

Caregivers' Challenges and adaptations in Managing Children with Autism in Malaysia: The Need for Family Support and Community Awareness

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Abstract: *Due to the many cases of Malaysians caregivers having children with autism and experiencing stress and psychological disturbances, caregivers need to make adjustments to fit the needs of their children as well as to accommodate the needs of other members of the family. The objectives of the study were to explore the challenges faced by caregivers in caring for their autistic children at home and how they overcome the challenges and adapted their lives to fit to the needs of having a special child. The study used a purposive sampling method and caregivers who had more than five years of experience looking after their child were chosen. The researcher used in-depth interviews and carried out four home visitations to observe the children at their homes. The findings indicated that all of the 11 respondents faced many challenges on a daily basis due to their children's behavioural problems. These included hyperactivity, temper tantrums, self-injury, aggressive behaviours, hyperactive behaviours, problems with toilet training, running away from home, problems when children are stressed like biting things, like to play with private parts, misbehaviours like jumping into a lake, self-locking in storeroom and creating noise, drawing on house's walls, difficulty to cater when the child is sick, have communication and socialization problems, slow in learning, separation anxiety, difficulty to express emotions and feeding problems. They were difficulty problems for respondents to overcome and some of them felt angry, worried, frustrated, sad, afraid, embarrassed, panic and ashamed of being scolded at by people around them such as their neighbours and the community that they live in did not understand the autistic behaviours of their children. They did not have enough sleep and rest and did not have enough time for work as well as no time to see their other children's needs. At the beginning, many of the respondents had socially isolated themselves and kept the child in the house. Other challenges included financial constraints as well as uncertainty about their children's future. Coping strategies used by respondents were problem and emotion focused strategies as well as adaptive and maladaptive strategies. The role of religion as an emotion-focused coping strategy has enabled respondents to use a more flexible practice intervention which help to improve their children's development and also overcome their challenges and cope with their lives. In addition, respondents noted that they were able to carry out their duties because they had social support from family members including the maid to maintain the child's wellbeing. However, the study found that there is a lack of awareness about autistic children among the Malaysian community.*

Keywords: Autism, Caregivers' Challenges, Community Awareness, Family adaptations, and Family support

1. 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). Smith et al. (2016) further explained that Autism Spectrum Disorder (ASD) affects people differently and there is a wide degree of variation. Similarly, Ashburn (2010) defined autism as a multi-factorial disorder and children and adults with autism have many behavioural problems. Earlier on the National Institute of Child Health and Human Development (NICHD) (2005) defined autism as a complicated neurobiological disorder that a person experiences for the rest of the person's life and that disorders experienced by each autistic child or adult is different so there may be a "spectrum" of disorders or a group of disorders with a range of similar features. Amar (2008) mentioned that children with autism, especially those with severe autism, have difficult behaviours that can be puzzling and confusing to their parents and family members. Many of these parents and caregivers in Malaysia have high prevalence rate of stress and experience psychological disturbances (Nikmat et al, 2008). Due to this, caregivers have to make adjustments to fit the needs of their children with autism as well as to accommodate the needs of other members of the family. Thus, family adaptation is crucial for

family well-being because they have to be able to understand and adapt themselves or make changes to their lives to suit the needs of the child with autism in the family. Thus, this would mean caregivers as well as the family members have to manage their lives and at the same time take care of their autistic children.

2. Background of Study

Researches concerning autism in Malaysia are relatively new if we were to compare Malaysia with the Western countries (See, 2012). Before 2003, most of the autistic children were classified under mental retardation and hearing disability category and it was only after 2008, children with autism were placed under the learning disability category (See, 2012). Jasni et al. (2011) in their article mentioned that autism in Malaysia was misconstrued as a mental illness and these children were mostly kept at home and not given any opportunities to improve their conditions.

