Challenges in nurturing HFASD teens: Emotional crises and expectations of mothers in Malaysia

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Abstract: The transition to young adulthood brings distinctive challenges for high-functioning autism spectrum disorder (HFASD) children and their families, especially post-formal education. This qualitative, case study research aims to explore hurdles faced by mothers navigating HFASD adolescents. The result shows that financial strain, stigma, and loneliness loom large, compounded by emotional crises tied to uncertainty and stress about their children's future. Mothers advocate for multiple work opportunities and independence, underscoring a notable gap between HFASD teens’ needs, available services, and community resources. The study enlightened mothers and inspired proactive measures, emphasizing the imperative for a collective, interdisciplinary effort to align services comprehensively—addressing residential, employment, and social aspects—to enhance the quality of life for HFASD individuals.

Keywords: adolescents; high-functioning autism spectrum disorder; mothers; nurturing; teenager

Abstrak: Transisi ke masa dewasa muda membawa tantangan tersendiri bagi anak-anak dengan Gangguan Spektrum Autisme Fungsi Tinggi (HFASD) dan keluarganya, terutama pendidikan pasca-formal. Tujuan penelitian studi kasus kualitatif ini menyoroti rintangan yang dihadapi oleh para ibu yang menghadapi remaja HFASD. Hasil penelitian menunjukkan ketegangan finansial, stigma, dan kesepian semakin besar, ditambah dengan krisis emosional yang terkait dengan ketidakpastian dan tekanan mengenai masa depan anak-anak mereka. Para ibu menganjurkan beragam kesempatan kerja dan kemandirian, yang menggarisbawahi kesenjangan besar antara kebutuhan remaja HFASD, layanan yang tersedia, dan sumber daya komunitas. Penelitian ini mencerahkan para ibu dan menginspirasi langkah-langkah proaktif, menekankan pentingnya upaya kolektif dan interdisipliner untuk menyalurkan layanan secara komprehensif—menangani aspek perumahan, pekerjaan, dan sosial—untuk meningkatkan kualitas hidup individu HFASD.

Kata Kunci: remaja; gangguan spektrum autisme berfungsi tinggi; ibu; pengasuhan; teenager

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Introduction

The prevalence of autism spectrum disorder (ASD) has risen dramatically in recent decades, lending credence to the claim of an autism epidemic (Chiarotti & Venerosi, 2020; Eric, 2020). Transitioning from school to adulthood is a difficult time for many adolescents with disabilities and their families (Cheak-Zamora et al., 2015; Leonard et al., 2016). This transition is especially challenging for ASD adolescents seeking postsecondary and employment opportunities. Whittenburg et al. (2020) emphasized that “young adults with postsecondary educational experiences increased rates of employment, earned greater weekly wages, and worked more weekly hours than individuals with ASD with less education” (p. 5). Those with ASD repeatedly face significant challenges to obtaining and securing meaningful employment (Ghuzal & Nordin, 2023). However, despite increased stress and uncertainties, families with ASD adolescents attract less support from formal education structures and have less access to appropriate resources needed by ASD sufferers and their family (Papoudi et al., 2021).

The transition of adolescents with autism into adulthood is a challenging and stressful time for parents trying to prepare them for work life (Meiring et al., 2016). Adolescence, as a transitional period, is marked by a rapid and dramatic intra-individual change in biology, cognition, emotion, and interpersonal relationships, as well as equally marked transformations in the major contexts in which children spend their time: the family, their peer groups, and school (Osher et al., 2020). Youths are experiencing a period of transition into increasingly independent roles and identities along nonlinear and non-uniform paths (Worth, 2009). This period is even more complex with the presence of a developmental disability such as ASD (Biggs & Carter, 2016). The transition to adulthood is a significant time for youths on the autism spectrum.

