

EXPERIENCES OF SIBLINGS OF INDIVIDUALS WITH AUTISM SPECTRUM DISORDER OVER THE LIFE COURSE

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A sibling bond is one of the longest and strongest relationships that can be made in an individual's life which starts during the early stages. The purpose of this study was to explore the experiences of siblings of individuals with autism spectrum disorder (ASD), their transition to adulthood and the kind of support needed for them from the perspectives of the siblings to enhance their experiences. A collective case study was employed to address the research questions of this study, using semi-structured interviews with 5 siblings of individuals with ASD aged 24 to 29 years old. Findings were analysed through thematic analysis, where themes were derived and discussed about sibling experiences, choices and support.

Keywords: Autism Spectrum Disorder, siblings, life course, experiences

INTRODUCTION

Autism Spectrum Disorder (ASD) is a lifelong developmental disability characterised by challenges with social interactions, repetitive behaviours, and speech and nonverbal communication (Jones et al., 2019). The wellness of siblings is crucial in a household with an individual with ASD as it focuses on creating a pattern of behaviour that can improve the health of the individual as well as increase their life satisfaction (Swarbrick, 2006). Growing up in a household as a sibling of an individual with ASD can be a different experience as most of the attention is given towards the individual with ASD, focusing on developing an effective educational intervention for them, causing typically developing siblings to feel neglected (Tsao et al., 2012). In terms of social wellness, siblings of individuals with ASD experience overall adjustment problems, such as, lower levels of prosocial behaviours compared to typically developing siblings (Hastings, 2003). Besides that, another research on sibling adjustment showed that siblings of individuals with ASD are at a higher risk of developing internalising behaviour problems, such as, anxiety and depression (Ross & Cuskelly, 2006). These negative outcomes to their wellbeing could also be due to the lack of understanding about ASD and other factors, such as, attention from parents and family dynamics (Molinaro et al., 2018). In this study, experiences refer to the positive and negative events that make up the conscious past of an individual that revolves around emotional, social and mental, which justifies one's belief about the external world, while life course describes

the different developmental stages (i.e., childhood, adolescence, adulthood, and old age) that an individual goes through in their life (Ferraioli & Harris, 2009).

LITERATURE REVIEW

Sibling relationships in Asian culture, especially in a family with an individual with ASD might negatively impact on the typically developing sibling due to their lack of understanding of their sibling's diagnosis because of parents who avoid sharing about their child's differences (Bhattashali et al., 2018; Sage & Jegatheesan, 2012). This affects the siblings of individuals with ASD by creating a misunderstanding about their sibling's challenging behaviour, perceiving that their sibling just has bad behaviour (Ferraioli & Harris, 2009). Other than that, creating such pressure on these siblings of individuals with ASD to be an example to their sibling and sacrificing their personal needs to accommodate to their sibling with ASD can also create a drift in siblings' relationship (Sage & Jegatheesan, 2012).

Siblings of individuals with ASD during the early stages of life also described that they were affected by growing up with their sibling by feeling socially isolated and needing to change their behaviour to accommodate to their sibling's strange habits and aggressive behaviour (Petalas et al., 2012). These siblings were more likely to report having truly little time spent with their family because of the attention given to their siblings (Petalas et al., 2012). Parents who foster understanding of the sibling with ASD in the family created less negativity between the siblings (Hesse et al., 2013).

As this is an important stage in an individual's life where peer relationships start to form, if they had a difficult sibling relationship due to lack of proper social interactions or if these individuals had negative experiences with their siblings' behaviours, it may affect their peer relationship (Pilowsky et al., 2004). Moyson and Roeyers (2011) also discovered that the dilemma of not being able to talk about their sibling with ASD had also caused a lot of tension and stress in these siblings due to the restriction. Hence, because of the inability to explain or understand the disability of their sibling, some children were more likely to report less favourable attitudes towards their sibling. However, these negative responses are not because of the diagnosis of their sibling, but rather the lack of understanding on how to approach the challenges faced. As Pilowsky et al. (2004) explains clearly, as individuals grow older, their ability to empathise with their sibling increases, creating a stronger bond.