See (2005) noted that there were different ministries in Malaysia which provided services for children with autism at this time. These included the Ministry of Education, Ministry of Health, and Ministry of Women, Family and Community Development which the Social Welfare

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Development played an important role. Along the same line, there were also Non-Governmental Organisations which also provided services for children with autism. She mentioned that the Ministry of Health was responsible to identify and screen disabilities in special children while the Ministry of Education was in charge of providing Early Intervention Programmes and educational services for children as well as individuals with autism. The Ministry of Education also catered for children with other disabilities such as children with hearing and visual impairment and learning difficulties such as Down syndrome, mild autism or Asperger Syndrome, Attention Deficit Hyperactive Disorder (ADHD), mild mental disabilities and also specific learning difficulties such as Dyslexia. The Ministry of Health and the Ministry of Education recognised the importance of early detection and intervention for children with autism and they provided services and facilities for parents and caregivers for early detection and intervention for these children. However, these were still not enough to face the fast growing number of disability cases. Therefore, there is a need to learn about Malaysian caregivers' coping strategies for children with autism and the sort of support they need to understand their children's challenging behaviours so as to cope with their lives.

3. Objectives of the Study

The research objectives are formulated to;

- 1) Investigate caregivers' challenges in taking care of their child with autism
- 2) Study caregivers' experiences in coping with their lives while living with a child or adult with autism

Parental or Family Stress

Caregivers who have children with autism have a challenging role to develop their children's learning. They are the ones who will decide and carry out any intervention that they think is good for their children. They experience many difficulties and researchers have found that caregivers experience a great amount of stress in dealing or managing children with autism. There are many researches on parental stress for parents of children with autism. In Malaysia, Liaw (2008) did a phenomenological study and explored lived experiences of 12 parents with autistic children in Sarawak, East Malaysia using in-depth focused interviews and found 5 emerging themes. From the interviews, 5 themes included parents who had multiple negative feelings and behaviours, prolonged stress, anger-love paradox, self-blaming, and fear and phobia. Addition findings showed that fathers had different views from their wives about their autistic children and having a child with autism had affected other siblings and relatives.

In another study, Yeo and Lu (2012) compared parenting stress and psychological distress among mothers of children with autism in preschool and elementary schools from Johor Bahru in Malaysia and Hangzhou, China. They used a sample of 128 mothers, 64 from Johor Bahru and 64 from Hangzhou, China. Three instruments were used to measure the depression anxiety stress, parental stress and autism rating scale for parents. The study identified factors that influenced parenting stress and psychological distress. From

the results, it could be seen that mothers of children with autism in Johor Bahru and Hangzhou with preschool children experienced a higher level of stress, compared to mothers who have autistic children in elementary schools. Results from this study showed there was no significant difference between mothers whose children were in elementary level in Johor Bahru and Hangzhou. However, there was a significant higher level of stress for parents with preschool children in Hangzhou but not in Johor Bahru. The study noted that in Hangzhou, mothers with pre-school children were more stress than mothers with elementary schools. This was due to the many hours that mothers of preschool children had to spend with their child compared to parents with children in elementary schools. So, mothers with children in preschool had less time for their own personal things and therefore, were more stressed. Two factors influencing psychological stress for mothers in Hangzhou were perceived autism symptom and spousal relationship.

Lastly, in a study done by a team of researchers from Universiti Teknologi Malaysia on 'Mothers' depression and stress, severity of autism among children and family income. Athari, Ghaedi and Mohd Kosnin (2013) investigated the relationship between mothers' depression and stress compared with the severity of autism in children as well as the effect of family income on the two variables. Briesmeister and Schaefer in AlHorany (2013) stated that families of children with autism faced many stressors and challenges. They explained that these included the unexpectedness of the children's behaviours, difficulties in facing answers and services, confusion and strained interactions with neighbours, relatives and people in community setting.

There are numerous researches on the impact of autism on the lives of the family of the autistic child. Nikmat et al. (2008) revealed that mothers of autistic children had greater impact on psychological well-being than the children's fathers. In addition, the mothers of autistic children were reported to experience greater depression, social isolation and a lower level of marital intimacy. They suggested having a proper programme to reduce and ease the burden of parents especially for the mothers. In addition, Tait and Mundia (2012) found that a child's disability poses a threat to parents' perceptions of life satisfaction and their ability to fulfil their responsibilities. This would indicate that some families would decide to limit family size because of the presence of a child in the family who is autistic and needed much care (Kheir et al., 2012).