Nurturing an adolescent into a young adult is particularly stressful for many parents, as they encounter challenges such as accessing services; difficulties in adapting to transition changes and managing multiple responsibilities; and vocation and higher education challenges (Aun et al., 2022; First et al., 2016). Most parents are concerned about their child’s level of independence and how they will cope when they can no longer care for them (Yaacob et al., 2021). Parents of youths with HFASD and their health professionals face difficulties during the transition process of HFASD teens. These professionals have difficulties designing and maintaining appropriate behavior modification programs due to limited research and access to information (Boyle & Arnedillo-Sanchez, 2022; Malik-Soni et al., 2022).

Parents have emphasized the need to integrate healthcare and educational services to create holistic, long-term care for children with ASD. Furthermore, the availability of such services and/or their cost are burdens to parents if they are not publicly provided or covered by insurance (Helkkula et al., 2020). Usually, health professionals are responsible for assembling a support group to prepare and support an ASD individual. However, in the years following formal education, the parents must also create a support group for ongoing learning, living and working opportunities. As a result of the difficulties experienced by parents and health professionals, daily living skills decline in adults with ASD, specifically after leaving school, which highlights the importance of such skills in normative adult outcomes (Clarke et al., 2021). However, there is limited research that explores the challenges faced by autistic adolescents and the support they require (Chu et al., 2020).
This study was guided by three research questions: 1) What challenges do mothers with HFASD teens face during this transition period? 2) What are the emotional crises faced in nurturing HFASD teens? 3) What are the expectations held by mothers of HFASD teens when preparing their children for the transition towards adulthood?

Methods

A qualitative method with a case study approach was used. A semi-structured interview technique was employed to explore informants’ perspectives of the challenges in nurturing adolescents with HFASD. A qualitative approach was identified as being the most appropriate as the study focuses on exploring the experiences and realities of the participants’ perspectives (Willis et al., 2016). The main research question was: what did the mothers with HFASD challenge when nurturing an adolescent with HFASD?

The research was conducted in the participants’ houses. Home-based interviews were selected for the study to create a distraction-free environment with minimal interruptions, in which the informants would feel free to talk about their experiences. The study population comprised mothers of clinically diagnosed high-functioning autistic adolescents aged between 12 and 24. Although the quantitative research approach encourages large sample sizes to ensure the generalizability of findings for better validity and quality, the sampling strategy for qualitative research is more concerned with the relevance and adequacy of the sample (Vasileiou et al., 2018).

The sample comprised seven informants (two working mothers and five full-time housewives). No male parents were represented, partly as a result of the field being feminized, with the participation of more females being in line with stereotypical roles. The male/female participant ratio creates an interesting bias concerning the parents. As evident in Rankin et al. (2019), fathers may be less involved than mothers in childrearing practices; having both parents highly involved may improve the overall family system across many levels. The informants’ ages ranged from 40 to 55. No further sociodemographic information was collected.

The informants’ ages ranged from 40 to 55. All were chosen based on their experience of handling young people with HFASD. Regarding ethnicity, all seven informants were Malay. Their characteristics are presented in Table 1.

<table>
<thead>
<tr>
<th>Parent’s ID</th>
<th>Age</th>
<th>Employment Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>R1</td>
<td>50</td>
<td>Working</td>
</tr>
<tr>
<td>R2</td>
<td>41</td>
<td>Housewife</td>
</tr>
<tr>
<td>R3</td>
<td>44</td>
<td>Working</td>
</tr>
<tr>
<td>R4</td>
<td>55</td>
<td>Housewife</td>
</tr>
<tr>
<td>R5</td>
<td>45</td>
<td>Working</td>
</tr>
<tr>
<td>R6</td>
<td>48</td>
<td>Working</td>
</tr>
<tr>
<td>R7</td>
<td>50</td>
<td>Working</td>
</tr>
</tbody>
</table>

Table 1
Sample Characteristics
The inclusion criteria were as follows:

i. Mothers with at least one clinically diagnosed high-functioning autistic child.

ii. Mothers willing to participate.

iii. Mothers having an HFASD child aged between 12 and 24.

