simple steps away from sources of stress. The study found that only A 1 participant reported ever distancing herself from their ASD brother when her brother struggled with emotion regulation disorders. She instead sought her mother's support when all her efforts in calming down her ASD younger brother who was having a tantrum failed.

"I always feel stressed whenever he screams (uncontrollably). If (any persuasion) doesn't work, (I would) carry on with my own thing, stay away from him, or just tell my mother". (A 1)

#### **Subtheme: Diversion**

Under this subtheme, two participants were found to use things that their ASD sibling was fond of, in distracting and curbing negative emotions or out-of-control behaviour that they

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are currently experiencing. For example, when her ASD younger brother sulked or was in a state of anger, A 3 knew that her younger brother's emotions would subside when he is offered his favourite foods such as sweets.

"My brother likes marshmallows. So, if like, for example, he sulked or got angry with me, if I showed him marshmallows, he would come back (to me)". (A 3)

In a different situation, A 6, on the other hand, recalled an event where her ASD younger brother, who was also diagnosed with Attention Deficit and Hyperactivity Disorder (ADHD), liked to run around in the restaurant they dined in while waiting for the food ordered to arrive. Various efforts have been made by her and her family to control the behaviour, including giving warnings as well as giving him electronic devices that he likes to play with.

"He would run around (if dining in a restaurant) so we told him to sit still, but sometimes (that doesn't work) he would be given the smartphone, only then he can sit still" (A 6)

In the meantime, video games or cartoon shows watched on smartphones that are suddenly interrupted often trigger one of the participants' brother's anger. However, A 6 was quick to deal with the situation by giving her younger brother several alternatives, whether by offering him to play video games on her smartphone, playing together with him or getting him his favourite food.

"(ASD sibling gets angry when) his phone is in loading mode. (So, I would) give him my smartphone instead, (or) just play with him, or give him food that he likes. (Such as) plain white rice".

(A 6)

#### **Subtheme: Wishful Thinking**

Under this subtheme, one of the participants expressed the hope that her ASD younger brother who is hyperactive and often acts aggressively when his wishes are not granted or take a long time to be fulfilled, to stay calm and not exhibit such behaviour. She added that a state of calm can often be achieved only when her ASD brother was totally tired and wanted to go to bed. An interview excerpt that explains this is expressed by participant A 6.

"I liked it when he was in a calm state. Like when he was about to sleep, he was calm. I like it because that's the only time that he doesn't hit people..because if he hits people, it hurts".

(A 6)

#### Discussion

This study explores the psychosocial adjustment strategies taken by typically developing adolescent girls when they faced challenges while growing up with their ASD siblings. Psychosocial adjustment in this study refers to how one adapts and balances their mental, emotional, behavioural and social functions when there are conflicting needs or challenges in the environment involving their ASD siblings. Among the challenges they often face are issues of sensorial sensitivity to loud noises and crowded places, emotional and behavioural regulation disorders, communication barriers, atypical socializing ability and aggressive behaviour shown by their ASD siblings.

