

A Narrative Inquiry of Malaysian Parents' and Caregivers' Experiences in Detecting Autism and Providing Interventions

Badariah Sani¹, Muhmad Noor Wan Chik¹, Nor Nadia Raslee², Mastura Badzis³

¹Academy of Language Studies, Universiti Teknologi MARA, 32610 Seri Iskandar, Perak, Malaysia

²Academy of Language Studies, Universiti Teknologi MARA, 35400 Tapah, Perak, Malaysia

³Department of Educational Psychology and Counseling, Kuylliyah of Education, International Islamic University Malaysia, 50728 Kuala Lumpur, Malaysia

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ABSTRACT

There is a lack of knowledge among Malaysian parents in detecting signs of autism in their children. This situation could lead to late detection and intervention. Children's condition would be harder to improve and this would affect the parents' and caregivers' well-being. This study explored parents and caregivers' experiences in recognizing signs of autism and providing intervention for their autistic children at home. The study used a qualitative research approach with a narrative inquiry method. A total of eleven respondents were interviewed. In-depth interviews and four non-participant observations were carried out. The study found ten signs of autism that parents and caregivers had noticed in their children's behaviour. Children's lack of speech or delay in speaking was common and the most noticeable sign for all eleven respondents. The respondents admitted having no knowledge and awareness about autism or signs of autism at the beginning. The periods before and after the detection of autism were difficult periods and many respondents had expressed feelings of sadness, worried as well as frustration. The severity of autism played an important role in alerting parents or caregivers to speed up the process of investigation. Respondents had used many types of interventions for their children and these included behavioural, developmental, family based, therapy based, alternative interventions and medications. Islamic practices were also used by Muslim respondents. The findings gave added knowledge and information on Malaysian parental concerns about signs of autism and provide suggested interventions for parents in caring for their autistic child.

KEYWORDS: Parental Concerns, Signs of Autism, Interventions.

INTRODUCTION

Autism is a brain disorder that affects an individual's ability to learn, communicate, socialise and develop normally and results in having repetitive behaviours and narrow interests (Jasni et al., 2011). According to UNICEF Malaysia (2014), children with autism have learning difficulties and their developments are not the same as normal children. Howlin (1999) described children with autism as more physically dependent on their parents, and people looking at the children's behaviours would think that they were misbehaving or had poor discipline rather than think that they were mentally disabled. There are many signs of autism in children but are parents and caregivers able to recognise the signs of autism in their children? According to Jasni et al. (2011), many parents and caregivers in Malaysia do not have the knowledge about autism. Amar (2008) noted that there were still some parents who did not detect their children's developmental problems early and did not know what kind of disability their children were having and thus, they did not start interventions early to improve their children's condition. He noted that parents would not bring their children to be checked by health professionals to determine the children's condition and therefore, lack of parental experiences in recognising signs of autism could lead to late detection and intervention. Parental concerns are important data and health professionals must assist parents by providing enough information for them to cater for their children. If not, it would be harder to improve the children's condition (Amar, 2008).

Detection of autism as well as other disabilities in Malaysia was mainly left to the Ministry of Health and the Ministry of Education. From parents and caregivers initial concerns about their children's behaviours, health professionals started the screening process. Amar (2008) noted that from 2005 to 2006, the Ministry of Health through its Health Development Division had conducted a pilot programme to screen disabilities among young children at the early age of 5 months, 12 months, 18 months and 4 years. In 2011, the Ministry of Health had started the Health Record for Baby and Child from infant to 6 years and in 2012, the health monitoring programme had

Corresponding Author: Badariah Sani, Academy of Language Studies, Universiti Teknologi MARA, 32610 Seri Iskandar, Perak, Malaysia, E-mail: badariah@perak.uitm.edu.my

extended to the national level whereby this programme had begun screening children at the prenatal stage to 6 years old. Early detection efforts to detect autism as well as ADHD and other learning disorders among children had utilised Modified Checklist for Autism or the M-CHAT to screen young children. Earlier, Amar (2008) noted that two other screening tools, which included the Denver-II Developmental Screening Test and the Schedule of Growing Scale II (SGS) were also used to detect developmental problems in children. However, he mentioned that these tools lack sensitivity and specificity because instead of screening for children's disability, health professionals used it to monitor the children's progress.

Next, do parents and caregivers know how to provide interventions for their children as well as manage their lives with the children with autism at home? In the article written by Amar (2008), he commented that many studies have concentrated mainly on autism centres and hospital interventions which use expensive tools and interventions. Therefore, these methods or interventions were not suitable or appropriate for Malaysian parents and caregivers to conduct intervention at their own home simply because they cannot afford to buy all the expensive tools or instrument. He mentioned that most of the autism centres and services provided in Malaysia have adopted models from industrialised countries and this may not be suitable or applicable to meet the vast needs of autistic children in Malaysia. He commented that most of the service providers for autism are currently fragmented, hospital based, inadequate and many parents have opted out from using these services. Similarly, Malaysian Psychiatric Association (2010) had emphasised that there is a need to find the best practices to manage children with autism within a local context and not merely adopting practices from established nations. Thus, with the problems faced by parents and caregivers, there is a need to have practical interventions to fit the needs of children with autism in Malaysia.

The research objectives are formulated to;

1. examine the experiences of parents and caregivers in detecting signs of autism in their children
2. study parents' and caregivers' experiences in providing interventions for their children with autism

Detection of autism starts from the child's parents or caregivers taking actions to enquire about the child's condition. They are worried that something is not normal in their children's behaviour or development and they observe the signs. Ozonoff *et al.* (2009) stated that parents' concerns about their children's development are useful to identify the need for screening process.