The exclusion criteria were:

i. Mothers not willing to participate voluntarily.

ii. Mothers with mental issues and who were unable to communicate well.

To explore the informants' experiences, the researchers developed and adopted in-depth interview guidelines based on a review of related literature and consultation with subject experts. The guidelines consisted of eight open-ended questions designed to elicit perceptions and experiences from the seven mothers with children with HFASD (see Table 2).

To enhance the data quality, the interviews were conducted in simple Malay language, and jargon was avoided where possible. The researchers observed verbal and nonverbal expressions during the interview, used two digital recorders, rechecking their functioning to ensure they recorded the interviews successfully. To ensure credibility or confidence in the truth of the data, the researchers conducted the in-depth interviews themselves and transcribed the information obtained, as well as making field notes. The researchers also read the transcriptions several times to get a sense of the whole and reviewed the field notes and digital recordings. To maintain the dependability or stability of the data, they were collected up to saturation point.

The Research Ethics Committee of Universiti Kebangsaan Malaysia gave ethics approval. After obtaining permission, the researchers contacted mothers who met the study criteria individually to ensure their consent to participation and to explain the study objectives. The researchers determined the dates, times, and places for the interviews according to the convenience of the informants. They also sent a reminder message on the day of the interview.

Table 2

In-depth Interview Guidelines

<table>
<thead>
<tr>
<th>No</th>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Could you please tell me about your child’s early life with ASD?</td>
</tr>
<tr>
<td>2</td>
<td>Tell me about the milestones in the diagnosis development: e.g., when were the first concerns about abnormalities in your child? How old was s/he? Where did you go for diagnosis? How was your experience? How did it affect you and your family members after the ASD diagnosis?</td>
</tr>
<tr>
<td>3</td>
<td>How did the diagnosis of ASD affect you? Your husband? Your family (Mum &amp; Dad)?</td>
</tr>
<tr>
<td>4</td>
<td>Tell me about your experience with special education services.</td>
</tr>
<tr>
<td>5</td>
<td>Intervention: was there any intervention? Was there any change in your child’s condition? How did they change?</td>
</tr>
<tr>
<td>6</td>
<td>Tell me about you as a mother of an ASD child. Was there any point in life when you felt like giving up? Were you frustrated? Were you angry?</td>
</tr>
<tr>
<td>7</td>
<td>Tell me about your experiences as a mother of a child with ASD in Malaysian culture and the relationship between ASD and society.</td>
</tr>
<tr>
<td>8</td>
<td>Can I finally ask you if you think there is any other aspect of your experience with ASD you would like to add?</td>
</tr>
</tbody>
</table>
Written informed consent, special permission for digital recording were obtained from each informant before the interviews. The participants were interviewed in a quiet place in their homes using the interview guidelines through a face-to-face interview method in simple Malay. Initially, general questions were posed to encourage the mothers to express their feelings and experiences of raising their children with autism. Each interview lasted for 45–60 minutes. The verbal and nonverbal expressions of the mothers were observed and noted during the interviews. Each in-depth interview was recorded on a digital voice recorder to obtain an accurate account of the mother’s words.

The data from the interview sessions were then reviewed and transcribed verbatim by the researchers. Open coding was initially used to identify broad concepts in the data. Subsequently, analytic coding was employed to identify themes and explore the informants’ experiences. Such coding was also used to examine and develop categories and concepts from the transcribed data. Selective coding was then performed to investigate each conceptual category thoroughly. Finally, the researchers analyzed all the codes and themes and collapsed them into conceptual categories. The validity of the results was then confirmed through research team checking. Finally, a thematic table was constructed to confirm that data saturation had been achieved.

Results

During the interviews, the informants discussed challenges in nurturing with adolescent HFASD. The themes that emerged from the interview responses related to the participants’ perspectives on challenge experienced. The second theme showed the emotional crisis, while the third concerned the expectations of mothers for their HFASD teens (see Figure 1 and Table 3).