All the participants were found to express negative feelings such as feeling depressed, disturbed, frustrated, angry, strange, confused, and uncomfortable with some unpleasant situations caused by the ASD siblings. These situations not only happen at home but also in public places they visited such as restaurants, social gatherings, schools and so on. In addition to feeling stressed and disturbed by the atypical behaviour and way of socializing, the typically developing siblings were also physically affected due to the aggressive behaviour shown by the ASD siblings. This finding is in line with the findings of Corsano et al (2017); Dansby et al (2018); Lovell and Wetherell (2016) where typically developing siblings are reported to face many issues involving emotional aspects when dealing with ASD siblings. According to Hanvey et al (2022); Thomas et al (2015); Tomeny et al (2016); Walton (2016) in Rixon et. al (2021) on the other hand, typically developing siblings feel confused, burdened, restless and embarrassed by the way ASD siblings show themselves throughout the process of growing up together, especially if the ASD siblings experience a severe level of ASD severity as well as behavioural issues and comorbidities. The same situation has been expressed by several participants who have ASD siblings with limited communication ability, suffer from sensory processing disorders and have comorbidities such as Attention Deficit and Hyperactivity Disorder. When their ASD siblings are enveloped in negative emotions and behaviours, the situation is often difficult to witness let alone to deal with for the participants of this study. Despite knowing the negative behaviour stems from the inability of their ASD siblings to express their feelings in other ways when the situation becomes increasingly uncontrollable where the behaviour of ASD siblings can cause injury to themselves and others, the participants of this study have given a strong emotional response including feeling depressed, despairing, angry and even distancing themselves from the pressure they face. The researcher believes that the passive type of coping approach taken by the typically developing adolescents not only acts to protect themselves from being a victim of tense situations but can also preserve the well-being of their mental health at that time. The findings were found to be in line with the findings of the study by Tsai and colleagues where their participants took an approach of distancing themselves when there was no other effective way to deal with and improve the situation that caused high pressure on them (Tsai et al., 2018). This type of passive response is said to be caused by increased activity in the hypothalamus pituitary adrenal axis in the brain which functions to control the reaction to stress (Koolhaas et al., 2007). However, in different situations, the participants in this study used an active type of coping approach where they were found trying to be patient, always think positively, try to tolerate, and had a great level of empathy when trying to put themselves in the situation that the ASD siblings were going through. According to Shivers (2019), higher levels of empathy and caring among typically developing siblings are likely to be contributed by better understanding and acceptance of ASD siblings. Typically developing siblings who think positively about the behaviour of ASD siblings are also found to be more successful in coping and adjustment (Petalas et al., 2012).

The selection of different approaches and strategies can be explained by the argument of Lazarus and Folkman (1984) in their Transactional Theory of Stress and Coping where there are three continuous processes that a person went through when stress existed. In the primary assessment, the situation faced will be identified as to whether it can pose a threat to oneself followed by a secondary assessment that scans all the responses that can potentially be taken to face the threat. The next process is to implement the scanned response. As these processes progress, the perceived threat at the initial stage can decrease or increase accordingly, and the response being considered can change according to the risk

faced. Therefore, the responses taken by the participants in this study can change according to the level of threat they are facing at that time. According to Olimov and Maxmudova (2022), in situations that are uncontrollably or not fully understood by humans, emotion-focused coping is effective in reducing stress, but problem-focused coping is the most practical way to reduce stress in the long term.

In addition, the participants of this study showed prosocial behaviour by trying to solve issues or reduce the impact due to emotional instability and behaviour shown by their ASD siblings and sought immediate help from parents especially when there was a situation beyond their control. Moral and physical support from both their parents is reported to be often obtained even without being asked. It is possible that the prosocial behaviour shown by typically developing siblings towards ASD siblings is the result of learning and observing the way their parents manage their ASD siblings (Longobardi et al., 2019). This proactive parental involvement shows that they are sensitive to the participants' emotions and do not marginalize themselves throughout the adjustment process of typically developing children. The involvement of parents in the adjustment process of typically developing siblings can reduce existing stress and conflict in the family. Parents who explain to typically developing children the cause behind any atypicality exhibited by ASD children will help in further increasing the understanding of ASD. This statement is supported by previous researchers where it is claimed that families play an essential role in the development, adjustment, and psychosocial well-being of typically developing siblings facing ASD individuals (Dellve et al., 2000; Kaminsky & Dewey, 2001). Furthermore, adolescents in this phase are vulnerable to changes in the environment and will often seek support from their families (Nawaz et al., 2021).