In Malaysia, a study done by Ting and Chuah (2010) on parents' recognition of autistic behaviours reported that parents had noticed the behavioural differences of their children but did not know that it was symptoms of autism. Like other characteristics of autism, the children had stereotyped behaviours as well as being hypersensitive towards sound and also sleep problems but it was the loss of speech that parents notice in their children that got them thinking that something was not right with their children. 12 parents from the Sarawak Autistic Association in Kuching were interviewed and results showed that more parents noticed differences in social interaction patterns and physical behaviours than speech impairment when compared to children with normal development.

Parents' interventions are aimed to make parents and caregivers understand and manage their children's behaviours to obtain quality parent-child interactions and improve children's development (Cowan *et al.*, 1998). Green *et al.* (2005) mentioned that there are many kinds of interventions offered to treat children with autism spectrum disorder (ASD). This depends on the type and the severity of autism the child has. Some interventions might be one-off events and some may involve many sessions spread over years. In addition, a well-designed intervention approach should include some level of communication and physical therapy, social skill development as well as behavioural modification with one parent or caregiver to one child (Amar, 2008).

METHODOLOGY

The research had utilized a qualitative research approach with a narrative inquiry method that looked at stories or reflections of parents' and caregivers' experiences in looking after their children with autism at home or outside the house. The researcher was able to find out what were the past stories or the experiences they had had in the past in dealing with their autistic children. The researcher also looked at the current or present stories or practices as well as what future plans parents and caregivers have in store for their children. In this study, the researcher used interviews and observations as the methods for collecting data. In-depth interviews were conducted. The study used a purposive sampling method since it needed to obtain rich and thick description of lived experiences from people who had experiences in dealing with autistic children. The researcher had chosen respondents who had more than five year's experiences looking after their autistic children. To get more respondents for the study, the researchers also resorted to snowballing sampling. Besides using snowballing samples, the researcher had also used Facebook where she obtained two caregivers who were willing to be interviewed. All interviews were more like telling stories

of their lives and all interviews were recorded on audiotape. Both English and Malay Language were used in conducting interviews (Clandinin, 2006).

Besides using interviews, the researcher carried out four non-participant observations to triangulate findings as well as to gather more information. The researcher collected data by noting down actions, behaviours, as well as conversations during the observations. They were descriptive notes to be added to the data collected in the interviews. Three observations were carried out at home while one observation was done at a childcare centre, which happened to be the respondent's workplace.

DATA ANALYSIS

To analyse the data, the researcher examined interview transcripts to get a better idea of information given by the respondents. Transcriptions of interviews were analysed and transformed into stories. The researcher had to carefully read and reread the whole transcriptions and then, stories or narratives for each interview were created (Clandinin, 2007). The analysis included analysing respondents' stories and 'restorying' them into a story that made sense. When restorying the interview data, the researcher used Ollerenshaw and Creswell (2000) narrative or plot elements in problem-solution approach where elements such as the problem, characters, settings, actions and resolutions were used in retelling the stories. The researcher also used Clandinin and Connelly (2000) three-dimensional space elements, which included interaction, continuity or temporality and situation. The continuity element was concerned about the past, present and future. The interaction element referred to the personal and social interaction while place or situation was concerned with the context, time and place when creating the stories. Hence, all transcribed interviews were reorganised into a chronology of events consisting of the past, present and future experiences or ideas, which were similar to the plot of a story or the storyline. The storyline included information about the settings or contexts of the respondents' experiences. Thus, the researcher applied both Ollerenshaw and Creswell (2000) problem-solution approach and Clandinin and Connelly (2000) three-dimensional space approach in retelling the stories. After reading and rereading the transcribed interviews, the researcher using the two approaches turned each of the transcribed interviews into respondents' individual stories. As the stories were being narrated, the researcher began the coding process where themes and categories appeared from the stories.

Data from the stories were coded and labelled categorically to allocate themes and sub-themes. All phrases and sentences that were noteworthy were highlighted. Since the study utilised thematic analysis approach to interpret data, the researcher first coded, then categorised and lastly formed concepts or themes. The data analysis was based on the study's research questions. The researcher narrowed down themes emerging from parents' and caregivers' experiences in detecting signs and symptoms of autism in their children, the routine or daily interventions carried out by them together with their methods or approach in dealing with children with autism, their challenges looking after their special children and how they came to terms accepting their children as having autism.

DISCUSSION

The first research question dealt with parents' and caregivers' experiences in detecting signs of autism. The study has found ten different signs of autism detected by respondents. The signs included speech delay or problems with communication; no eye contact; living in own world or like to play alone; tantrums or meltdowns; self-injury like head banging or self-biting; late development or not meeting developmental milestone such as delay in walking; like to play with round rotating things and have a different way of playing; have impulsive behaviour like wandering; hyperactive and; have childish behaviours. Table 1 shows the signs respondents noticed in their children's behaviours.