**Figure 1**

*Themes and Subthemes*
Challenges Experienced

Financial Strain

Finance is considered to be a major concern for mothers caring for a child with disabilities in Malaysia. Some informants (n=3) reported financial difficulties due to intense and costly interventions, speech therapy, and private special education. Moreover, they reported that they could not afford the costly therapy. Some said they had to end their child’s speech therapy and medication due to financial difficulties. Informants stated that:

“I have to send him to Altuz Academy just for his dyslexia. It does not include any life skills syllabus. For his life-skills, I have to send him to NASOM. Sending him to different centers is costly and time consuming.” R1

“We used to send him to this one center specifically for early intervention for autism. But the center is only available in the urban area which is Ipoh, so I have to travel from here to Ipoh and it is costly. Plus, I have to pay RM180 per session.” R7

Stigma

The informants experienced stigma, with five out of the seven reporting that their ASD children were treated differently by society. Informants also felt embarrassed about their child’s behavior or ashamed about their condition. They reported that they had prevented their children from playing with their relatives and were worried they would behave inappropriately. As ASD is not a visible physical disability, most people condemn it as ‘odd’ behavior and attribute everything to bad parenting or the mother's inability to control their children. Consequently, the informants reported they were forced to hide with their autistic child at home and felt socially isolated. They explained:

“I used to send him to this one kindergarten, and the principal told me that I failed to raise him well because my son cannot follow the instructions and say bad words to the other kids. I felt so useless at that moment.” R1

“I prevent my son from joining any social activity such as “kenduri” (social gathering) just to avoid crowds. I know my son will get tantrums. People will just look at him in such a weird way.” R4

“At one time when my family organized a family gathering, I asked my daughter to play with her brother, just to ensure that my son wouldn’t feel isolated because I’m scared he’ll havetantrums.” R5

“Our neighbor used to restrict other kids from playing with my son. She told others that my son was very odd.” R3

Emotional Crises

Loneliness

Three informants (42%) talked about feelings of isolation and lack of support when managing their child’s mental health condition, evoking a sense of loneliness. One informant, reflecting on her child’s suicidal ideation, felt unable to handle the situation alone:

“He used to take out the knife in the kitchen. He asked me whether I loved him or I loved my daughter. He provoked me. I just can’t bear it alone.” R3

“I used to feel that lonely that I only needed my son only in my life. I still breastfed him until he was at primary school. But I don't mind spending my time only with him.” R1

R2 described feeling lost when left to research strategies and support on the internet. Taking responsibility and independently finding strategies to manage life also resonated with R2:

“I always look up any opportunities for him by myself. I used to send him to a swimming class. But sometimes I just don’t know how I can find something to do for him. I just couldn’t find anything suitable for him.” R2

Uncertainty

The findings indicate a general feeling of uncertainty about the future, with 42% of the
informants thinking about the transition of their HFASD adolescent to adulthood. The transition of young adults with HFASD to independent living is expected to happen around the time they finish their studies or when the educational support available ends. R4, a 55-year-old housewife, stated that parental uncertainty and worries about their children’s potential to move on to live independently were evident.

“I always come to check my son. For example, I need to remind him to pray. I don’t think he can live independently without me. But I did try to find a suitable class or courses for him to join after he finishes school.” R4

“My son still breastfed until he was seven. The attachment that we built makes me think that I can’t live without my son even though he’s getting older.” R1

“I don’t know where to put him after he finishes school. I don’t even know the placements that are suitable for him.” R5

Stress

In defining crises, many informants referred to their emotional crisis related to current life challenges, and the stress that emerged from their responses to these challenges. Regarding extreme stress three informants described factors that resulted in high stress levels, the intensity of these negative emotions, and how they related to other aspects of their daily lives. Some described this experience as being stressful, especially during meltdowns:

