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Parents' Experiences during Child's Autism Spectrum Disorder Diagnosis Process

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Abstract

Current research has shown a substantial increase in the prevalence of Autism Spectrum Disorder. This study aims to explore parents' experiences in getting their child's autism diagnosis. The research design is a mixed research through a survey using a questionnaire as an instrument that also contains several open questions. A total of 110 respondents who were parents of children with ASD were involved in this study. Quantitative data were analysed descriptively. The findings of the study show that parents are very satisfied with the information shared by professional officials regarding their child's condition. Parents also stated that they need information that can help them get the appropriate intervention or education for their child after the diagnosis process. This study also found that parents experienced high emotional stress during the diagnosis process due to financial problems such as high diagnosis costs and pressure from family and community members who do not understand the issues faced by their children. Support for parents after the diagnosis process should continue in order to reduce the burden and stress they bear. The findings of this study could be a guide so that better services can be channelled to parents during and after their child's diagnosis process. Further studies need to be conducted to identify the types of services that can be channelled to these parents after the diagnosis process.

Keywords: Diagnosis, Autism Spectrum Disorder (ASD), Parent, Stress.

Introduction

The diagnosis process is an important process to identify the type of disability experienced by a child so that appropriate services can be channelled to him. In addition, making a diagnosis at an early stage can help parents understand their child's needs and subsequently provide the right support and care. This is very important especially for Autism Spectrum Disorder (ASD) because from a medical point of view, there is still no medicine that can treat autism. Autistic children need multidisciplinary treatment or therapy involving various experts from different fields. This is to help them overcome problems related to developmental delays.

The parenting phase is one of the phases full of challenges and fun for every human being. However, for parents of children with autism, this phase is very different when compared to raising children with typical development. According to Pisula (2007), parents face very complex challenges and pressures in the process of raising children with autism. They need

to give full attention to their child by delving into the character, nature, language, needs and others depending on the level of ASD of their child.

The experience of getting a diagnosis for their child with autism is a harrowing experience for parents involved. Accepting the diagnosis given by professionals may not be an easy experience for these parents. Through this diagnosis process, parents sacrifice their time for scheduled appointments, finances, and emotional stress. So it is not surprising that they need support from family members and the community around them.

As such, there are some issues related to this diagnosis process. Among them is the way in which professionals provide information related to their child's diagnosis of autism. Parents want clear and accurate decisions regarding the problems faced by their child with autism. The accuracy of the information delivered by professionals can reduce their anxiety and determine the next process in an effort to start treatment and therapy.

In addition, the diagnosis process should reduce the burden on parents in terms of time. This is because the long time needed for the process may be very burdensome for parents as well as their children with autism. Long waiting lists to access initial paediatrician appointment, as well as allied health and specialist assessment services have also been reported in Australia (Randall et al., 2016; Ward et al., 2016).

The process of getting an ASD diagnosis is also a drawn-out and stressful experience for parents. Further research that examines parents' experiences during diagnosis and future planning states that this process is very stressful with some parents showing increased levels of despair and self-blame leading to a decline in mental health and life satisfaction. The stress identified during this period can also contribute to the parents' difficulty in reaching a resolution with the diagnosis. This period is described as distressing, unclear, and difficult to understand, leading to uncertainty about what to do after diagnosis. Although the pressure of parents in relation to the care of children with autism has been carried out a lot (Mori et al., 2009), research on the diagnosis process of these children is still lacking. Siklos and Kerns (2007) stated that 82% of parents found the diagnostic process stressful.

Research Objective

Studies in developed countries show that there are several issues that parents face during the diagnosis process of their child's autism. However, this kind of research is very lacking in Malaysia. So the purpose of this study is to identify the experience of parents getting a diagnosis of Autism Spectrum Disorder (ASD) for their child.

Research Questions

The following are research questions to help improve our understanding of parents' experiences during the diagnosis process of their child's autism:

Do parents experience obstacles throughout the diagnosis process for their child with autism?
Are the parents satisfied with the diagnosis process?