There were some signs that were similar in their children's behaviours, even though they had different types of autism. Among the noticeable signs or behaviours, the most noticeable sign was speech delay and problems communicating with other people. All 11 respondents had noticed this sign in their children. This finding is similar to Jasni et al. (2011), who found that children and adults with autism have problems socialising with their peers and this had affected their learning, communication and socialisation. In addition, the study has identified the lack of speech in the children as the main concern for parents and caregivers to find the diagnosis for their children's inability to communicate. This study supports a research done by Siklos and Kern (2007) in which they found that communication impairments in children had made parents take actions to diagnose their children. They added that parents were concerned about their children's language development right from the start. Similar findings were found in Midence and O'Neill (1999) study who noted parents reported that their children's main problems were language, pointing and awareness, rituals and behavioural problems, eye contact and sleep. Therefore, lack of speech or delay in speaking was the main concern for parents and caregivers in this study.

However, the findings in this study differed from Young et al. (2003) findings who noted four behavioural categories which included gross motor difficulties, social awareness and play deficits, language and communication difficulties, and unusual preoccupations. They added that though there was language delay detected among the children, but other signs such as lack of eye contact and feelings were observed much earlier before language delay became a problem. In contrast, this study has found that not many parents and caregivers noticed about their children's lack of eye contact. Only four of the respondents had mentioned that their children lack eye contact.

The study had identified two of the respondents' children who had regressive autism or had late autism onset after a period of two years old. The other children had experienced early autism onset that is having autism signs by or before 3 years old. From the analysis, the study found that many of the respondents' children who had early-onset autism did experience a significant developmental delay in gross motor skills such as talking and walking. The study found that five of the children who had early-onset autism did experience delay in talking while one of the respondents' son had both delays in talking as well as walking. The developmental delays such as walking and talking were delayed by one to 5 months and to more than a year delay. However, the study had also found that two children with late-onset autism or autism regression did not experience any developmental milestone until the age of 2 years old. Then, they regressed to no speaking. In cases of regression, parents like Mrs Jamillah and Mr Ali, they did not notice anything wrong with their 2 and a half year old son until their daughter and a relative mentioned that their son had not ever made any response or said anything. Only after this incident, they started looking at their son's behaviour more closely. Mr Mansur and Mrs Zetty were in the same situation. Their son was behaving like any normal child, talking and smiling until he turned 2 years old and he slowly became silent and lost his eye contact. This study's finding was similar to a study done by Adams et al. (2012) on early-onset and late-onset autism and typical children. They found that there was a noticeable delay of 2 months to 4 months and to 5 months in children's reaching developmental milestones such as the age of a child able to crawl, sit up, walk and talk. However, they found that the late-onset autism had no problem in this area and had the same development as typical children's development. Therefore, the results showed that children with early-onset autism, experienced developmental delays while children with late-onset autism have a typical development at first but later experienced speech delays just like children with early-onset autism.

From the analysis, the study has found three comorbidities co-occurring between Autism Spectrum Disorder (ASD) and Attention Deficit Hyperactive Disorder (ADHD), ADHD and dyslexia, the third comorbidity was ASD and epilepsy. The findings showed one of the respondents' son had been diagnosed with having both ASD and ADHD. In addition, from the four respondents whose children had ADHD, one had ADHD and dyslexia. However, the other three children with ADHD were not having dyslexia. Thus, the two disorders ADHD and dyslexia had co-occurred. Another respondent's son who had ASD, was also having dyslexia. This study showed that children who had ASD and ADHD, could also have dyslexia at the same time. Boada et al. (2012) stated that each comorbid with speech sound disorder would have language impairment. Besides this, two of the respondents' children with ASD had experienced epilepsy when they were 1 year old. Thus, epilepsy is also associated with autism. This finding supports Gillberg and Cederlund (2005) who discovered that epilepsy in childhood is significantly associated with severe mental retarding and autism. Having the knowledge of comorbidity in autism is important as it alerts and prepares parents and caregivers on how to manage their children who have two or three comorbidities at the same time. Table 2 shows the presence of autism and other comorbidities found in the respondents' children.

Table 1: Parents and caregivers noticing signs in their children's behaviours

Respondents	1	2	3	4	5	6	7	8	9	10	Total No. of Signs Detected
Mrs Azizah	✓	✓		✓		✓		✓	✓		6
Mrs Shaz	✓	✓		✓		✓	✓		✓		6
Mrs Rohaya	✓		✓				✓				3
Mrs Azni	✓		✓	✓	✓	✓	✓			✓	7
Mrs Hana	✓	✓	✓	✓	✓			✓	✓		7
Mrs Jamillah and Mr Ali	✓ R	✓		✓	✓			✓	✓		5
Mrs Zetty	✓ R		✓	✓	✓	✓	✓				6
Mr Mansur			✓	✓	✓	✓	✓				5
Mrs Lee	✓			✓	✓				✓		4
Mr Hassan	✓		✓				✓			✓	4
	10	4	5	9	6	5	6	3	5	2	

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|----|--|
| 1 | Speech Delay/Problems with communication (R) Regression |
| 2 | No eye contact |
| 3 | Living in own world/Like to play alone |
| 4 | Tantrums/Meltdowns |
| 5 | Self-injury (head banging/self-biting) |
| 6 | Late development/Don't meet milestone - Late walking |
| 7 | Like to play round rotating things/Have a different way of playing |
| 8 | Impulsive behaviour/Wandering |
| 9 | Hyperactive |
| 10 | Childish behaviour/Like to play with small children |

Table 2: Children's age when autism was detected and types of autism and comorbidity in children

