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Satisfaction of Early Intervention Programme among Parents of Children with Autism Spectrum Disorder (ASD): A Pilot Study in Malaysia

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Abstract

Early intervention services play an essential role in order to support families of the children with autism spectrum disorder (ASD). In Malaysia, initial development of early intervention services has started for children with ASD. In order to improve the quality of early intervention services, it is important to ascertain the perceptions of parents with children with ASD. Thus, this study was aimed to determine the correlation between demographic of parents with children with ASD related to parental satisfaction to the early intervention services at GENIUS Kurnia Centre, Malaysia. A total of 156 parents of children with ASD aged between 3 to 7 years old who were receiving the early intervention programme, participated through stratified random sampling completed the sociodemographic survey and Client Satisfaction Questionnaire (CSQ-8). All 156 respondents reported a high level of satisfaction through calculation of the mean score of CSQ-8, which was 28.69, with a range from 20 to 32 (SD = 3.17). Sociodemographic characteristics such as child's gender, child's current and diagnosis age, presence of health problems, parent's age and educational level, and family monthly income were found to be not related to satisfaction. Our pilot study suggested that this early intervention programme provides essential support for families of children with ASD regardless of their demographic background. In future research, it is recommended to explore other variables that are linked with parents' satisfactions. Additionally, qualitative approaches such as interviews, should be used to measure parental satisfaction, as this will provide more insight on the parents' experiences.

Keywords: Autism Spectrum Disorder, Early Intervention, Family-Centred, Socioeconomic and Sociodemographic.

Introduction

Autism spectrum disorders (ASD) is a neurodevelopmental interference, which exhibits delayed and disability in the area of communication, social interaction, as well as display restricted and repetitive behaviours (Wing, 1996). It is essential to acquire an early diagnosis to access valuable and advantageous services in early intervention that benefits children with special needs and their families. Early diagnosis is essential and it's important to provide intervention as early as possible especially in the area of social and communication since the impairment may inhibit the functioning of the child in the future (Hwang & Hughes, 2000). Parents are also suggested to benefit in coping with frustrations from early intervention, as well as able to assist them in dealing with the challenges in parenting children diagnosed with ASD (Rogers, 1998). Many studies have also acknowledged that parents are the main expertise regarding their ASD child in the family-centred care (Rosenbaum et al., 1998; De Geeter et al., 2002).

At present, the focus is slowly changing from practice of child-focused and expert-driven to family-centred services due to the importance of collaboration discovered as an essential part of best practice (Johnson, 2000; Minke & Scott, 1995). Therefore, association of the parents of children with ASD in the early intervention services has led the providers to explore information on the level of satisfaction, so that the improvement could be assessed in service delivery through quality assurance. Proactive techniques through promoting and enhancing the existing strengths in the families can advantage them in fulfilling their needs as well as their child's need (Dunst et al., 1994). Formation of partnership helps in identifying the families' needs, strengths, and resources. Additionally, the collaboration could also assist families in making decisions that may encourage changes in their function positively.

Besides that, family-centred attitudes, beliefs, and behaviours among the healthcare professionals are empowered in addition to encourage positive outcomes, since the family can experience more sense of control regarding their child's care and capability in engaging completely during the therapeutic process. Parents have shown improved level of satisfaction with the intervention programme when they have more control over their children's programme activities (Banspach, 1986). Goals can be achieved when parents collaborate and practice partnership with the healthcare professionals in setting the goals (Bass et al., 1963; Latham et al., 1979). The practice of family-centred in programmes were designed mainly to assist families with special needs children has been linked with the positive progress by the children and benefits the parents by skills acquisition (Caro & Derevensky, 1991), family empowerment (McBride et al., 1993), and raised the satisfaction of the parents. The family-centred intervention included direct family concerns and needs as interventionists who could help achieve goals by building trust and a positive collaborative relationship with the families (Garshelis et al., 1993).