Coping Strategies Employed by Parents of Autistic Children

Hastings et al. (2005) conducted a study on the coping strategies among parents of different circumstances. Their samples included 89 parents of which 48 were fathers and 41 were mothers of preschool children with autism, together with 26 mothers and 20 fathers of school aged children diagnosed with autism. They studied the psychological functioning in families of children with autism and discovered that maternal depression was a significant predictor to parental stress. They found that there was no

significant difference between mothers and fathers of children with different age groups. The overall results showed that mothers as caregivers experienced more depressive symptoms and have lower level of well-being than fathers. The parents had used four types of coping strategies namely, active avoidance, problem-focused, positive coping and religious or denial strategy. Their findings noted that active avoidance coping was an unhelpful coping strategy or maladaptive strategy for parents with autistic children because they caused parents to have more mental health and stress problems. Problem-focused and positive coping strategies were effective in reducing parents' stress. However, the researchers found that the religious coping or denial coping strategy did not reduce stress or depression among parents. Therefore, they concluded that active avoidance coping strategy and religious or denial coping strategy were associated with parents' stress and anxiety, while parents who used positive coping strategies had less stress and a lower level of depression.

In a research done by Ting and Chuah (2010) on coping strategies used by parents found that most Malaysian parents handled their stress by religious means and having family support. In their study, they highlighted parents' recognition of autistic behaviours in their children and the strategies the parents used to handle their children. They took their 12 samples from Sarawak Autistic Association and used semi-structured interviews. Their findings indicated their children's behaviours as stereotypic, sleep problems, hyperactive and hypersensitivity to certain sounds. Concerning parents coping strategies, the study discovered that the parents used two main parental coping strategies, which were religious means and family support. They disagreed with Hastings et al.'s (2005) ideas that coping strategies based on religious were actually denial strategy. Instead, they believed that religious coping was more towards seeking divine strength to help them manage their children's conditions.

4. Theoretical Framework

The study uses Bronfenbrenner's Ecological systems theory as a theory to guide the researcher. The theory believes that the children's development is affected by the context or the environment surrounding them and their development is influenced by the different types of environmental systems. In this theory, a child's development is influenced by things in the environment that surrounds the child. Thus, a child would be most influenced by his or her home environment as well as the class teacher and the child's peers in a school setting, in which the child spends most of his or her time. Bronfenbrenner (1998), explained that a child will develop progressively through the interaction between the child and the people, objects or things that are closest to the child's environment and for interaction to be effective, it has to be done on regular basis and over a period of time. There are five environmental systems that could affect a child's development. The five environmental systems or levels are the microsystem, mesosystem, exosystem, macrosystem and chronosystem. **Fig 1** illustrates Bronfenbrenner's five different levels or environmental systems. The following

figure on Bronfenbrenner's five environmental is adapted from Berk (2000).

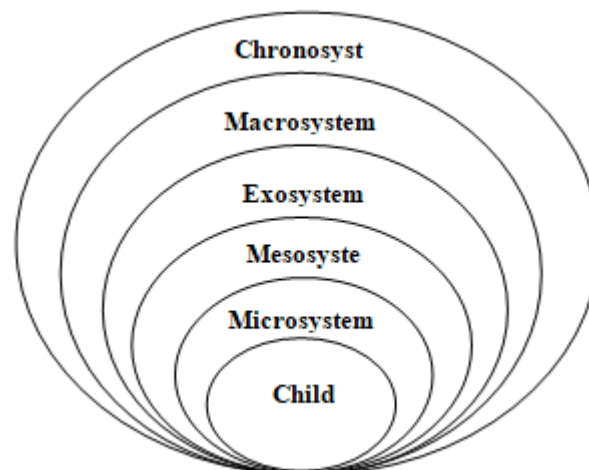


Figure 1: Bronfenbrenner's Ecological Systems Theory

5. Method

In the study, interviews and observations were used. The researcher had conducted in-depth interviews where the researcher had used probing questions. During the interview, the researcher tried to create a conversational atmosphere with her listening to the respondents as they speak and then asking more questions for deeper understanding of the situation. As for the observations, the researcher's role was that of a non-participant observer where the researcher had observed and recorded interactions as well as behaviours seen as objectively as possible.