Respondents	Children's Age when Autism was Detected	Types of Autism and Autism Comorbidity
Mrs Azizah	3 years old	ADHD
Mrs Shaz	2 ½ old	ADHD and Dyslexic.
Mrs Rohaya	6 years old	Mild Autism and epilepsy
Mrs Anis	4 years old	ASD
Mrs Hana	3 years old	ASD and ADHD
Mrs Jamillah and Mr Ali	2 ½ years old	ADHD
Mrs Zetty	2 ½ years old	ASD and epilepsy
Mr Mansur	2 ½ years old	ASD
Mrs Lee	2 ½ years old	ASD and Dyslexic
Mr Hassan	6 years old	Mild autism

The next findings dealt with the age of the children when their parents or mothers had taken actions to screen them for disability. Their ages were between the ages of 2 and half years old to 4 years old. With regard to parents and caregivers referring their children to experts for screening process, the study had found nine of the respondents sought help from hospitals which directed them to experts such as ear, nose and throat specialist, speech therapists, paediatricians, psychologists and psychiatrists. Thus, seeing experts to screen for children's disability had helped parents and caregivers to detect early signs of autism in their children's behaviours, as early as 2 and half years old. From Table 2, 7 respondents had realised their children had abnormal behaviours after the age of 2 years old. They sent their children for developmental screening test and later specialists and paediatricians had diagnosed their children with autism at the age of 2 and half years old to 3 years old. Five respondents had their children diagnosed with autism while 4 others had ADHD and 1 had mild autism. Two other respondents who were husband and wife had their daughter checked at the age of 4 years old and was diagnosed with mild autism at the age of 6 years old.

On the whole, the period of parents and caregivers noticing their children's abnormal behaviours to the diagnosis of autism was between 6 months to 28 months. From the analysis, 8 respondents had to wait 6 to 24 months to get their children's diagnosis. As for Mr Azizah who had noticed her son's abnormalities early, but had to wait until her son was 3 years to be diagnosed. This meant from the moment the parents and caregivers noticed their children's behaviours to the diagnosis made, there was a period of waiting before the diagnosis was given. From Table 3, the diagnosis of autism for the respondents' children in this study was made between 6 months to two years 4 months.

In studies done by Young et al. (2003), Holdt (2008), Siklos and Kern (2007) had noted a significant gap between parents noticing children's abnormalities and their diagnosis. In Young et al. (2003) study, the diagnosis delayed was 34 months. Siklos and Kerns (2007) stated that their study had found that parents had significant difficulties in getting the diagnosis and it took them 36 months from the moment they detected behavioural problems to the diagnosis. Similarly, in a study done by Holdt (2008), the number of years before the diagnosis was 3 years and 3 months. However, the findings in this study showed a shorter waiting period of 6 months to 30 months, compared to studies done by Holdt (2008), Siklos and Kern (2007) which took parents more than 36 months to know their children's conditions. Table 3 shows the gap between the time the parents or caregivers first detected signs of abnormalities and the diagnosis of autism. Robson (2010) did a study and found that autism related symptoms in infants were observable from early infancy and in some cases, it can be detected from birth. Therefore, this study found that parents had to wait a much shorter time period to diagnose autism in their children and thus would enable them to start treatment or interventions early. This would reduce the anxiety felt by parents and caregivers.

The study found that long waiting periods before the diagnosis put a strain on parents' and caregivers' well-being. This is because the period before the diagnosis can be described as the most difficult time for parents or caregivers. Respondents in the study did not recognise the signs of autism regression until they saw their children behaving abnormally. This finding is similar to a study done by Ting and Chuah (2010) on parents' recognition of

autistic behaviours and they reported that parents noticed some behavioural differences in their children, but they did not know the behaviours were symptoms of autism. Similar to the respondents in the study, they were all first timers in having a child with autism and they had no idea at all on how to provide for their special children. Only Mrs Azizah who had done a blood test on her son, knew that her son had a disability and was anxious to find out and provide early intervention. Midence and O'Neill (1999) noted parents' confusion and despair because they were not being able to understand why their children were behaving in such manners.

From the analysis of the respondents' personal feelings before and after the detection showed that respondents did not know what to do and many had expressed feelings of sadness, worried as well as frustration. Mrs Shaz cried when she found out her daughter had hyperactivity, ADHD and was Dyslexic too. She cried because she did not know what to do for her daughter. She could not find any source of information and she thought of her daughter going to school not being able to read when her older brother could read well three months after entering school. As for Mrs Azni, she was worried that her son could be dumb or deaf because he did not speak. After he could speak a bit, he started talking backwards. She also felt angry, worried, frustrated and hopeless in what she was supposed to do to help him. Other parents had similar feelings like Mr Hassan who felt sad and angry at the same time when his daughter started hitting him and his wife. His daughter had a tendency to hit them when she was angry. Mrs Hana did not bother so much about what the doctor had said until her son started injuring himself. She was afraid if her son continued his behaviour, his head would get injured because he was constantly knocking his head at the sliding door or at the wall. She was afraid that her young son's delicate head could be injured or fractured. She cried many times because she was so unhappy with her son's condition. She knew there was something wrong somewhere, so before the detection of her son's condition, she was having a hard time trying to understand her son's behaviour. However, after the diagnosis, respondents were still anxious on what interventions to provide for their child.

However, these findings differed from Midence and O'neil (1999) study in which they noted parents' difficulties and confusions of not knowing or understanding their children's behaviours had lessened once the correct diagnosis was made. They added that after receiving the diagnosis, parents and caregivers of children with autism got help from experts which later help parents and caregivers to provide immediate interventions to reduce their worries and take control of their lives.