Literature Review

Diagnostic Process

The diagnosis process is not an easy process because of the various challenges that parents have to face throughout the diagnosis process such as financial problems, time, places far from the therapy centre, emotions, travelling during and after the diagnosis process and others. Legg et al (2019) found that the diagnosis process is full of stress and challenges for parents involved. It is difficult for parents who do not understand the role of professionals such as paediatricians, specialists or general practitioners to understand the long journey for the diagnosis process and struggle to understand the difficulties of their own children. Through this difficult diagnosis process, parents want a faster, easier process with a more coherent structure and content.

The diagnosis process requires a long waiting time such as an appointment that takes a long time, sometimes weeks or months for the next appointment. Daniel et al (2021) stated in his study that delayed diagnosis causes significant stress for parents. The biggest concern for parents in the diagnosis process is the long waiting process to see a specialist to determine the diagnosis of their child with autism. This study also found that parents face multiple obstacles when getting an ASD diagnosis. A higher level of satisfaction with the overall diagnostic process is associated with, receiving a formal diagnosis at a young age, a shorter period of time between the initial concerns observed and the final diagnosis received and receiving a clear diagnostic decision from a professional as opposed to an unclear diagnostic term such as characteristics, traits or tendencies of autism. The views of parents with children with autism should be considered together with the perspective of professionals involved in the diagnosis process of their child's autism to obtain a more holistic view of the diagnosis process. With that, to ensure the quality of the diagnosis process goes well, expertise from several perspectives needs to be integrated between individuals, their families, and professional officers.

Emotional stress during and after the diagnosis process

Raising a child with autism is a struggle that parents have to face. They need to equip themselves with specific strategies and initiatives to raise their children. The stress faced by parents with children with autism is in a different phase and will not be understood by parents with typically developing children. A number of these parents experience emotional stress and problems during the diagnosis process. The emotional pressure faced by these parents include no support and understanding from family members and the surrounding community as well as several related matters during and after the diagnosis process as well as financial problems.

Eggleston et al (2019) stated that among the causes associated with the emotional stress of parents during the diagnosis process, are due to significant difficulties in the delivery of diagnosis services and the referral path for them to reach the appointment session for diagnosis. In addition, the diagnosis process includes the waiting list for evaluation which takes a long period of time for parents and they have to meet with several professionals before the diagnosis is carried out on their child.

Financial issues are one of the challenges that parents have to face when bringing up their child with autism. Siti Marziah & Shahirah (2018) stated that many parents expressed concern

because they had to spend a lot of money to get treatment or therapy for their children, usually at therapy centres run by non governmental organisations. A study by Wong (2015) also acknowledges that raising children with autism is challenging and costly because parents have to sacrifice time, energy and finances to deal with their child's issues. Therefore, due to the financial constraints faced, sometimes parents have to make sacrifices by not sending their children to therapy centres and only access therapy in government hospitals which take a very long time to get an appointment (Marziah & Shahirah, 2018).

On top of this, the process of finding a suitable school for their child with autism also puts pressure on parents, especially when dealing with kindergartens. Daniel et al (2021) stated that clinicians recognize that parents face barriers when seeking services related to their child especially in school and health service settings. In Malaysia, there are not many special kindergartens for children with special needs. Placements in special education preschools are limited and most likely are located far away from home. Therefore, most children with autism are placed together with other students in regular day kindergarten. Although placement in an inclusive setting is a good move, there have been cases where teachers, parents and students themselves were not willing to accept children with autism in their classrooms. There are teachers who do not want to accept the presence of children with autism in their classes even though parents have given explanations regarding their child's issues. When these teachers ignore the needs of these children during the teaching and learning process, parents feel stressed and emotional as they need to find a school that is suitable and accepts their child.

Methodology

The design of this study is a mixed method, collecting both quantitative and qualitative data. This research design was chosen because it is hoped that the qualitative data would yield better understanding of the quantitative data, which in turn will clarify the issues being investigated even further.

Instrument

The questionnaire used in this study was adapted using selected items taken from the studies by (Howlin and Moore, 1997; Crane, 2016). The final questionnaire has six parts with a total number of items in this questionnaire is 51 items. The six parts are the background of the respondents, the beginning of the parents' concerns, the parents' efforts to get help, the diagnostic process, the parents' satisfaction with the diagnostic process and open questions. There are 5 open questions that parents were invited to answer in the space provided. The questionnaire was distributed in softcopy using Google Form.