Among the special needs children, co-occurring threats from the environment or limitation of care giving abilities often affecting the development and growth, and frequently supports are required (Guralnick, 2007). The fundamental challenges faced by these children and families include problems in providing effective early intervention programme. Development of an intervention programme requires components that consist of findings from researches as well as advocates for resources and policies consistent with the base of knowledge and objectives of early intervention (Guralnick, 2007).

In Malaysia, both governmental and non-governmental organizations (NGOs) provide services in responding to the needs of the children with disabilities in the country. For example, community-based rehabilitation, NGOs intervention centre, as well as the government-based early intervention centre, was developed to cater to the needs of early intervention. However, there is no proper standardized programme as a model for early intervention practices in Malaysia and each centre practices differently based on their own developed method. Currently, the Malaysian government has initiated development of early intervention services for the children with ASD and their family to provide the service and eventually become a model for current and future early intervention programme nationwide (Syamsul, 2016). Therefore, there is a need to measure and assess the perceptions and experiences of parents towards the services are required to establish the continuous quality in providing family-centred early intervention services to the children with ASD and their family.

Based on our study, we foresee that, by measuring and evaluating parents' perceptions and experiences of the services, the weakness and aspects that need improvements can be determined and implemented as a model for current and future early intervention programme for general practices in Malaysia. Hence, this study was aimed to highlight the requirement needed within the family-centred context and establishment of awareness among parents of children with ASD on how the information can be used to practice and assist in identifying the strengths. Additionally, by understanding the needs of the families, we would also enable the appropriate authorities to design and the needful service policies and programmes in the future.

Methods

Ethical Consideration

This study was carried out in accordance with relevant guidelines and regulations and approval was obtained from the University of Technology MARA (UiTM)'s Research Ethical Committee (Ethics approval number: 600-IRMI (5/1/6)). All information from the participants kept private and confidential.

Study design and settings

This cross-sectional survey design involved parents of children with ASD, who were attending an early intervention programme in GENIUS Kurnia, the first government-operated early intervention centre for children with ASD and their families in Sentul, Kuala Lumpur, Malaysia. GENIUS Kurnia centre provides a high-quality early intervention and education for children with autism to prepare them for mainstream schools. The GENIUS Kurnia applies transdisciplinary approach, where the team consists of various professionals such as occupational therapists, speech therapists, early childhood educators, special educators and social workers to give the best services for children with ASD in Malaysia. Intervention strategies practice in the centre incorporate evidence-based practice and naturalistic teaching as well as active participation by parents. This study, was based on a quantitative study and carried out according to Babbie (2015) as it allows for a broader insight, involving a higher number of respondents, and improving the generalization of the results.

Recruitment of participants and data collection

A total of 182 parents or families of children with ASD whom have participated in the early intervention programme for at least six months or more were included in this study. The participation and selection was made using stratified random sampling. A written permission was obtained from the centre for the data utilization and collections (Reference letter: KURNIA.500-2/6/1(116)). Upon receiving consent from parents, the questionnaire was given to individual parents and later collected in two or three weeks once they had completed the survey forms. However, only 156 out of 182 responses completed the whole survey. This cross-sectional survey design implemented where data was collected at one point in time between July and December 2018.

Research instruments

The prepared questionnaire consists of three sections which were on demographic profile and Client Satisfaction Questionnaire (CSQ-8). A demographic questionnaire consists of personal and demographic questions of the family, such as the child's gender, presence of health problems, relationship with the child, parent's educational level and family's monthly income were also included and the child's current and diagnosis age, and parental ages were also recorded. The CSQ-8, a standardized scale consists of eight questions with a four-point response scale was used to access the satisfaction with a programme (Larsen et al., 1979) (Table 1). This was a questionnaire-based on the Likert scale rating, which to measure the level of agreement among the respondents. The items in the questionnaire implied various aspects of the programme. The response scale scores vary with '4' representing high satisfaction and '1' expressing low satisfaction of the respondents based on their perception regarding the services they are currently receiving.