Table 3: Time gap between parents' or caregivers' concern to diagnosis of autism

Respondents	Parents' or Caregivers' Concern/Notice About Autism and Diagnosis	Age of Child Diagnosed With Autism	Time Gap Between Parents' or Caregivers' Concern and Detection of Autism
Mrs Azizah	8 months old	3 years old	2 years 4 months
Mrs Shaz	2 ½ years	3 years old	6 months
Mrs Rohaya	4 years	6 years old	2 years
Mrs Anis	4 years old	5 years old	1 year
Mrs Hana	3 years old	5 years old	2 years
Mrs Jamillah and Mr Ali	2 ½ years old	3 years old	6 months
Mrs Zetty	2 years old	4 years old	2 years
Mr Mansur	2 years old	4 years old	2 years
Mrs Lee	2 years 6 months	3 years old	6 months
Mr Hassan	4 years old	6 years old	2 years

From the analysis done, the study found there were 5 different types of interventions used by parents and caregivers in the study. These included the Behavioural, Developmental, Complementary and Alternative Intervention, Therapy based and Islamic Interventions. Table 4 displays the different interventions used. The findings showed the behavioural interventions were the most used interventions. The respondents used behavioural interventions to teach their children new behaviours such as self-care and self-help skills, so that they would be able to go to toilet on their own and manage themselves independently and also to obtain eye contact. Parents and caregivers in the study simplify the learning skills to be learned into small achievable tasks so as the child would learn the desired behaviours. Apart from learning life skills, the respondents used the behavioural intervention to reduce children's disruptive behaviours or improve the children's negative behaviours. The study found that using Behavioural Interventions as well as other interventions were effective in dealing with children's behaviours. Remington et al. (2007) findings were similar and that there were significant differences favouring the group, which had received intensive behavioural treatment. The findings also indicated that behavioural intervention was effective for young children with autism.

Other interventions such as developmental interventions were also used to improve social skills as when children had indoor and outdoor activities. In addition, respondents whose children were hyperactive or ADHD had

used complementary and alternative interventions such as paying attention to the children’s diet and food intake, giving the children supplements to improve speech and also using a small amount of medication as and when needed. These interventions had helped to reduce their children’s hyperactivity. Next, respondents who took their children to the autism centres for intervention continued to use the therapy based intervention or Communication Focused Intervention at home which included the use of Picture Exchange communication system, massaging brush for speech improvement, use visuals and also make schedules. Lastly, Islamic beliefs such as prayers or ‘doa’, and ‘zikir’ as well as performing the ‘solat’ and ‘fasting’ during the fasting month were practiced as daily routines.

Table 4: Types of interventions used by parents and caregivers

Behavioural Interventions	Toilet training and self-help <ul style="list-style-type: none"> ● To gain eye contact ● To deal or reduce Tantrums ● Giving instructions verbally and using pictures ● Ask questions frequently or repeatedly
Therapy Based Intervention (Communication Focused Intervention)	<ul style="list-style-type: none"> ● Picture Exchange communication system ● Massaging for speech improvement ● Visuals ● Make a schedule
Complementary and Alternative Interventions	<ul style="list-style-type: none"> ● Diet and food Intake ● Supplements ● Medical interventions
Developmental Intervention	<ul style="list-style-type: none"> ● Improving social skills ● Indoor and outdoor activities
Islamic Interventions	<ul style="list-style-type: none"> ● Islamic daily routines, ‘Doa’, ‘Zikir’, Prayer or ‘Solat’ ● Handling issues about sex

After the diagnosis was made, respondents in the study had used different interventions to reduce their children’s challenging behaviours and decrease their stress. Parents and caregivers used many types of interventions that worked for their children. Interventions that parents and caregivers had chosen depended on what was suitable for the child’s needs. From the analysis done, interventions, which parents and caregivers had carried out, were done with a purpose to reduce their children’s negative behaviours such as temper tantrums, aggressive behaviours and self-injury behaviours. From the Table 1, it shows that 9 out of 11 respondents mentioned that their children had disruptive behaviours and therefore, they had to focus on improving or reducing their children’s negative behaviours. Thus, there were many ways respondents used to curb these behaviours. Hence, besides teaching their children new skills, respondents had a bigger task and that was to reduce their children’s problematic behaviours. Estes et al. (2013) added that the child’s behavioural problems would influence the intervention used by the parents for early intervention. Once the child’s behaviour had improved, then there would be positive impact on the parents’ and caregivers’ adaptive skills.

To gain the child’s eye contact, one of the respondents used balloons and mask. This technique was also used by Carbone et al. (2009) who stressed that the procedures taken were to give the subject vocal or physical prompt to produce eye contact form. Based on the findings, the procedures offered were effective in increasing the child’s eye contact. Similar findings were found by Mrs Jamilah and Mr Ali, their son had gained his eye contact after a few months trying the technique.

Dietary intervention had also proven effective in reducing hyperactivity in children and they were calmer after parents and caregivers had changed their diet. Hence, parents and caregivers whose children had ADHD or they were hyperactive had resorted to using a change diet of soya milk, brown rice and no sugar or chocolates. This study had discovered that by changing the diet of the child could lessen children’s hyperactivity. So, at the beginning, when the children were hyperactive, parents and caregivers had relied on the alternative and complimentary diets to reduce their hyperactivity. They had also resorted to using supplements to improve the children’s conditions. However, many parents and caregivers were against the use of medicines to reduce hyperactivity for fear it would cause negative side effects. So, only very small doses of the less commercial medication were used when it was absolutely needed.