“Sometimes I feel so stressed when he has tantrums. He’ll just knock down he door until I can’t remember how many times I’ve changed the door.” R7

“We used to call our neighbor to help us make him calm again. We called him “Atok”. So, when he has a tantrum we force him to call Atok. I just get so helpless and I decide to ask for help from my neighbor.” R4

“I get very stressed if no one can help me to take care of him. I just can’t let him stay alone even though he convinced me that he can.” R1

Expectations

Education Reforms

Most informants shared the opinion that daily living skills are more important than basic literacy knowledge. The results indicate a general feeling of fear and uncertainty when they thought about the education of their adolescents with HFASD and their future.

The informants shared their views on how education in Malaysia only focuses on the achievement of the cumulative grade, which causes HFASD students to be rejected by mainstream schools, even though they have the ability to study. This situation has caused the informants to have similar expectations regarding education and employment for their children.

“You know how schools only focus on how many A’s. They refuse to take a risk by accepting an ASD student. While in Singapore they have a school that only focuses on ASD education. It’s a good example you know.” R7

“I still remember when I received a call from the principal saying that my kid refused to go to class. They told me straight to my face that they could not cater for a special child. I asked my son what he did and he told me that he was scared because of the teacher. Not because he didn’t want to study.” R1

“After 18, my son has been sent to PDK. Because that’s the limit for the school for special kids. And then they asked me to send him to PDK. But then, the PDK catered for a variety of disabilities. And because my son is high-functioning he is a very tidy person. Then he refused to mingle with other kids and he refused to go there again. I think in Malaysia the government should provide specific schools for high-functioning ASD children.” R4

Opportunities

The informants were asked to reflect on the possibilities of adolescents with autism leaving home and gaining employment after having left
The responses were categorized into three areas of interest: their thoughts on independent living, the working pace, and their perspectives on employment possibilities.

"My son is working with his dad at an interior design company. But my husband only lets him do the clerical stuff as he thinks he is not capable enough to do other things, even though my child is good at closet installation. I think my son can actually do the work. But his pace is slow." R5

"My son used to tell me that he loves history. But special education in Malaysia does not provide subjects like History at the school level." R6

The decision regarding alternative residential options appears to be one of great difficulty. The informants expressed fear, concern, and uncertainty about available support services. Although they highlighted the benefits of moving away from home, many obstacles were perceived to impede the possibility, as evidenced below:

"Sometimes I think it's a brilliant idea for them to move out; one of my main concerns is care and what happens when I'm not there to protect him." R1

Discussion

In this qualitative study, we have used thematic analysis to identify challenges experienced by mothers in nurturing HFASD teens. In this section, the discussion deals with the findings, conclusions, and recommendations. The findings are discussed in light of the established facts and published studies related to the challenges and experiences of mothers raising children with HFASD. The study’s objectives were to explore the daily challenges of mothers raising children with HFASD. Seven mothers’ experiences with HFASD children were explored through in-depth interviews, and their experiences were interpreted as reflecting their crises and expectations of overcoming their situation.

"I know there is center for skills training. But since they have to stay at a hostel, I don't think my child could go through living there. He'll have tantrums if there is no internet connection." R4

Independent Living

Independent living is one of the three areas of expectation for the informants. It is associated with the acquisition of various domains of independence; individuals who live independently are more likely to run a household, form relationships, and have a stable job status. Some of the mothers stated:

"I wish my son could live independently. I worry when I think of him living alone if I have already gone (passed away)." R5

"My son can manage himself. He can fold and wash the clothes by himself. Sometimes he can cook a simple dish for himself. So, I hope he can survive without me or other family members." R2

"He is currently working with his dad in an interior design business. But I wish he could get a job suitable for his passion. Sometimes I feel sorry for him." R3