Table 1:
CSQ-8 question domain

Item (abbreviated)
1. Quality of Service
2. Kind of service required
3. Met needs of service
4. Recommend to a friend
5. Amount of assistance
6. Overall satisfaction
7. Come back

Scores for each item ranging from ‘1’ to ‘4’, and for an overall score, total item responses ranging from ‘8’ to ‘32’ (higher score indicates high satisfaction). This questionnaire shows adequate psychometric properties and reviewed by several independent sources (Ciarlo et al., 1981; Corcoran & Fischer, 1987). For the concurrent validity, scores on the CSQ-8 correlated highly with clients' ratings of global improvement of symptomatology and therapists' ratings of clients' progress and engagement. CSQ-8 Malay (Malaysian national language) version was also used for this study (Siok-Ping & Mohd Jaladin, 2013).

Data Analysis

Data analysis involves three primary steps which were 1) cleaning and organizing the data for analysis, 2) describing the data and testing hypotheses (descriptive statistics) and 3) models (inferential statistics). The data analysis was divided into two categories, which consist of 1) descriptive data analysis and 2) inferential data analysis. Inferential statistics involves generalizing from a sample to the population from which it was selected (Larson, 2006). Multiple linear regressions were used to determine the predictor of the dependent variable, which in this study was satisfaction. Simple linear regression was also used to determine which variable to include in multiple linear regressions. The p-value of 0.05 was chosen for significance values aligned with health sciences studies.

Result

The age range of the parents who participated in this study were 25 – 48 years old (Mean= 34.96, ±4.34). Of the total 156 survey completed, 132 were of male children (84.6 %) and 24 female children (15.4 %) parents. The children were aged between 2 to 7 years (Mean= 4.72, ±0.81). Among the 156 children, 141 children (90.4 %) were reported with no health problems; while the remaining (9.6 %) had other health issues (Table 2).

Majority of the respondents in the study were mothers (67.3 %). There were four different groups of ethnicity, 128 Malays (82.1 %), 17 Chinese (10.9 %), six Indian parents (3.8 %), and five of the parents (3.2 %) were from the other ethnicity. The highest percentage (46.2 %) of the parents was bachelor degree holder, and only 0.6 % of the parents did not complete high school. Apart from that, the families involved in this study were majority from low monthly salary less than RM4, 000 (<USD1, 000) per month (34.6 %), and only 9.6 % of them had a monthly salary above RM15, 001 (>USD3, 500) (Table 2).

Table 2:
Descriptive Analysis of Demographic Variables (N=156)

Description	**N (%)**
Parents' ethnicity	
Malay	128 (82.1)
Chinese	17 (10.9)
Indian	6 (3.8)
Others	5 (3.2)
Parents' education level	
Secondary school	32 (20.5)
Diploma	34 (21.8)
Bachelor degree	72 (46.2)
Master or higher	17 (10.9)
Others	1 (0.6)
Family's monthly income	
RM 4,000 and below	54 (34.6)
RM 4,001 – RM 5,000	27 (17.3)
RM 5,001 – RM 7,000	17 (10.9)
RM 7,001 – RM 9,000	13 (8.3)
RM 9,001 – RM 11,000	20 (12.8)
RM 11,001 – Rm 13,000	6 (3.8)
RM 13,001 – RM 15,000	4 (2.6)
RM 15,001 and above	15 (9.6)
Relationship with child	
Mother	105 (67.3)
Father	51 (32.7)
Child's gender	
Male	132 (84.6)
Female	24 (15.4)
Child's presence health problems	
Yes	15 (9.6)
No	141 (90.4)
Age median	
Child's current age	4.72 ± 0.81
Child's age of diagnosis	3.15 ± 0.98
Parent's age	34.96 ± 4.34

All the 156 parents who completed the eight items using a four-point rating score, scored satisfaction level in the range of 20 to 32 (Figure 1). Based on the Larsen et al. (1979), the total score of CSQ-8 can range from 8 to 32, with higher scores reflecting higher satisfaction among the respondents. The mean score of CSQ-8 among the parents was 28.69, with a range from 20 to 32 (SD= 3.17), indicating a high level of satisfaction among the parents who receive the early intervention programme at the centre.