Procedure

Before starting the study, the researcher identified several support groups for parents of children with autism who have experience going through the diagnosis process for their child. A softcopy version of the questionnaire was disseminated to parents through social media such as Whatsapp and Facebook. Respondents were also recruited by contacting centers for children with autism. The time frame for answering the questionnaire was not fixed. Respondents were asked to answer honestly and were informed that the information provided was only used for this study and that their identity was guaranteed to be kept confidential.

Quantitative Data Analysis

Data was analysed using Statistical Packages for the Social Sciences (SPSS) software version 26.0 using descriptive statistics. Through descriptive statistics, characteristics of a group or sample can be understood by looking at the percentage, mean score and standard deviation. The interpretation of the mean score was obtained from Kamaruzaman (2009) as detailed in Table 1

Table 1
Level / Interpretation of Mean Score

Mean score	Level/Interpretation
3.5 until 4.0	High
2.7 until 3.4	Medium
1.9 until 2.6	Low
1.0 until 1.8	Very low

[Source: Kamaruzaman (2009)]

Reliability & Validity

Reliability means the degree of appropriateness and confidence in the measurement of a measurement tool should have the characteristics of stability, consistency and accuracy (Kerlinger, 1986). Reliability testing was also done on the questionnaires before being distributed to respondents. In the context of this study, the value of Cronbach's alpha coefficient obtained for parts B and E is $\alpha = 0.689$ and 0.702 . This is consistent with Nunnally and Bernstein's (1994) view that reliability coefficient values above 0.6 are acceptable and can be considered. The content validity of the questionnaire was done by inviting experts in the field of special education to evaluate the items.

Respondents

Recruitment of respondents was carried out via convenient sampling, namely through invitation and from several parent support groups on social media, such as Facebook. Data was successfully collected from 110 parents of children with autism.

The respondents consisted of 101 (91.8%) females and 9 (8.2%) males. The highest age of the parents who participated in this survey was 31 years to 40 years (70%) followed by 41 to 50 years (20%), 20 to 30 years (8.2%) and 50 years and over (1.8%). The Malay race is the highest with a percentage of 86.4% (n=95), others 6.4% (n=7), Indian 3.6% (n=4) and Chinese 2.7% (n=3). As for academic qualifications, it has been divided into several levels, namely 45 people with a bachelor's degree (40.9%), followed by a certificate or diploma of 33 people (30%), SPM / MCE / SC and 16 people (14.5%), 11 people for Master's degree (10%), three for SRP/PMR (2.7%), while primary school and Ph.D each recorded one (0.9%). The findings of

the study for income have been categorised into 3 levels, namely B40, M40 and T20. The highest percentage for B40 is income less than RM2500 which is 33 people (30%), M40 is RM4851 up to RM5880 (16.4%) and for T20 it is RM10971 up to RM15041 (9.1%). Demographic data of the respondents can be found in Table 2a below:

Table 2a
Parents' Demographic Information.

Item		Frequency (N)	Percent (%)
Gender	Male	9	8.2
	Female	101	91.8
Age	20 – 30 years	9	8.2
	31 – 40 years	77	70
	41 – 50 years	22	20
	50 years and above	2	1.8
Race	Melayu	95	86.4
	Cina	3	2.7
	India	4	3.6
	Others	7	6.4
Academic Qualifications	Primary School	1	0.9
	SRP / PMR	3	2.7
	SPM / MCE / SC	16	14.5
	Sijil / Diploma	33	30
	Degree	45	40.9
	Master	11	10
	Ph.D	1	0.9
Income B40	Less than RM 2500	33	30
	RM 2501 – RM 3170	12	10.9
	RM 3171 – RM 3970	7	6.4
	RM 3971 – RM 4850	11	10
Income M40	RM 4851 – RM 5880	18	16.4
	RM 5881 – RM 7100	15	13.6
	RM 7101 – RM 8700	7	6.4
	RM 8701 – RM 10970	8	7.3
Income T20	RM 10971 – RM15041	10	9.1
	RM15041 and above	3	2.7