The study used a purposive sampling method and parents or caregivers who had been taking care of their autistic children for more than five years were chosen for the study to ensure they had plentiful of knowledge to share. To get more respondents for the study, the researcher had also resorted to snowballing sampling. The researcher had to use this method because parents and caregivers of children with autism were hard to reach and by using snowballing samples, the researcher had gained access to more parents and caregivers who were in similar situations. Besides using snowballing samples, the researcher had also used Facebook where she obtained two of the caregivers who were willing to be interviewed and later arrangement for the interviews were made through phone calls as well as using short message system (SMS). The study also used respondents from different context, cultural background and social economic status so as to obtain varied and different information that would provide valuable insights concerning the respondents' everyday life with their children who have autism.

Three observations were carried out at home while one observation was done at a childcare centre, which happened to be the respondent's workplace. The researcher acted as a non-participant observer and she was able to fully observe the situation and collect data without missing any important details. Thus, respondents were aware of the researcher's observational activities. Routine activities of the children with autism were observed and noted down. The researcher

paid attention to children's behaviours as well as other people in the setting and she tried to memorise as what went on at home or any setting or places they were in. She jotted down all information after each observation was completed.

6. Results

From the data analysis, all of the 11 respondents faced challenges due to their children's problematic behaviours. All respondents reported their children had problematic behaviours. These included temper tantrums, self-injury, aggressive behaviours, hyperactive behaviours, problems with toilet training, run away from home, misbehaviours, problems when children are stressed, like biting things, like to play with private part, jumping into a lake, self-locking in store room and creating noise, drawing on house's walls, difficult to cater when child is sick, communication and socialisation problem, slow in learning, separation anxiety, difficulty to express emotions and difficult to feed. From the analysis, many parents and caregivers had experienced a lot of stress whenever their children threw tantrums. Some of their feelings were angry, worried, frustrated, sad, scared, afraid, embarrassed, struggle, panic and ashamed being scolded at.

From the four observations, there were challenges faced by parents and caregivers in dealing with their children's behaviours such as aggressive behaviours, unable to show emotions and dependency behaviours. Though one of the respondent's son had improved his hyperactive behaviour but he still could not control his temper tantrums and he would show his temper by shouting loudly. While another respondent's daughter was not able to show emotions such as make arguments or show anger and this had led her mother to worry for her daughter's future for fear she would be bullied by others. In the second observation, the 18-year-old teenager was still dependent on her mother to get food and she lacks the ability to talk and communicate with others. Thus, from the observations, the researcher saw that children's autistic behaviours are difficult to overcome and are still prevailing. This finding was consistent with a research done by Estes et al. (2013) on parenting-related stress and psychological distress in mothers of toddlers with ASD where they found problematic behaviours of the children contributed significantly to parenting-related stress and psychological distress in mothers of children with autism. Thus, from the observations, it was found that caregivers' tasks are never over as their children's behaviours are constantly changing. This suggests that children's problematic behaviour is a factor that increases stress in caregivers whose children have developmental disabilities.

The next theme that emerged from the data was teachers' lack of training and knowledge in handling children with autism at Special Education schools. The data collected showed that school teachers had caused many of the respondents to be unhappy or not satisfied with the teachers at the Special Education school. All of the respondents' children had reached school aged and only 3 caregivers did not send their children to learn in Special Education school. Two of the caregivers had sent their children to regular schools while one caregiver had sent her son to NASOM.