Indoor and outdoor activities were also carried out by respondents. However, for children who were difficult to control, they would do activities at home. From Table 5, it can be seen that the respondents did more indoor activities than outdoor activities. Thus, hyperactive children were most likely to have more indoor activities than outdoor activities. These activities had provided training for the children’s social skills. Many parents and caregivers in the study reported their autistic children having problems such as temper tantrums. So many of them preferred not

to have outside activities with their children because they were afraid something bad would happen should they bring their autistic child along. So, this study agreed with the study done by Jasni *et al.* (2011) who discovered that many children with autism in Malaysia were mostly kept at home.

The respondents in this study taught their children to follow Islamic practices and values. They taught their children to learn and perform the Muslim prayer or ‘Solat’ and to fast in the month of Ramadan just like their other siblings and like any other normal Muslim children practice daily routines such as reciting ‘Doa’, ‘zikir’ and ‘wirid’. Parents became role models for their children to follow during prayer times. But after a while, they let their children to pray on their own but they sometimes monitored the children’s progress. Even though the respondents were aware that their children did not really understand the full significant of performing the prayers or the fast, they still insisted the children to follow. Mrs Hana and Mrs Zetty who believed reciting Quranic verses as an intervention to calm their children whenever they have temper tantrums discovered that after many times reciting the verses, the child had stopped crying and became quiet.

Table 5: Summary of parents’ and caregivers’ experiences in providing interventions and the types of interventions used

<p><u>Daily living skills</u> (Personal hygiene and self-care)</p> <p>Using the toilets and self-help skills.</p> <ul style="list-style-type: none"> ● Use Chinese pots for urination and defecation ● Use pictures on how to use the toilets and bathe ● Direct method-step-by-step instruction what to do ● Set time to go to the toilet ● Wearing clothes and taking off clothes ● Eating on own and clearing plates after meal and wiping table etc. ● Toilet training taught at intervention centres or autism lab and parents and caregivers continued at homes ● Able to go to toilet at home but use diapers at school because do not like to go to school toilets are dirty <p><u>To obtain eye contact</u></p> <ul style="list-style-type: none"> ● Use balloons and wear masks ● Use self-made threading equipment ● Use capital letters from newspapers and paste on flashcards <p><u>Dietary and food intake</u></p> <ul style="list-style-type: none"> ● Back to nature/change lifestyle <ul style="list-style-type: none"> ● No use of preservatives ● Use organic food such as organic chicken, organic vegetables or village food or vegetables pesticides free such as sweet potato and tapioca ● No plastic containers ● No Styrofoam – only use stainless steel or glass ● Stop using microwave ● Eat lots of salad ● Green juices ● Fish found in the middle of the ocean ● Food for the stomach such as yogurts ● No junk food ● Ways to cook food – baked, steam, soup or barbeque ● Diet elimination to reduce problem behaviours ● Supplements such as A, B, C and C plus, E, B6, Primrose for speech development ● Massaging brush and chewing sweet-less marshmallow to improve speech development ● Change menu to reduce hyperactivity ● Powdered milk to soya milk ● White sugar to brown sugar, No sweets or chocolates ● White rice to brown rice ● Gluten and gliadin free diet ● Medication <ul style="list-style-type: none"> ● Mild or less commercial medicines
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- In small dosages-to avoid overuse/overdose
- No more drugs after 6 months

Outdoor and indoor activities

- Outdoor Activities
 - Physical exercises such as running, jogging, balancing on road curbs, swinging exercises, Holding therapy,
 - Gardening, squeezing water/water play, Clay games/Play-Doh
 - Shopping at supermarkets and malls
- Indoor Activities
 - Play with toys such as water toy gun
 - Play Computer Interactive games
 - Drawing, colouring and writing
 - Reading using visuals such as pictures in the form of social stories, word cards or reading cards and timetables or schedules such as feeding schedule for the child and work schedule for the maid
 - Cooking
 - Listening to Music/Playing Musical instrument

To reduce tantrums

- Use music to calm child
- Cuddle walk to cool down child
- Ask child to count numbers to cool down
- Observe child's behaviour to see a meltdown or tantrum
- Put child in an empty room/ask child to go to own bedroom to cool down
- Substitute things for different things other than the things wanted
- Less talks but more hugs and kisses

Use Islamic Practices

- Daily routines insert Islamic values
- Reading 'Doa', 'Zikir' and 'Wirid' 'Solat'/Prayer

The study had analysed the approaches used by the respondents to manage their children with autism. From the analysis made, respondents had controlled their children's behaviours by using different methods. They used different types of interventions for different purposes. For instance, Behavioural Interventions are effective to deal with child's problematic behaviours, while Dietary Interventions are used to reduce hyperactivity. For respondents who had received parenting training from therapists, they used the therapist approach to control their children. They trained their children to obey their instructions and that they were the 'Boss' and the children with good behaviour will be given a reward to reinforce the good behaviour. However, should the children show negative behaviours, then the reward was withheld until the children obeyed the parents' or caregivers' instructions. Thus, the approach used by parents and caregivers in this study emphasised that they give attention and show warmth, responsiveness and sensitivity to their children's behaviours that were positive while negative behaviours such as tantrums were ignored.