The results of the study related to the gender of the children are boys with a high frequency with a percentage of 72.7% which is 80 people, while girls are 30 people (27.3%). The age of children with the highest frequency is 45 people (40.9%) are between 6 years old and 8 years

old. The second highest frequency value is 38 people (34.5%) who are aged between 3 and 5 years. The lowest frequency value is between 5 months to 10 months and 15 months to 20 months each - each has a frequency value of one person (0.9%). The highest frequency value for questions related to having already received a diagnosis is 95 people have already received a diagnosis with a percentage of 86.4%, followed by in the process with a frequency value of 14 people (12.7%) and one person (0.9%) has not yet received a diagnosis. Table 2b below summarised the demographic information of the respondents' children

Table 2b

Child's Demographic Information.

Item		Frequency (N)	Percentage (%)
Sex	Male	80	72.7
	Female	30	27.3
Current Age	5 months – 10 months	1	0.9
	11 months – 15 months	-	-
	15 months – 20 months	1	0.9
	21 months – 40 months	4	3.6
	3 years – 5 years	38	34.5
	6 years – 8 years	45	40.9
	9 years & above	19	17.3
Diagnosis received?	Yes	95	86.4
	Not yet	1	0.9
	In the process	14	12.7

The findings of the study related to the position of specialist who gave the diagnosis, the highest frequency was paediatrician which was 48 people (43.6%), the second place was psychiatrist 25 people (22.7%), followed by developmental paediatrician 17 people (15.5%), psychologist (clinical) with a frequency of 10 people (9.1%), followed by occupational therapists with a frequency value of 4 people (3.6%), children's mental health services with a frequency value of 3 people (2.7%) and the lowest is a psychologist (Education) 1 person (0.9%).

The findings of the diagnosis given, autism has the highest frequency of 92 people (83.6%), followed by learning disabilities of 8 people (7.3%), other - others of 5 people (4.5%), speech delay of 4 people (3.6%) and the lowest is developmental delay with a frequency of 1 person (0.9%). Table 3 below summarised the information of the diagnosis:

Table 3

Child's Diagnosis

Item		Frequency (N)	Percentage (%)
The position of a specialist who gives a diagnosis?	Paediatrician	48	43.6
	Developmental Paediatrician	17	15.5
	Speech Language Pathologist	1	0.9
	Occupational Therapist	4	3.6
	Psychiatrist	25	22.7
	Clinical Psychologist	10	9.1
	Educational Psychologist	1	0.9
	Neurologist	-	-
	Teacher	-	-
	Child & Adolescent Mental Health Professional	3	2.7

Diagnosis received	Autism	92	83.6
	Learning disability	8	7.3
	Speech delay	4	3.6
	Language delay	-	-
	Developmental delay	1	0.9
	Others	5	4.5

The overall level of parents' initial anxiety as shown in Table 4 was at a moderate level with a mean score of 2.57 and a standard deviation of 0.26. This shows that this matter is still at a moderate level. The item with the highest mean score is item B15, which is "Does your child with autism suffer from speech delay problems?" with a standard deviation (SP) of 1.90. While the lowest mean score of 1.23 standard deviation 0.50 is question B21 "Does your child with autism have hearing problems?"

Table 4

Early onset of parental anxiety

No	Item	Mean score	Std. deviation (SD)	Interpretation
15	Does/did your child have speech delay?	3.46	1.90	Medium
16	Does/did your child have other delays such as in walking?	1.90	0.97	Low
17	Does your child talk and/or play with other around him?	2.43	0.91	Low
18	Can your child move from one activity to another easily, for example from playing to eating?	2.88	0.95	Medium
19	Does your child have behavioural issues such as being hyperactive and tantrums?	2.80	1.04	Medium
20	Does your child follow rules at home and in school?	2.64	0.76	Low
21	Does your child have hearing problems?	1.23	0.50	Very low
22	Does your child have sensory disorder issues?	3.15	0.82	Medium
23	Does your child sleep at least 8 hours in the period of 24 hours?	3.12	0.93	Medium
24	You were not worried until a professional (doctor, nurse, preschool/kindergarten teacher) brought up the issue of your child's development.	2.15	1.20	Low
	Overall	2.57	0.26	Low

Table 5 displays the interpretation of the data on which professionals parents see for consultation related to the diagnosis of their child. For the first consultation, a total of 54 parents saw a paediatrician with a percentage of 49.1%. While the second highest percentage with a total of 21 parents for the first consultation of 19.1% were occupational therapists.