The rest of the respondents had registered their children in Special Education schools. They were all not satisfied with the methods used by the teachers in Special Education schools. The respondents stated that the teachers were not trained and they did not seem to know what to do. They had neither idea nor knowledge about autism and they did not know how to teach children with autism. One caregiver saw her son sleeping in class while the teacher was doing something else with other children and ignoring her son. Two of the respondents who are husband and wife, felt very disappointed with the special education program, the light-air attitude of the teachers and the out-dated syllabus. A respondent whose son is autistic claimed that the teacher had messed up his son's life. Another caregiver, was also unhappy and was feeling puzzled about Special Education school because they had no initiatives to train their teachers who were not experienced to teach children with autism. One caregiver took her daughter out of the Special Education school and enrolled her daughter into regular school because the teachers were not helpful because her daughter was not only having autism but she was also dyslexic. Thus, from the data collected, teachers who teach children in Special Education schools were untrained and lacked knowledge and awareness of autism as well as they did not know how to cater the needs of these children.

The next theme was challenges from the family and the society. The data clearly showed there was a lack of support from family members and the surrounding community. Even the children's grandmother and extended family members did not know about the child's condition due to their lack of awareness and understanding about autism. One of the respondents, Puan Azizah added that it was not easy for her family members like her parents, siblings and grandparents to accept her son who has autism. She added that her grandmother felt ashamed to have a grandson with a disability. Due to this, caregivers in the study had isolated themselves from family gatherings because they were afraid their children's behaviour would disturb other family members and people at the occasions. Another caregiver, Puan Zetty stated that her mother did not understand and thought that she pampered my son like a king. She noted that her mother did not understand about her grandson's autistic condition who often cry and could not sleep and would only sleep at 4 am in the morning". As for Puan Shaz, who stated, "I did not get my husband's support because he did not accept our daughter's condition as being dyslexic, mild autism and hyperactive and he would always say to his friends that his daughter was just hyperactive".

From the data, it was clear that there was a lack of awareness and understanding about autism among the community. The community including neighbours also would think of the worst and make accusation that the caregivers were abusing their children due to the loud cries their children made. Puan Azizah said, "My husband would think ten times before bringing our son to a Muslim prayer room or 'surau'". It would be easy for Puan Azizah and her husband if the community were able to accept her son being autistic. Next, Puan Hana mentioned that the community was still unaware and they did not understand the behaviours of children with autism. She mentioned, "When my family went out for dinner at the Satay restaurant, they sometimes

had to leave earlier because other guests would be staring at them". She added that they had to leave the restaurant due to the noise her son was making due to his tantrums. In another occasion, Puan Hana mentioned that they were at a restaurant and suddenly her son went to another table where a girl was playing with an ipad. She stated that though she went over and apologised to the family saying that her son was a special child, the mother of the girl was not so forgiving.

Apart from her family members, Puan Azizah's neighbours also did not understand her son's autistic conditions especially with his crying and shouting. They thought that she and her maid were abusing the child because he was forever shouting and crying continuously. She had to explain to her neighbours about her son's autistic behaviours. There was another incident where her son had run away from home because the gate was opened. Her neighbour was angry with her for leaving her son unattended. She admitted, "It was my fault that my son is now tired and drained and I got scolded from my neighbour for letting him run out of the house." Thus, the lack of support from family members and the community made many of the caregivers isolate their autistic children from the eyes of the public. They also excluded themselves because they thought the people could not tolerate the noise or their children's abnormal behaviours.

Care givers also faced challenges from the hospital and service providers. After the diagnosis of their children, caregivers were anxious to find treatment for their child. Unfortunately, there were shortage of facilities and support system. Many had to wait for a long while before getting their children treated. So, many caregivers had to turn to private agencies or Non-governmental organisations. Caregivers were not only concerned with money but the time taken to send the children for treatment was long because most of the centres were located in the heart of the

city. For families who were not able to pay for the fees, they had to seek help from government hospitals which had a long waiting time. One of the respondent and her husband had to wait for two years before their daughter was diagnosed with autism. Another two respondents also husband and wife wanted to get treatment from the General Hospital in Ipoh though it was far away from their home. However, they found out that the speech therapists were very seldom around. So, they had to use private agencies. However, they were not happy with the treatment given to their son. They stopped sending their son because they could not bear to see their son being treated so harshly. So they kept looking for the right therapist until they found one.