The first major study theme concerned the challenges experienced while nurturing HFASD teens. These included financial strain and stigma. The informants said they experienced financial strain from the overall care cost and current and future expenses. In the sample, all the informants were mothers who were the primary caregivers and who perceived their central role as providing and coordinating care for their child’s education and caregiving demands. The findings support those of previous studies, which found an increased financial burden associated with raising a child with autism (Papadopoulos, 2021; Sim et al., 2018). Raising an autistic child requires a significant amount of parental time (Singh, 2016), physical energy (Ayvazoglu et al., 2015), emotional strength (Acharya & Sharma, 2021; Razuan et al.,
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2023), and financial support from parents (Ayvazoglu et al., 2015). Thee findings are also consistent with previous research, which indicates that having a child with autism is associated with a decrease in family income (Ou et al., 2015). According to Stoner and Stoner (2016), childcare concerns affect the employment decisions of parents and cause career disruption. This scenario implies the necessity of support and education for this often-overlooked group of carers (Hill et al., 2015).

Stigma plays a significant role in making life difficult for the parents/caregivers of HFASD children. The informants worried about being treated differently, were ashamed of or embarrassed by their child’s condition, or even tried to keep their child’s condition a secret. This theme concerns the mothers’ social burden concerning the stigma and the overall impact of HFASD on their social life. The informants in this study reported a significant social impact, including increased isolation from friends and extended family, due to greater childcare responsibilities and concerns about their child’s potential behavioral outbursts in public, which is consistent with previous research (Kinnear et al., 2016). The informants also expressed concerns regarding the stigma of autism, which reflect the social stereotypes and discrimination in Malaysian society. In our study, community members were shown to frequently reject and isolate the informants. This rejection included exclusion from school activities and derogatory remarks by community members, which caused parents to limit their outside activities, which most found distressing.

The informants expressed feelings of stress and uncertainty, that all their work would come to nothing after formal schooling ended. Other feelings experienced included unpreparedness and helplessness. These findings correlate with the literature, in that unique stressors are faced alongside concerns about support opportunities (Das et al., 2017; McConachie et al., 2018; Padden & James, 2017). Emotional challenges appear to be the most challenging for parents (Yalim & Mohamed, 2023). Hence, parents require support from various entities in order to navigate them successfully (Seeridaram & Rashid, 2023). Health professionals have referred to more positive feelings alongside hope and optimism in seeing adolescents mature. Büyükşahin Çevik and Ali Yıldız (2017) state that for adolescents, receiving support from parents, teachers and peers in problematic academic or social relationships may improve their positivity, as it can help them develop positive considerations of their lives, be optimistic about the future, and be able to solve their problems.

The informants stated they did not have a plan for their children with HFASD post-school. Nevertheless, they indicated that they had been preparing the adolescents during puberty. This support included the process of explaining religious obligations when they reach puberty. Some planned to encourage the schools to keep their child with HFASD for as long as possible, indicating that no transition plans existed. Although there is a growing awareness of the needs and support for adolescents and young adults in international publications (Hillier et al., 2019; Lord et al., 2020; Mace & Beckert, 2017; Płatos & Písula, 2019), there is limited accessible information and service facilities in Malaysia, especially regarding HFASD. Families, schools and services require assistance in transferring knowledge into actionable strategies for these unique individuals. Adolescents with ASD appear to receive little support in Malaysia. Nazri and Ismail (2016) conducted a study to determine education facilities for ASD and found that building construction and environmental services had a significant influence on children with autism, especially in learning.
The shift in emphasis from academic to functional skills taught in school and at home appears to be consistent with previous research (Ivy & Schreck, 2016; Wong et al., 2021), and is thought to increase the likelihood of a successful transition. In this study, learners with HFASD were perceived to require a different curriculum due to their different learning style, one with more relevant, individual, and meaningful content, such as communication, independence, coping with change, vocational skills, and community engagement. Functional learning, coping in society and work contexts, emotional management, leisure possibilities, and the characteristics of the triad of impairments were expressed as skills required by individuals with HFASD. However, Tso and Strnadová (2017) indicate that transitioning from primary to high school is a period of anxiety with reduced support for students with ASD and their families. Transition-focused education needs to take place before leaving school and should be a collaborative and active process (Strnadová et al., 2016).