Next, the lowest percentage is with the number of one parent with a percentage of 0.9%, which is a psychologist (education).

For the second and third consultations, the highest percentage, 34.5% (n=38) and 27.3% (n=30) were occupational therapists. The second highest percentage for the second and third consultation refers to a speech and language therapist which is 20.9% (n=23), while for the third consultation it is 26.4% (n=29). The lowest percentage for the second and third consultations refers to mental health services for children and adolescents. Each showed a percentage of 1.8% (n=2) for the second negotiation and 0.9% (n=1) for the third negotiation.

Table 5

Parents' efforts to get help

No	Item		Frequency (N)	Percentage(%)
25.	Which professional did you see for the first consultation?	Paediatrician	54	49.1
		Developmental Paediatrician	14	12.7
		Speech Language Pathologist	5	4.5
		Occupational Therapist	21	19.1
		Psychiatrist	9	8.2
		Clinical Psychologist	4	3.6
		Educational Psychologist	1	0.9
		Neurologist	-	-
		Teacher	2	1.8
26.	Which professional did you see for the second consultation?	Paediatrician	12	10.9
		Developmental Paediatrician	14	12.7
		Speech Language Pathologist	23	20.9
		Occupational Therapist	38	34.5
		Psychiatrist	12	10.9
		Clinical Psychologist	5	4.5
		Educational Psychologist	-	-
		Neurologist	-	-
		Teacher	4	3.6
Child & Adolescent Mental Health Professional	2	1.8		
27.	Which professional did you see for the third consultation?	Paediatrician	4	3.6
		Developmental Paediatrician	6	5.5
		Speech Language Pathologist	29	26.4
		Occupational Therapist	30	27.3
		Psychiatrist	14	12.7
		Clinical Psychologist	10	9.1
		Educational Psychologist	3	2.7
		Neurologist	-	-
		Teacher	3	2.7
Child & Adolescent Mental Health Professional	1	0.9		

Data interpretation for figure 1 for the child's age when parents start to worry about their child's development. Referring to the bar chart above, the age of 2 years shows the highest percentage with 20% (n=22) followed by the age of 1 year and 6 months which is 18.1% (n=20) and the age of 3 years which is 14.5% (n=16). This shows that the frequency of parents starting to worry about their child's development is between the ages of 1 year and 3 years. There are also parents who start to worry about their child's development at a late age which is 10 years 3 months and 12 years with a percentage of 0.9% (n=1).

The data interpretation for figure 2 refers to the age of the child at the time of diagnosis which is at the age of 4 years with the highest percentage being 15.5% (n=17). There are also children with ASD who get a late diagnosis at the age of 12 with a percentage of 1.8% (n=2).