There were other challenges faced by caregivers which included physical tiredness of not having enough sleep and rest, not having enough time for their work and to see to the children, financial constraint as well as uncertainty of the children's future. One of the caregiver was having a hard time because she could not sleep or rest because of her son's behavioural problem, which happened mostly at night. The severity of her son's ADHD condition, made her life very stressful. Another challenge that some parents and caregivers faced was managing time to be with their autistic children due to their workload. Caregivers who were housewives also had problem attending to their child with autism because they had other things to do like housekeeping, cooking and at the same time teaching and taking care of their other children. They could not find enough time to do everything and be with the children and often enough, the children would be on their own either watching television or playing video games where the two activities were passive activities and they did not exactly help the children to develop their communication and socialisation skills. Parents' and caregivers' challenges are shown in **Table 1** and **Fig 2**.

Table 1: Challenges faced by parents and caregivers of children with autism

Child Problematic Behaviours	Other challenges	Effects on siblings	Special Education teachers	Family, community, and neighbours	Hospital / Service providers
hyperactivity, temper tantrums, self-injury, aggressive behaviours, hyperactive, problem with going to toilet, run away from home, child's 'naughty' behaviours, problem when child is stressed, likes to bite things Like to play with private parts Jump into lake lock self in store room and create noise, draw on house's wall, difficult to cater when child is sick Communication and socialisation problem -do not like other people to teach, play, talk and see or look at what the child is doing Slow to learn - have to teach many times Difficult to express emotion - not able to fight back or show emotion Difficult to feed – picky eater	Fatigue /Lack of sleep Financial Problem Distant and time constraints Maid abuse Deal with child's sexual urges Difficult to teach abstract words Child do not listen to parents instructions Unpredictable future	Lack of confidence Neglect siblings, focus on child with autism	Difficulty to enrol in special education school Module/Syllabus outdated Teachers lack of knowledge on autism - Tearchers were not trained Teachers did not help child much	Lack of awareness and understanding of family members and community such as neighbours	Lack of facilities and specialist / therapist Have to go to Private organization Disagree with approach used by service provider

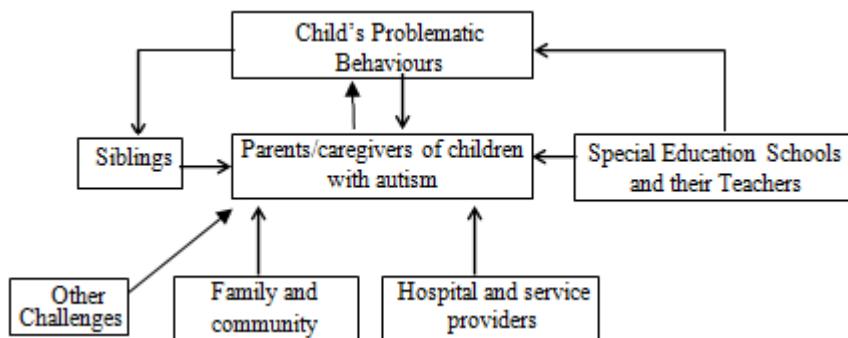


Figure 2: Challenges Faced by Parents and Caregivers

Next, the data collected on caregivers' use of coping strategies showed that caregivers had used several coping strategies to help them manage their children. From the data analysis, many of the respondents had used emotion-focused strategies more than they used problem-focused coping strategy. They used emotion-focused strategies to release and manage emotion mechanism such as seeking for social support, thinking positively, accepting their special child as a responsibility and using avoidance strategy. **Table 2** illustrates the adaptive coping strategies used by the respondents as well as two maladaptive coping strategies. Some of maladaptive coping strategies include safety or overprotective behaviours, social isolation and separation anxiety. These coping strategies would allow caregivers to cope temporarily.