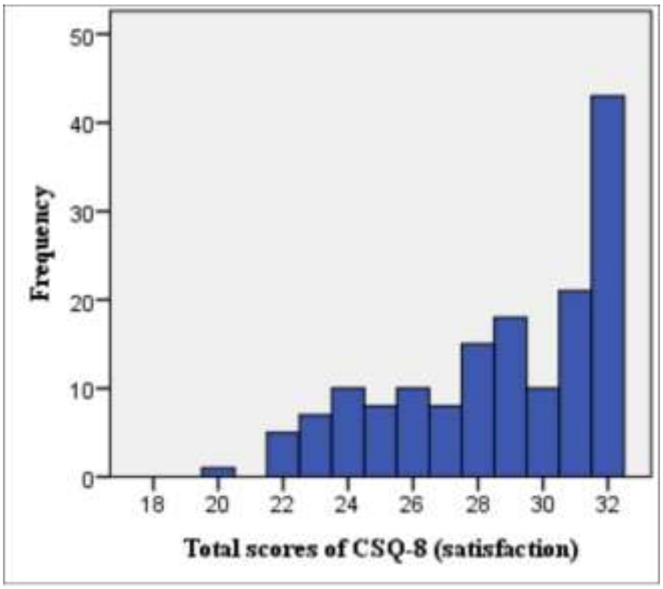

Figure 1: The total score of CSQ-8 on level of satisfaction among parents of children with ASD

Inferential analysis was conducted to determine the difference between satisfaction and demographic profile such as child's gender, presence of health problems, relationship with the child and parent's educational level. A Mann-Whitney U test indicated that satisfaction level were different between parent with male child (Median=29.00, IQR=5) and female child (Median = 27.50, IQR = 8), Z = -0.901, p = 0.37. Therefore, there is no significant difference was observed between the parental satisfaction and gender of the child.

An independent samples t-test was used to compare satisfaction among the parents with the presence of a health problem of the child and relationship with child (Table 3). The results showed that no significant difference on the level of satisfaction between child with no health problem (M= 28.66, SD= 3.15) and presence of health problem (M= 29.00, SD= 3.49) with a difference of -0.34 (95% CI, -2.05 to 1.37), t (154) = 0.39, p= 0.69.

Table 3:
Comparing mean satisfaction between mother and father of children with ASD

Variable	*n*	Satisfaction Mean (SD)	Mean difference (95% CI)	*t* statistics (df)	*p*-value*
Relationship with child			-1.19 (-2.16, -0.22)	2.40 (122.06)	0.02
Mother	105	28.30 (3.34)			
Father	51	29.49 (2.65)			

**p*<0.05

An independent samples t-test was also used to compare the level of satisfaction among the parents with the relationship with the child (Table 3). The results indicated that satisfaction level were significantly between father (M= 29.49, SD= 2.65) and mother (M= 28.30, SD= 3.34) with a difference of -1.19 (95% CI, -2.16 to -0.22), t (122.06) = 2.40, p= 0.02.