During the teenage years, adolescents can understand better about what ASD is and how their sibling with ASD is slightly different from them (Ferraioli & Harris, 2009). When adolescent siblings focus on tackling problem behaviours in their sibling with ASD, the interaction between the siblings were observed with fewer behavioural problems (Orsmond et al., 2009). This is shown to be more significant in larger families because the pressure on one child to tackle the challenges would be eliminated, as larger families would delegate responsibilities among each other, reducing the feeling of pressure while strengthening sibling relationships (Orsmond et al., 2009). Another study measuring adolescent sibling relationships, also claimed that the adolescents were engaging in fewer interactions with their siblings due to the difference in interests and preferences as well as lacking the willingness to share as how one would in a typical sibling relationship (Petalas et al., 2012). Siblings who acknowledge the maladaptive behaviour of their sibling with ASD, prioritise protecting their sibling from being bullied or teased (Ferraioli & Harris, 2009). These siblings who formed a

strong bond with their sibling with ASD, tend to appreciate their sibling despite the additional responsibility given (Braconnier et al., 2018; Tsai et al., 2018). They are also more thankful and are able to show empathy as they understand the nature of their sibling's behavioural difficulties. Such behaviour creates a positive experience for siblings as they can review their experiences from young and are able to view their sibling from a positive outlook (Petalas et al., 2009).

Adult sibling relationships with a sibling with ASD is similar to having a parent-like relationship due to the exposure to the real world, in terms of career, creating a family of their own as well as supporting their elderly parents (Ferraioli & Harris, 2009; McHale et al., 2016). With aging parents, siblings of individuals with ASD are assumed the role of taking care of their sibling with ASD, causing them to have difficulty in balancing their responsibilities (Tozer & Atkin, 2015). The siblings of individuals with ASD also experience the regret of never having the opportunity to experience a normal sibling relationship as they endure rejection from their peer groups or feel like their lives are constricted (Moss et al., 2019). Sibling relationships were capable of transforming into a caretaker role as they develop the sense of needing to take care of their sibling or deciding on their living arrangement in case of parental illness or death (Tomeny et al., 2017). Furthermore, some siblings of individuals with ASD did have a positive effect in their sibling relationship mainly when their sibling with ASD has a high level of independence and when they live closer to one another (Orsmond et al., 2009). Heller and Arnold (2010) have briefly explained that there are high chances of siblings being influenced by their sibling with ASD in choosing their romantic partner or career path. A study by Moss et al. (2019) also showed worries of siblings of individuals with ASD in terms of their future planning.

PURPOSE OF THE STUDY

This research aims to understand siblings' experiences of growing up with an individual with ASD throughout their life course. This study seeks to address the question 'What is the experience and impact of living with an individual with ASD from the perspective of siblings?' By exploring their experiences from childhood to adulthood, it is hoped that, by understanding the impacts individuals with ASD have on their siblings, in terms of their relationships with each other, transitioning into adulthood, and the influence behind their decision making, it may be useful to identify the types of support siblings may need from young (Mascha & Boucher, 2006).

METHODOLOGY

Research Design

A collective case study was conducted to address these research questions. A collective case study approach is considered significant for this study as it permits the examination of more than one case, contributing to better comprehending and theorising the data gathered. Moreover, it helps create a deeper understanding of the significance of the study through a more detailed description and explanation of their feelings and experiences of growing up with their siblings (Angell et al., 2012).

Sample of the Study

Participants included five siblings of individuals with ASD. The demographic information of the participants is presented below.

Table 1

Demographic Information of the Siblings and Individuals with ASD

Name	Gender	Age	Marital Status	Occupation	No. of siblings	Age of siblings with ASD
Spencer	F	25	In a relationship	Student	1	24
Emily	F	28	Single	Weight management and health consultant	4	31
Aria	F	28	Single	Engineer	4	26 & 21
Allison	F	29	Married	Human resource specialist	2	18
Hannah	F	24	Single	Student	4	30

Sampling Method

Participants were recruited using a purposive sampling method for this study because it was targeted to specific individuals who fit the criteria of the research and were willing to discuss the topic of interest as it was relevant to them and their experiences. The selection of participants was determined by the following criteria: participants have to be between the ages of 18 to 35 years old, they should have at least one sibling officially diagnosed with ASD, and they have to be a Malaysian citizen as these are the main focus of the current study.