From the observations, the signs or characteristics of autism were still prevailing and the researcher could see that two of the respondents' children still have problem speaking or they lack speech. In the second observation and the fourth observation, the respondents' children were quiet most of the time especially in the fourth observation, only towards the end of the observation he said one word 'sedap' which means delicious, referring to food he was eating. Similarly, in the second observation, the teenager daughter still faces communication problem and merely repeated the last few words and repeated the same answer over and over. In the interview conducted earlier with Mrs Rohaya, she noted that her daughter would keep quiet and would speak only if someone were to ask her many times (Dia..diam, kecuakalaukitadudukan, kitatanya, tanya, tanya..dia Barudiajawab).

In the first observation, the child was still quiet most of the time but responded to questions asked by the mother correctly. She used simple words and though she did not use full sentences, her words were meaningful. She spoke with soft voice and smiled a lot and sometimes laughed softly. In the third observation, the respondent's child had no problem speaking and could express well with siblings as well as other people. Thus, with regards to speaking or communication as well as socialising, two of the caregivers, Mrs Shaz's daughter and Mrs Lee's son had improved in these areas. On the contrary, the other respondents who were husbands and wives, Mrs Rohaya and Mr Hassan, and Mrs Jamillah and Mr Ali's children were still having problem in speaking and socialising. In Mrs Jamillah and Mr Ali's case, their son still had problem in speaking and socialising with other people. There were still feelings of

discomfort when sitting with other people for a period of time and did not say much. Mrs Rohaya and Mr Hassan's daughter did not have problem socialising, but she merely repeated the last few end words of the questions and needed prompting before giving one word answer.

In addition, there were other signs of autism still present in the respondents' children such as the preference to play alone or be alone. Two of the respondents' children still preferred to do activities alone like playing alone or watching television alone. In the last observation, the son was uncomfortable being with other people. However, there was an exception in the third observation where the child could play with his siblings easily but he had problems controlling his anger or temper. This caused his siblings to feel uncomfortable because of his loud and angry shouts. Thus, from all the four observations, the children still have communication problem and they preferred to be alone.

Though some signs of autism were still present, there were some improvements in the children's behaviours. All of the respondents' children had obtained eye contact and were able to focus their attention and they were engrossed with whatever they were doing. Three of the respondents' children who were diagnosed with ADHD were observed to have improved in their hyperactive behaviour and were able to sit for long moments.

However, showing emotions was a problem for children with autism. They did not show correct emotions or showed no emotions at all. In the first observation, Mrs Shaz's daughter could not show her anger or be able to argue with her sister. It was observed that she was not capable of arguing with others and she did not show the correct emotions such as anger at her sister and her brother for not washing his own dishes after using them. The researcher noticed that Aishah does not know how to argue with her mother and so she follow her mother's instruction and did the dishes. She also allowed her younger sister to play with her tablet, leaving her to wait for some time while she plays with it. The researcher noticed that Aishah just sat quietly and waited for her sister to return the tablet. It would seem she did not know how to argue and just gave in to her sister's arguments. Her mother had mentioned that others could easily bully her because of this.

Another improvement that could be seen was the children were capable of doing daily activities independently. One of the respondents' children was capable of doing daily routines housework. In the interview, Mrs Shaz said that her daughter was able to clean the kitchen and prepare drinks (she's 14 now... like she can clean the kitchen... bolehbuat air) and during the observation, Aishah had helped Mrs Shaz to do word cards using the marker pen. Her handwriting was quite good writing two or three syllable word cards and she did not mind writing the word cards as she had minded washing the dishes.

Next, the observations also showed parents' and caregivers' interactions and communication with their children at home and outside home were very important. From the observations, it showed that parents and caregivers had used clear instructions to communicate with their children to understand what they were supposed to do. Mrs Shaz had started training her daughter to do housework and her daughter was able to clean the kitchen and do the dishes by herself as well as help out at the centre where she could write words on manila cards. She followed her mother's instructions to wash all dishes, not only the ones she used but also the rest of her family members. Mrs Shaz had not only instructed Aishah, but she also explained to Aishah the reason why she had to do the dishes. In the third observation, Mrs Lee gave clear instructions to her sons on what they were supposed to do and her children obeyed them. This showed them that she was in control of their behaviours. In the last observation, the respondents' son had immediately obeyed when he was instructed to take the cat out of the house.

Lastly, in the second observation, the respondents' daughter only obeyed the mother's instructions to speak and eat the food but not her father's instructions. Her mother had to take the food and passed it to her and only then she would eat the food. This showed that she was still dependent on her mother to serve her food and because she was closer to her mother than her father, she would only listen to her mother's instructions. Therefore, from all observations carried out, parents and caregivers must have a good relationship with their children. Then, they can use clear instructions to instruct the children on what they need to do and indirectly mould their children's behaviours. Another way, parents and caregivers could get close to the children was to have similar hobbies or interests as their children. This would be a way to spend time with their children. Mrs Shaz takes her daughter bowling and her daughter enjoys doing the activity and being with her mother. She enjoyed talking about the time they went bowling together.

CONCLUSION

The study has found that parental concerns about their child's abnormal behaviours and developmental delays have helped respondents to detect autism early. There were many signs of autism in children and comorbidities that existed were identified. The more severe signs of autism play a role in speeding the process of detection. There were many interventions used to reduce children's problematic behaviours. Behavioural and dietary interventions were used

initially to help improve the child's self-help skills and reduce his or her problematic behaviours. Islamic intervention or practices also helped in curbing unwanted behaviours and at the same time, inculcate Islamic values in their children. Suggestions from therapists or experts gave ideas to parents and caregivers on how to manage their child's behaviours were also used. Parents and caregivers used many trial and errors to provide the best practice for their child.