Based on the definition adopted by the World Health Organization (WHO, 2022), adolescents aged between 10 and 13 years old such as the research participants in this study are early-phase adolescence. The adolescence phase is generally known as a critical phase in life and can be one of the most challenging periods where it is a phase in which individuals experience significant growth and development from all aspects, namely neurological, physiological, physical, and emotional; be an independent person; develop socio-emotional skills and learn behaviours that will last throughout their lives (Sawyer et al., 2012; WHO, 2022). Their self-adjustment is a dynamic process that can be influenced by various internal factors such as individuality and personal health level; external factors such as position in the family and relationships with friends; and socio-demographic factors such as age, gender, and socioeconomic status (Revenson & Hoyt, 2016). Although the psychosocial adjustment and well-being of an adolescent are said to be at risk of being at an unstable level, the adolescence phase is also associated with greater brain plasticity where their brains can be shaped because of the experiences they went through (Fuhrmann et al., 2015). Based on the study of Petalas et al (2012), most typically developing siblings by adolescence have reached a level of logical and emotional acceptance and use their previous experiences to alleviate any future concerns. However, difficulties in psychosocial adjustment during childhood if present and allowed to continue, are feared to have the potential to increase the risk of mental health issues and psychological well-being later in life. Thus, there is a clear need to understand the experiences of typically developing siblings and understand what can support their psychological well-being while growing up with ASD individuals.

There were participants that expressed mixed feelings by expressing acceptance of the situation experienced by their ASD siblings but at the same time also hoping for a different situation for ASD siblings. Having listeners who can empathize, as well as validate and

reassure them that it is acceptable to love and feel frustrated with ASD siblings, may benefit the psychosocial adjustment of these typically developing adolescents. The involvement of all family members in daily activities can also reduce the coldness and tension that may occur in sibling relationships while the intervention of parents themselves can reduce the additional burden that typically developing children bear when dealing with ASD children. Without a doubt, this study raises awareness of how ASD affects the psychosocial well-being and adjustment of close families. All the approaches mentioned earlier will shape parents to be more sensitive and aware of the feelings their typically developing child is going through and then respond appropriately in the future. The help and support these typically developing adolescents need can also be immediately identified and channelled.

In addition, the community is advised to be open-minded and positive, and not arbitrarily make any assumptions or evaluate the challenging situations faced by typically developing adolescents with their unique families. This helps these typically developing adolescents become more transparent about their own emotions and feel more comfortable when stepping out of the home environment.

#### Conclusion

Having a sibling diagnosed with Autism Spectrum Disorder (ASD) presents significant and unique challenges to the psychosocial development of typically developing siblings and the dynamics of a family. The impact not only involves the direct effects of ASD symptoms such as emotional, behavioural, and social atypicality on family members but also the continuous efforts that family members need to make to reduce and manage the severity of the symptoms. The typically developing adolescents involved in this study, who are in the early adolescence phase were found to be emotionally, behaviourally, and socially well-adapted. In addition, they were found to tend to apply more than one adjustment strategy when facing certain situations. This is due to several cognitive evaluation processes that evaluate the level of threat that arises in a situation that triggers stress.

The result of this study also contributes valuable insights into how parents, the community, and medical and academic professionals can help support the psychosocial development of typically developing adolescents who have siblings with ASD. Intervention programs in the form of psychological education or parenting and sibling training should be carefully planned, implemented, and expanded to benefit not only typically developing siblings but also parents who have ASD children as the number of affected families is increasing day by day. Such programs are believed to be able to help these families achieve better family well-being.

The extremely small sample size in this study however prevents the generalisation of the results. Findings for this kind of study in the future also cannot be assumed to be the same for all typically developing adolescents who have ASD siblings considering that the adolescents involved are all teenage girls. Nevertheless, the same experience they reported still strengthens the findings.

Further studies should continue to explore typically developing siblings' perceptions of self-adjustment from their perspectives, particularly by collecting data from typically developing adolescents who have ASD siblings with different demographic characteristics (age, gender, birth order, age difference between typically developing siblings and ASD siblings, different family types, ethnicity, socioeconomic status, and geographic area). This is because the data can add to our previous understanding of the experiences and challenges as well as the continuous efforts taken by typically developing siblings to ASD individuals in

coping and adjustment. The psychosocial adjustment strategies chosen by these typically developing female adolescents are also unknown for their long-term effects, so a longitudinal study can be conducted in the future. In addition, triangulating the data by exploring their parents' perceptions of typically developing children's experiences growing up with ASD children and then comparing the responses between them may be beneficial. Further studies can also be focused on the additional forms of support that these typically developing adolescents need either from outside or within the family.

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