Using the emotion-focused coping strategies had helped respondents accept their children's disability. Two of the respondents had thought positively about having a child with special needs. She was not sad having an autistic son and she had never considered him a burden. Another caregiver did not think that her problems were difficult to handle, instead she just did everything she could. Two of the caregivers had social support from their family members, friends and from parents in similar situations. Thus, the study agrees with Ben-Zur (2009) who stated that positive emotion-focused

mechanism is one form of emotion-focused coping that adaptively manage a problem.

From the analysis, the respondents had used more of the emotion-focused coping strategies because of their religious beliefs. They used Islamic practices such as '*doa*', '*zikir*', '*wirid*', '*solat*' and Islamic values in managing their children's daily lives. Three of the respondents had accepted their children with autism as their responsibility. When one respondent first knew her daughter had autism, she accepted it and stated that it was God's will to give her a child with autism. Another caregiver thought that Allah was testing her and so she was positive about having her autistic son. One caregiver added that it took her 5 years for her to understand and accept what god had given her and after the doctor had diagnosed her son, she accepted his condition. Thus, Muslim respondents had resorted to using religion as a coping strategy. Similar findings were found by Jegatheesan et al. (2010) who claimed that Islamic beliefs had made parents accept their children with a disability. Similarly, Stacey (2010) noted that in Islam, it is the responsibility of each individual to treat all of God's creation with respect, honour, and dignity and God expects adult believers to treat children with respect and to nurture them with love and educate them at the same time.

Table 2: Parents' and caregivers' coping strategies

Appraisal Focused	Problem Focused	Emotion Focused	Adaptive Coping Strategies (Positive)	Maladaptive Coping Strategies (Negative)
<ul style="list-style-type: none"> • Not being used 	<ul style="list-style-type: none"> • Seek information from therapist, the Internet, teachers & Facebook 	<ul style="list-style-type: none"> • Accepting responsibilities • Positive reappraisal • Social supports • Avoidance 	<ul style="list-style-type: none"> • Change work schedule to bring child for intervention • Change food intake • Be physically fit • Find suitable time to attend social functions • Have quality time with child • Do/plan business for child's future • Draw up a will • Plan a future care by sibling • Conduct training for child's future 	<ul style="list-style-type: none"> • Overprotectiveness/Safety behaviours • Social isolation

7. Discussion

Challenges faced by respondents also affect their children's development. This is because from the Bronfenbrenner's ecological model, the family and the extended family, the child's teacher and school, neighbours and community as well as hospital are located in the child's microsystem and mesosystem. Therefore, they have direct impact on the child's development. The presence of active or positive

interactions from the people in the child's microsystem give positive impact on the child's development while negative interactions function as negative connectors. The closest people to the child have greater influence on the child's development and progress. This includes the child's family members as well as the helper or the maid. However, from the analysis, some of the respondents did not get much support from their family members, their spouse and in-laws as well as from the children's teacher, school and the

community who did not understand about autism. Thus, without the support from family members and the community, the respondents had to manage their children alone and because of this their well-being is affected and indirectly, it also affected the children's progress. Due to the caregivers being stressed or physically tired, they were not able to give the needed interventions for their children. This led to little or no improvement in the children's behaviour.

The study found that the respondents had used emotion-focused and positive adaptive coping strategies, which enabled them to manage their lives. They were less stressed in caring for their children. However, findings in the study found that respondents had external barriers such as lack of time, resources and lack of organised constraints were not because they lack of knowledge about autism but because of other work commitments. This showed that having knowledge about autism does not ensure external barriers would not happen. The results showed that respondents in the study had used more emotion-focused strategies to manage their children. They had accepted their children's disability and from the positive reappraisal, they had viewed the disability in a positive light and focus on giving attention to the children's required needs. From the analysis, respondents had used the flexible approach because they also used problem-focused coping strategy to seek information to deal with their children's problems. Their relationship with their children was good and many of respondents did not overprotect their children with exception of two respondents, who used safety precautions or overprotective measures to safeguard their children during outdoor or shopping activities. They took measures such as having family members guarding and monitoring movements of the child when shopping at supermarkets.