Kruskal-Wallis ANOVA was used to compare satisfaction with parents' educational level and family's family income. We notice that there was no statistically significant differences between parents with educational level from secondary school (Median= 30.00, IQR= 8), diploma (Median= 29.00, IQR= 4), bachelor degree (Median= 29.00, IQR= 5), and Master/PhD (Median= 28.00, IQR= 7), X2 (4)= 2.52, p= 0.64. Similarly, there were no statistically significant differences observed between families with monthly income less than RM4, 000 (Median= 30.00, IQR= 6), monthly income RM4, 001 to RM5, 000 (Median= 29.00, IQR= 4), monthly income RM5, 001 to RM7, 000 (Median= 28.00, IQR= 6), monthly income RM7, 001 to RM9, 000 (Median= 30.00, IQR= 4), monthly income RM9, 001 to RM11, 000 (Median= 28.00, IQR= 7), monthly income RM11, 001 to RM13, 000 (Median= 30.00, IQR= 9), monthly income RM13, 001 to RM15, 000 (Median= 27.00, IQR= 7), and monthly income more than RM15, 000 (Median= 29.00, IQR= 6), X2 (7)= 5.75, p= 0.57.

In assessing the correlation between satisfaction and demographic profile such as child's current age, child's diagnosis age, and parental age, Spearman's correlation coefficients (r) was calculated to assess the size and direction of the relationship (Table 4). Results of the Spearman's correlation coefficients indicated that there was no significant association between satisfaction and child's current age (rs (154) = -0.15, p = 0.07), child's diagnosis age (rs (154) = -0.12, p = 0.15), and parental age (rs (154) = - 0.07, p = 0.41).

Table 4:
Correlation coefficients (r) demographic profile and satisfaction of child's current age, child's diagnosis age, and parental age (n=156).

Variable	Median (IQR)	*r*	*p*-value*
Child's current age	5.00 (1)	-0.15	0.07
Child's diagnosis age	3.00 (2)	-0.12	0.15
Parental age	34.00 (6)	-0.07	0.41

*Correlation is not significant

Overall, families reported being satisfied with the early intervention services. Sociodemographic characteristics such as child's gender, child's current and diagnosis age, presence of health problems, parent's age and educational level, and family's monthly income were found to be not related to the level of satisfaction. However, level of satisfaction were significant between mother (M= 28.30, SD= 3.34) and father (M= 29.49, SD= 2.65) with a difference of -1.19 (95% CI, -2.16 to -0.22), t (122.06) = 2.40, p= 0.02.

Discussion

Parental satisfaction established an essential element for early intervention programme assessment. The opinions from parents contribute valuable insight into the impact of early intervention and provide feedback for the improvement of the services offered (McNaughton, 1994). Our study was found to be consistent with a similar survey conducted by McIntyre & Zemantic (2017), as they also examined the services for young children with ASD and reported high satisfaction among parents in general. The various type of interventions received by the sample of the study may fulfil the child's need as almost all of the children in the study sample received special education and related intervention including occupational therapy, speech therapy, adaptive physical education and physical therapy, which may support skill acquisition across domains including social, communication, adaptive and motor skills. In association with the present study, different settings, as well as different type, frequency, and approach of interventions may become cofounding variables that influence the study findings.

Our study also in parallel with previous studies carried out by other researchers, among parents with developmental disabilities children who were highly satisfied with early intervention programs (Favez et al., 2008; Iversen et al., 2003; Lanners & Mombaerts, 2000). Our results showed that no significant findings found between the level of satisfaction and the demographic profile such as gender of the child, presence of health problems, parental educational level, as well as family's monthly income. Additionally, the presence of healthcare problems was not related to parental satisfaction. Although there was no significant correlation found in our findings, the status of health may influence the level of satisfaction in other healthcare services, such as in hospitals and different healthcare settings. Many past studies in other healthcare services have investigated the contribution of both individual and service provider characteristic for healthcare services satisfaction. The individual factors, such as health status and age were found as stronger determinants of satisfaction with healthcare services when compared with the organizational factors (Hekkert et al., 2009; Thi et al., 2002; Young et al., 2000).