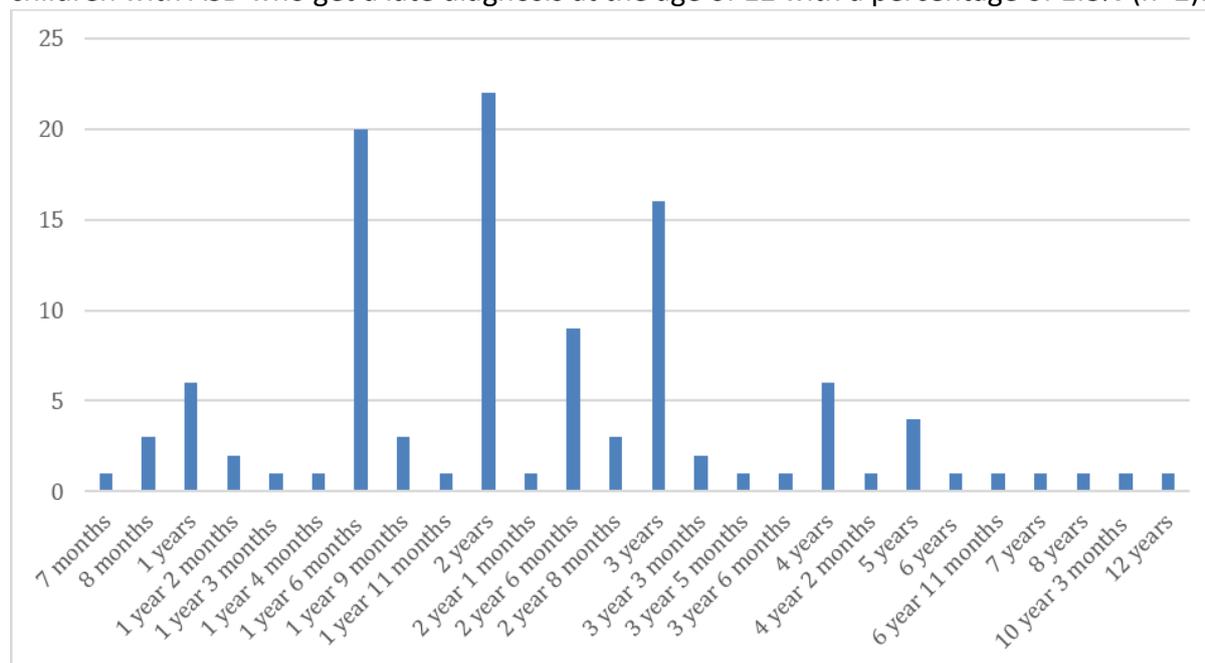


Figure 1: Child's age when parents start to worry about development

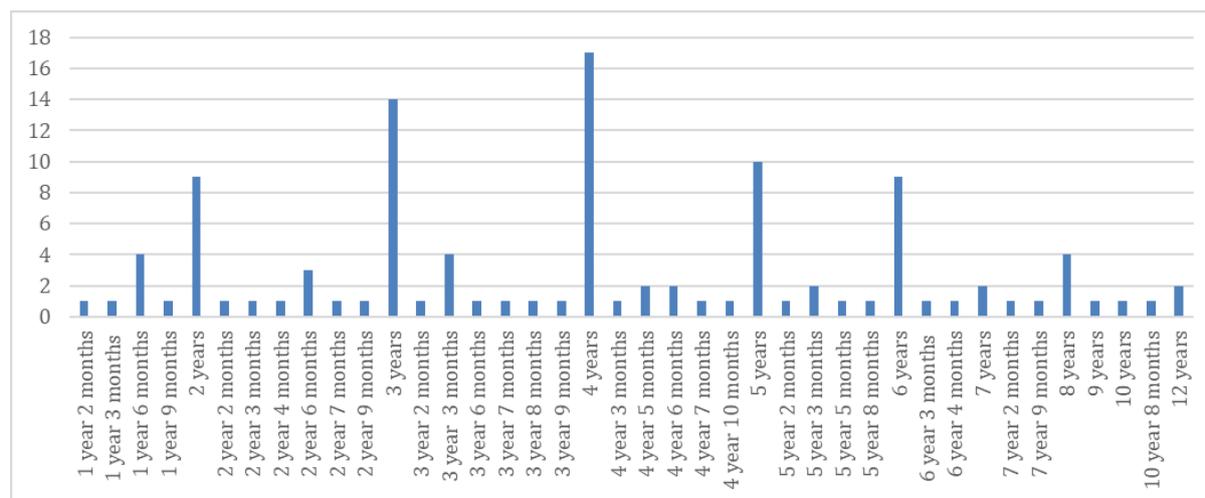


Figure 2: Child's age at diagnosis

Data interpretation through who diagnoses children with autism, referring to table 6, shows that paediatricians are the highest experts found by parents with a percentage of 40% (n=44)

followed by specialist doctors with 25.5% (n=28). The lowest percentage is Occupational Therapy with 3.6% (n=4).

The government hospital is the most frequent place for mothers to make referrals related to the diagnosis of their child with autism with a percentage of 78.2% (n=86). While the place for parents to get the diagnosis process is a private hospital with 10% (n=11).