Instrumentation

The main instrument that was used to gather data was semi-structured interview protocol. The participants were asked a series of open-ended questions that were structured based on the past literature and the objectives of this study. The open-ended questions that were included were divided into categories such as, demographical questions, their experiences during each stage of their lives, their transition phase (career choice, higher education, relationship and moving out), their overall wellbeing and support needed.

Procedure

The interview sessions took place for approximately 45 minutes to one hour. The data from each participant serves as triangulation to provide a more reliable finding.

Data Analysis

The data collected was analysed using thematic analysis which was conducted on the transcriptions of the interview sessions by summarising the key aspects from the interviews. This analysis is especially useful to identify meaning and shared experiences across the data collected from the different research participants as a way of understanding the commonalities as well as differences including generating unanticipated insights.

RESULTS

The findings show the involvement of siblings of individuals with ASD throughout their life course, namely from a very young age up till adulthood by growing up with an individual with ASD. There were a wide range of emotions experienced by the siblings.

Understanding ASD

During the early stages of their life, participants stated that they did not really understand their sibling's diagnosis, whereas one participant knew about ASD early on. Participants reported of approaching their siblings differently when communicating with them, whereas one participant reported no difference in the way she approached her siblings.

“I began to realise she absorbed things differently. So, I tend to slow down a bit when I speak to her (S1).”

Participants had similar responses stating that it is important to spread awareness by educating others with accurate information about ASD because people's perception of ASD is not similar to what the siblings experience while growing up with their sibling with ASD.

“When they make movies about ASD, they claim that autistic individuals are genius or something, which is kind of misleading. They don't actually know that it's really hard to live with them (S4).”

Participants in this study had a range of experiences that could have turned out differently if they were guided in the appropriate direction based on their needs.

“I would want to know about early intervention programmes and on ways to minimise his meltdowns because that was such a huge thing growing up. It would've been helpful if I had learned more about ASD to be more confident to help my brother (S2).”

This theme encapsulates the necessary support that siblings of individuals of ASD need for the betterment of the siblings.

Experience Responsibilities Early

Siblings shared their emotional response of having taken upon responsibilities that were given to them. They reported of having mixed emotions when they were asked about their roles and responsibilities in their household.

“I had a lot of responsibilities and making sure that he is well taken care of when my parents are not around (S1).”

“I had to mature faster because the role of taking care and providing by my parents, naturally fell upon me (S2).”

Given those responsibilities, two participants reported of feeling angry and unhappy to be put in a position that restricted them from being able to do the things they wanted to do but also felt guilty if they did not oblige. On the contrary, the other participants shared that they had accepted and that it was a part of their lives.

“You’re not exactly like, at an age where you want to be a parent. You just want to be free. I was just angry all the time but at the same time, I felt bad for not helping (S3).”

Being aware of having a huge responsibility in taking care of their siblings, the participants also reported their concerns about their siblings. Three participants had similar worries about their siblings’ present and future.

“When he goes out to the public and if he does something that is not really understood by others, he might be getting into trouble with the authorities or with the public. They don’t know what is danger (S4).”

They emphasised on the safety of their siblings, expressing their worries of people hurting their sibling or the other way around.

Choice of Career

In terms of the career and education path that was taken by the siblings, the choice of career was influenced by their sibling with ASD.

“I wanted to look for a job that gives a steady income so that I can support myself as well as my siblings because I know they can never stand on their own two feet, and I would have to continuously support them their whole lives (S1).”

“If it weren’t for my brother, I wouldn’t be like this. I wouldn’t want to do this. I actually wanted to do law (S2).”

Participants agreed that they were influenced by their sibling with ASD. Two participants were influenced directly, where they chose a path related to psychology in order to help their siblings, while one participant was focused on sufficient earnings to be able to support their siblings for the rest of their lives.