REFERENCES

1. Adams, J.B., S.M. Edelson, T. Grandin, B. Rimland and J. Johnson, 2012. Understanding autism: Advice for parents of young autistic children. Retrieved from <http://www.autism.com/understanding.advice>.
2. Amar, H.S.S., 2008. Meeting the Needs of Children with Disability in Malaysia. *Medical Journal of Malaysia*, 63(1): 33-37.
3. Boada, R., E.G. Willcutt and B.F. Pennington, 2012. Understanding the Comorbidity between Dyslexia and Attention-Deficit/Hyperactivity Disorder. *Topics in Language Disorders*, 32(3): 264-284.
4. Carbone, V.J., L. O'Brien, K.E.J. Sweeney and K.M. Albert, 2013. Teaching Eye Contact to Children with Autism: A Conceptual Analysis and Single Case Study. *Education and Treatment of Children*, 36 (2): 139-159.
5. Clandinin, D.J., 2006. Locating narrative inquiry historically. In: *Handbook of Narrative Inquiry: Mapping a Methodology* (ed D.J. Clandinin) pp. 3-34. Sage, California.
6. D. Jean Clandinin, 2007. *Handbook of narrative inquiry: Mapping a methodology*. Sage.
7. D. Jean Clandinin and F. Michael Connelly, 2000. *Narrative inquiry: Experience and story in qualitative research*. Jossey-Bass.
8. Cowan, P.A., D. Powell and C.P. Cowan, 1998. Parenting interventions: A family systems perspective. In: *Handbook of Child Psychology: Child Psychology in Practice* (eds I.E. Sigel and K.A. Renninger) pp. 3-72. John Wiley and Sons, New Jersey.
9. Estes, A., E. Olson, K. Sullivan, J. Greenson, J. Winter, G. Dawson and J. Munson, 2013. Parenting-Related Stress and Psychological Distress in Mothers of Toddlers with Autism Spectrum Disorders. *Brain and Development*, 35(2): 133-138.
10. Gillberg, C. and M. Cederlund, 2005. Asperger Syndrome: Familial and Pre- and Perinatal Factors. *Journal of Autism and Developmental Disorders*, 35(2): 159-166.
11. Green, V.A., K.A. Pituch, J. Itchon, A. Choi, M. O'Reilly and J. Sigafos, 2005. Internet Survey of Treatments Used By Parents of Children with Autism. *Research in Developmental Disabilities*, 27(1): 70-84.
12. Holdt, N., 2008. Parents' experiences of their child being diagnosed with autistic spectrum disorder, Master thesis, University of Kwa Zulu-Natal, Pietermaritzburg.
13. P. Howlin, 1999. *Children with autism and asperger syndrome: A guide for practitioners and carers*. John Wiley and Sons.
14. Jasni, D., A.W.Y. Wan and S.C. Toh, 2011. A Preliminary Investigation: Potential of Interactive Multimedia Learning Awareness (IMLA) in Enhancing Awareness of Autistic Characteristics among Parents and Society in Malaysia. *Electronic Journal of Computer Science and Information Technology*, 3(1): 19-25.
15. Malaysian Psychiatric Association, 2010. Money and distance letting down children with autism. Retrieved from <http://www.psychiatry-malaysia.org/article.php?aid=1249>.
16. Midence, K. and M. O'Neill, 1999. The Experience of Parents in the Diagnosis of Autism: A Pilot Study. *Autism*, 3(3): 273-285.
17. J.A. Ollerenshaw and J.W. Creswell, 2000. Data analysis in narrative research: A comparison of two "restorying" approaches. *American Educational Research Association*.
18. Ozonof, S., G.S. Young, M.B. Steinfeld, M.M. Hill, I. Cook, T. Hutman, S. Macari, S.J. Rogers and M. Sigman, 2009. How Early Do Parent Concerns Predict Later Autism Diagnosis? *Journal in Developmental and Behavioral Pediatrics*, 30(5): 367-375.
19. Remington, B., R.P. Hastings, H. Kovshoff, F.D. Espinosa, E. Jahr, T. Brown, P. Alford, M. Lemaic and N. Ward, 2007. Early Intensive Behavioral Intervention: Outcomes for Children with Autism and Their Parents after Two Years. *American Journal on Mental Retardation*, 112(6): 418-438.
20. Robson, D.C., 2010. The development of infants with an increased risk of autism spectrum disorders, PhD thesis, Flinders University, Adelaide.
21. Siklos, S. and K.A. Kern, 2007. Assessing the Diagnostic Experiences of a Small Sample of Parents of Children with Autism Spectrum Disorders. *Research in Developmental Disabilities*, 28(1): 9-22.
22. Ting, S. and H. Chuah, 2010. Parents' Recognition of Autistic Behaviour and Their Coping Strategies: A Case Study at Sarawak Autistic Association. *International Journal of Social Policy and Society*, 7: 52-65.
23. UNICEF Malaysia, 2014. Children with disability in Malaysia: Mapping the policies, programmes, interventions, and stakeholders. Retrieved from http://www.necicmalaysia.org/view_file.cfm?fileid=129.
24. Young, R.L., N. Brewer and C. Pattison, 2003. Parental Identification of Early Behavioral Abnormalities in Children with Autistic Disorder. *Autism*, 7(2): 125-143.