Table 6

Diagnosis -Place and professional

Items		Frequency (N)	Percentage (%)
Who diagnosed your child?	<i>Occupational Therapy</i>	4	3.6
	Medical specialist	28	25.5
	General Practitioner	5	4.5
	TherapistPSichologisdt	-	-
	Psychologist	10	9.1
	Paediatric	44	40
	Psychiatrist	19	17.3
Place of diagnosis	Government hospital	86	78.2
	Private hospital	11	10
	Private clinic	-	-
	Health clinic	6	5.5
	Intervention centre	7	6.4

For table 7 referring to overall satisfaction with the diagnostic process, the mean score of 2.98 with a standard deviation of 0.45 is also at a moderate level. The item with the highest mean score is item E34 which is "Are you asked to refer to other professionals? for example an occupational therapist?" with mean 3.36 standard deviation 0.80. While the lowest mean score is 1.85 with a standard deviation of 0.92 which is question E41 "Are your appointments with the professional officer who diagnoses your child often delayed?".

Table 7

Overall satisfaction with the diagnostic process

No	Items	Mean score	Standard Deviation (SD)	Interpretation
33	Did you receive clear information from the professional who diagnosed your child during the diagnosing process? Eg: Information about your child and his symptoms of autism.	3.31	0.79	Medium
34	Was your child referred to other professionals? Eg: An occupational therapist.	3.36	0.80	Medium

35	Was your child sent for further tests?	3.10	0.80	Medium
36	Were you advised to see other professionals if the issues related to your child's autism persisted	3.31	0.78	Medium
37	Were you satisfied with your child's diagnosis process?	3.30	0.81	Medium
38	Was the information given to you regarding your child's autism during the diagnosis process helpful?	3.31	0.71	Medium
39	Were you satisfied with the way the professional informed you of your child's autism diagnosis?	3.31	0.81	Medium
40	Did you receive any support after your child's diagnosis?	2.93	1.02	Medium
41	Was your appointment with the professional diagnosing your child often postponed?	1.85	0.92	Very low
42	Were you satisfied with the quality of information you received during your child's diagnosing process?	3.20	0.80	Medium
43	Were you satisfied with the emotional support given by the diagnosing professional after the diagnosis was delivered?	3.10	0.78	Medium
44	Did you experience stress during the diagnostic process?	2.22	0.98	Medium
45	Did the diagnosis process take too long?	2.55	1.03	Low
46	Did you get support from professional officers and family members throughout the diagnosis process?	3.06	0.80	Medium
	Overall	2.98	0.45	Medium

4.2 Open question section data

This section reports the finding from the data that has been collected by the researcher from the open questions in Google Form. This section aims to make the description of the respondent's questionnaire analysis more focused and clear. Most respondents wrote their answers in the Malay language which was translated for this article.

Most parents agree on the importance of diagnosis, especially early diagnosis. They are also aware of the importance of beginning therapy as early as possible.

"Don't be late in bringing your child to be diagnosed" - MOTHER 101

"Keep trying to get your child diagnosed and don't give up." - MOTHER 4

"Don't postpone therapy. Therapy at an early age is very important." -MOTHER 69

"Get therapy help as early as possible." MOTHER 8

With regards to information needed, some of the parents' inputs are shared below. They agree that early support and information can help them to deal with their child's autism, especially after the diagnosis process is over.

"Experts need to give more information, not just listen to parents' stories and collect information. Parents need guidance to raise special children." -MOTHER 37

"Government hospitals/clinics need to provide more information to raise the awareness of parents and guardians. Therapy or other measures need to be known."-MOTHER 50

Having a child with autism is not an easy thing. Various challenges that parents have to overcome to provide the best education for their ASD child. Growing up and providing the best education and thinking about the future of this child with autism puts a little pressure on parents. The results from the quantitative data showed that 32 (30.9%) of the parents agreed and 11 (10%) indicated that they strongly agreed to experience stress throughout the diagnosis process. The pressure faced by parents is not only related to family and the surrounding community not understanding but also related to finances, finding a therapy centre, the future of their child with autism and others.