Choice of Life Partner

This theme highlights the importance of acceptance of their partner toward their sibling with ASD. This was evident when siblings were asked about the qualities and importance of having a partner that accepts their siblings’ differences, all five participants agreed that it is of

utmost importance when choosing a partner. Three participants added that, this was because they will eventually be the main caregiver of their siblings.

“I would say pretty important because my parents in the future, won’t be here anymore. So definitely having a relationship with someone who understands them, it’s important (S2)”

The participants also spoke about the importance of an understanding, non-judgemental and open-minded person towards their sibling’s differences as qualities when choosing a partner.

DISCUSSION

The findings of this study indicated limited understanding of sibling with ASD’s differences while they were growing up. This study also found a positive outcome that siblings grew up to be more patient and empathetic towards others which were consistent among other findings in Chu et al. (2021). Thus, parents assisting the siblings in coping with having a sibling with ASD by catering to their needs, such as being emotionally available to them, spending time specifically with them and prompting the engagement between the siblings can also smoothen the process of development and enhance a more positive experience for their children (Sage & Jegatheesan, 2010; Schmeer et al., 2021). Donaldson (2015) have stressed the importance of educating siblings of individuals with ASD on ways to communicate with and understand their sibling better from a very young age, which insinuates the significance of an early diagnosis for the young children with ASD. With that, early intervention programmes are equally crucial for the involvement of the individuals with ASD and their siblings to help strengthen their sibling interactions and enhance the functioning of the family as a whole (Donaldson, 2015; Tsao et al., 2012).

This study found that the siblings’ life choices were influenced by their sibling with ASD as career choice was related to disability and they were focused on having a stable job and a steady income that is sufficient to provide for themselves and their sibling with ASD. This finding is consistent with past studies that siblings of individuals with ASD tend to be influenced by their sibling when making important life choices, such as career path or higher education (Heller & Arnold, 2010; Krauss et al., 2005; Martins, 2007). It has been an unspoken rule in some families with or without an individual with ASD, whereby older siblings take on the caretaker role when their parents are not able to provide the necessary support needed for their children (McHale et al., 2016; Macks & Reeve, 2007). The findings of this study agree with past study by Moss et al. (2019), that siblings generally feel morally obligated to support their sibling, especially the ones with a disability, after their parents pass on. This, however, can have an impact on the relationship between the siblings as it is an added responsibility on them, which should be explored in the future. Wellbeing of siblings are important (Green, 2013). Therefore, it is important for parents to make necessary arrangements for their child with ASD early on, to relieve the stress in their typically developing child. Smith and Elder (2010) advises that, reducing their burden can pave the way for siblings of individuals with ASD to choose their path of interest without any restrictions.

Siblings in this study who are very clear about taking care of their sibling with ASD for the rest of their lives had a requirement when choosing a romantic partner which is acceptance of their sibling with ASD, because, as the participants in this study described, their sibling with ASD is their priority. Apart from career paths and higher education being part of the transition to adulthood, a romantic relationship or marriage is also a part of the life cycle of many adults (Ferraioli & Harris, 2009). Generally, many individuals that are close to their family, tend to give importance to their potential partner being able to get along well with their family members (Conger & Little, 2010). There is no past research that have emphasised on the siblings' importance in choosing a partner or spouse based on their acceptance of their sibling with ASD, even though it is a significant factor in this study that was considered to be a part of the siblings' transition to adulthood. As a relationship is a two-way street, it is important to acknowledge that individuals with ASD are also required to adapt to the change in their sibling's life which is a challenge for them (Tozer & Atkin, 2015).

CONCLUSION

This study has helped in the understanding of some siblings' perspective, be it, choosing their higher education, career, or life partner, revolves around accommodating to the needs of their siblings with ASD. A number of limitations were identified when interpreting the results of this study. One of the main limitations is, the small sample size due to limited time, which had reduced the generalisability of the results. All the participants interviewed were female siblings, thus, it lacked in gathering information from the perspectives of the male siblings. Hence, future research could recruit a larger number of participants, while giving importance to having male and female participants to provide data that would contribute to a stronger observation.

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