The findings showed that respondents had used coping strategies which helped to reduce their children's problematic behaviours. They also accepted and employed positive adaptive strategies as well as maladaptive strategies whenever necessary. From the analysis done, the religious belief or Islamic faith in the respondents as one of the emotion-focused coping strategies had made the respondents able to accept the children's disability and think positively of the situation they were in. Religious beliefs such as Islamic faith had enabled the respondents to take control of their actions, thinking and feelings. Thus, they were better at coping with situation and were less stressed because they understood and were aware of their responsibilities. Due to this, they managed to make adjustments in their lives and were less stressful. Though respondents had used some maladaptive coping strategies to cope with the problem but these strategies were used temporarily to prevent negative circumstances. Therefore, it was the respondents' strong religious beliefs that had actually helped them to manage their children and made them develop coping and adaptive strategies to help their children improve. Having religious beliefs encouraged them to use problem-focused strategies to seek information and other supports to maintain their well-being and health. With these beliefs, parents and caregivers tried many ways to handle their challenges and adapt their lives to suit their children's and family's needs. Respondents make decisions on what strategies to use and able to manage their negative emotions such as their grief,

fear, shame and so on. Caregivers were aware of the children's well-being as their responsibility as parents. From the daily challenges they faced, they were patient and tried to cope with their lives and family. They used other emotion-focused strategies such as social or community supports to guide them on effective actions to take, and this helped improve the children's conditions. Therefore, the study discovered caregivers having children with autism had used more emotion-focused strategies to overcome their challenges and adapt themselves to living with autistic children.

From the analysis, the respondents had used more of the emotion-focused coping strategies because of their religious beliefs. They used Islamic practices such as '*doa*', '*zikir*', '*wirid*', '*solat*' and Islamic values in their daily lives with the children. Puan Shaz, Puan Azni, and Puan Hana, had accepted their children with autism as their responsibility. When Puan Shaz first knew her daughter had autism, she accepted it and stated that it was Allah's will to give her a child with autism. Puan Azni thought that Allah was testing her and so she was positive about having her autistic son. Puan Hana said it took her 5 years for her to understand and accept what god had given to her and after the doctor had diagnosed her son, she accepted his condition. Thus, Muslim respondents had resorted to using religion as a coping strategy.

Similar findings were found by Jegatheesan et al. (2010) who claimed that Islamic beliefs had made parents accept their children with a disability. Similarly, Stacey (2010) noted that in Islam, it is the responsibility of each individual to treat all of God's creation with respect, honour, and dignity and God expects adult believers to treat children with respect and to nurture them with love and educate them at the same time. In two studies done by Kheir et al. (2012) and Ting and Chuah (2010), both noted that religious faith has helped caregivers to accept the children with autism. They emphasised that the Islamic teaching stresses on endurance, resilience and acceptance of ill health, just like good health and good fortune. Similar findings were found in a study done by Tait and Mundia (2012) where parents in Brunei with autistic children have coped with their lives because of their religious faith as well as their use of emotional-focused strategies. Parents and relatives turned to God to ease their intensity of distress and it acted as an important coping strategy.

8. Conclusion

The study has found that parents and caregivers faced many challenges but the most challenging was from their child's problematic behaviours. There were also challenges from other sources or components located in the child's microsystem. This meant that the challenges not only affect the caregivers but also the child in the microsystem. Thus, handling and overcoming challenges are utmost important to reduce parental stress and improve the child's conditions. Caregivers had resorted to using religious and emotion-focused strategies because the strategies enable them to strengthen their inner self and allowed them to accept their child's disability. Problem-focused strategies were also used by caregivers to get ideas on what actions to take. Though

caregivers are using many strategies to manage their special children, there is still a strong need for more social support from their own family members as well as other parents in similar situations, the community, teachers and the government as a whole.

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