Parents shared the causes of their stress

"My child's future, the high cost of therapy treatment and support from other parties for him and the community view of him."-MOTHER 91

".....money and energy." -MOTHER 18

"Self-management and finding the right place for intervention"-MOTHER 31

"Looking for a cheap therapy place. The cost of therapy outside is very expensive." -MOTHER 54

"Work hours are interrupted and I take a lot of time off" - MOTHER 64

"Not able to help from the point of view of children's education due to financial constraints and appropriate knowledge." - MOTHER 14

"I hope I can raise money to treat my son through naturopathic detox and persuade my wife to also be patient. The biggest challenge is the test, even death is the biggest challenge

because I'm worried that my wife will have to take care of my child if I'm not there." -FATHER
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The findings of the study found that 87 (78.4%) parents got their child diagnosed at a government hospital. One of the reasons is because the cost of getting treatment is free. Some of them pay RM5 for each visit to see a specialist doctor at a government hospital. There are also parents stating that the cost of diagnosis is RM100, RM500 and the highest is RM4000. For parents, the cost of seeing a specialist doctor at the hospital is still affordable, but the financial cost of going to the therapy centre is overwhelming for some of them.

"Choosing a special needs school is expensive." -MOTHER 7

"Financial - Early Intervention Program which is expensive."-MOTHER 21

"The problem of the cost of the Early Intervention Program and the expensive occupational therapist class."-MOTHER105

"Not able to bear the cost of the private Early Intervention Program." MOTHER 55

"Alone in doing therapy activities at home because I can't afford to send my child to a therapy centre where the cost is too high." MOTHER 47

The hope of these parents is great even though they experience various obstacles to provide the best education for their child with autism. This is because for them early preparation is very important for the future of their child with autism.

Discussion

The results of the research that has been carried out found that the experience of parents during and after the diagnosis process is only moderate. Out of the 14 items measuring parents' satisfaction with the diagnosis process, 12 items were rated medium, 1 was rated low and another item was rated very low.

The items that were rated medium included parents' satisfaction with: the diagnosis process, the information received during the diagnosis process, information about their child's autism, the manner in which their child's diagnosis was relayed to them, emotional support and support in general during the process. To a certain extent, the qualitative data supported most of these data from the questionnaire.

Clearly, there is room for improvement during the diagnosis process. This improvement can be easily implemented by providing training to elevate the soft skills of the professionals when interacting with the parents during the diagnosis process. Further research should be carried out to clearly outline the needs of the parents so that a package could be put together for the professionals to use when supporting parents.

Previous research has shown the need for information about autism, their child's condition and intervention needs. Accurate information about their child can help parents use appropriate methods even after the diagnosis process has ended. In addition, parents also reported that in order to better understand autism, they had to struggle to get the right information and ask a lot of therapists and those who have experience related to autism.

Interestingly, despite the mediocre rate given to the process in general, parents' stress was not rated high. Instead it was also rated medium in the questionnaire. However, in the open question section, parents wrote that they were stressed with the cost of therapy and problems in finding a program for their child with autism. It is true that intervention services for children with autism in Malaysia are not easily available and if they are, the cost is very high. It is high time that these intervention services are made available and free as it is the right of these children to get these services for a brighter future. Research has also shown that early intervention for children with autism is a good investment as it saves the country from the need to provide services for adults with autism who are not able to take care of themselves.

Conclusion

For children with autism, an early diagnosis is important as it leads to the much needed early intervention that is vital for their development. Therefore it is pertinent to study the diagnosis process of these children from the view point of their parents, to investigate the challenges they face during the process. This has found that their experience is mediocre as they did not get the information and support that they need in order to help their children. They also reported a huge struggle financially and hardship in looking for intervention for their children.

Among the suggestions made to provide better services during the children diagnosis process, are to provide training and an information package to the professionals. The dire need of accessible and affordable early intervention for young children with autism in Malaysia is also highlighted in this study which calls for the attention of the policy makers for action.

From this study, suggestions for further research include developing a training module and a package kit for the professionals. Also noteworthy for further research is understanding the stress and hardship of these parents in order to look for a solution to alleviate these condition that they face.

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