The decision about post-school opportunities seems to be approached with great difficulty. Two informants expressed fear, concern, and uncertainty about available support services. Although they highlighted the benefits of moving out of home after secondary school, many obstacles hindered this possibility. Previous studies have shown that increased independence from the family is viewed as beneficial for the individual’s and family’s quality of life (Bishop-Fitzpatrick et al., 2016). Some evidence highlights that many autistic adults or their families desire independent living, participation in education or employment, and intimacy and social relationships.

However, they often lack the skills or resources to achieve these outcomes successfully. Therefore, the decision and process are difficult, and often delayed (Bennett et al., 2018; Gaona et al., 2019). Despite some evidence that the advantages of placement in an institution include reduced stress from constant caregiving, some researchers have noted that for autistic individuals, these experiences might be particularly traumatic due to the challenges of predicting the behavior of others (Kemps et al., 2022). As a result, theoretical understanding of the benefits is hampered by family members’ fear and uncertainty. Increased awareness of the positive impact on the family is needed, alongside a wide range of possibilities for residential provision.

Black et al. (2019) suggest that removing environmental barriers and enhancing environmental facilitators may assist in remediating ASD-related difficulties in the workplace. Pillay et al. (2022) also suggest the need for educational and socially inclusive interventions to support heterogeneity in individual, social, communication, and behavioral challenges in employment for autistic young adults. In addition, Lindsay et al. (2021) propose that employers need to be understanding towards ASD workers. However, the number of autistic condition disclosure and being given workplace facilities varied considerably. The benefits of disclosing the autistic condition in the workplace included greater acceptance and inclusion, receiving accommodation, and increasing awareness about autism. Support is required in modifying tasks and environments, aiding communication, and teaching appropriate behavior. The informants agreed that adolescents with autism would not cope within a fast-paced environment, or in demanding, high-pressure positions, but would engage with tasks with increased ease and precision if not reliant on social interaction. This study should have an impact in Malaysia in terms of improvement in the education of medical
professionals, teachers, family members, and the community regarding HFASD, which is urgently needed to improve the overall understanding and care of individuals with HFASD. Furthermore, there also needs to be coordination of care between all the different parties involved in managing individuals with HFASD. Finally, a better financial, social and psychological support structure is also required to ensure that parents have the necessary assistance. Based on these findings, in the future it is important to develop modules to train mothers and caregivers to overcome challenges and emotional crises. This could be in a virtual reality form, in line with today's technological developments.

**Conclusion**

Nurturing autistic children into adulthood is a challenging and stressful time for mothers involved in the process, owing to fear and uncertainty about what the future holds and a sense of not having done enough to support them due to a scarcity of resources and support. The study findings are believed to be relevant and original in the Malaysian context because they provide insights into the challenges faced by autistic adolescents and the support they require. Given the continued rise in autism and the average life expectancy of sufferers, greater awareness of the potential societal consequences is required.

**Acknowledgment**

Special thanks to the Ministry of Higher Education, Malaysia, for funding this research (TRGS/1/2020/UKM/02/6/3).

**Author Contribution Statement**

Shima Dyana Mohd Fazree: Conceptualization; Formal Analysis; Writing Original Draft & Writing
Nur Saadah Mohamad Aun: Conceptualization; Writing Original Draft; Review & Editing; Data Curation. Siti Marziah Zakaria: Formal Analysis, Review & Editing. Abdul Rahman Ahmad Badayai: Conceptualization & Methodology. Tuti Iryani Mohd Daud: Resources; Review & Editing. Idayu Badilla Idris: Conceptualization; Methodology & Formal Analysis.

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