Similarly, Konstantina et al. (2014) also studied on parental satisfaction with early intervention specifically for children with visually impaired and multiple disabilities in Greece, where no correlation found between satisfaction and educational level. Additionally studies by Iversen et al. (2003), also support that no significant differences with parental education. On a contrary, Bailey et al. (2004) reported that positive experience was found in higher household income compared to mothers with less education and low household income who are more likely to describe negative experiences. The differences in demographics may influence the satisfaction among the families due to the awareness of the early intervention, and demanding of services as highly individualized. The parents with higher education and income exposed to the awareness and information regarding the condition of their child and availability of the intervention services; thus early identification received and the efforts required were lesser compared with low family background. Based on our findings, majority of the families were from the lower monthly income, perhaps explains why the parental satisfaction in this study was higher, due to less demanding of the services compared to more-advantages families.

We also noticed that fathers have higher satisfaction with the early intervention services received compared with the mothers. Bailey et al. (1998) described that mothers have higher awareness and service demand compared to fathers. Greater awareness was associated with greater dissatisfaction with the services. Due to mother's higher awareness and concern of their child, they demand a better quality of services and higher expectations. In general, mothers participated more actively in the intervention programs and are more aware of requirements and need of their children (Bailey et al. 1998). Mothers expect more consultation and information from the professionals to apply the intervention at home. Linder-Pelz (1982) explained that 8 % of the variance in patient satisfaction influenced by the expectations and appeared as the most important social psychological predictor of satisfaction. Similar study conducted by Jackson et al. (2001) also underlined that lack of unmet expectations was a strong satisfaction predictor. Mothers of children with disability demanded detailed information on a range of aspects related to their children and expected the intervention programme would meet all the needs of the child, family and the community involvement in the designing and performing the intervention goals (Dromi and Ingber, 1999).

In addition, their demand for guidance and support from practitioners in many fields, including counselling, therapy, comprehensive childcare training and assistance in familiarizing themselves with their children's disabilities, requires one specialist as a family case manager to gather and analyze all available information about the child (Dromi and Ingber, 1999). Besides, mothers expect professionals to be experts in area of intervention, well trained, as well as experienced in interpersonal skills such as active listening, considerate, empathy, and available and reliable in times of need (Dromi and Ingber, 1999). However, when a young child has a disability and high support needs, carers usually involve mothers in specialist services to help their child (Thompson, 1998). It may encourage the need for mothers to be concerned and aware of the knowledge in a wide variety of areas related to the impairment and rehabilitation of their child, as well as awareness of available resources, options, and their own needs. Moreover, function of the mothers, who are more vocal and prefer to openly express their views and desires as they pose themselves, could also lead to more demand and less satisfaction.

The opinions of family and acquaintances and media influences were also linked with satisfaction (Crow et al., 2002). This may explain the level of less satisfaction among the mothers compared to fathers, as more significant informal social support for assistance and advice, such as family and friend were found to encourage higher expectation from the intervention programme. Dromi and Ingber (1999) also suggested several possible explanations; including mothers who were relieved from pressing daily tasks have more free time to think about their expectation from the intervention programme. However, mothers have been encouraged to openly discuss their needs with greater social support.

In the evaluation of family-centred care, Arango (2011) described the need in considering three aspects of context, process, and outcomes. In the process of service delivery, the manner of family-centred service emphasized, including the relational and participatory aspects of service (Dunst, 2002). Study suggests that enabling, partnership and comprehensive care of the healthcare provider as well as providing general information to the families were the best predictors for satisfaction among parents of children with ASD who received early intervention (Dunst et al., 2007). Additionally, study by Ziviani et al. (2014) suggested coordinated and comprehensive care predicted the highest parental satisfaction, followed by providing general information. Hence, services delivered by healthcare providers significantly influence the extent to which families are satisfied with the services.

On the other hand, generic information was included in relation behaviours, which practice good clinical practice and help families to have a positive confidence in families' strength and abilities (Dunst & Dempsey, 2007). The greater satisfaction of early intervention services may be demonstrated by several information delivery mechanisms for the parents. For example, by including the family during the intervention session, the specific information given to the parents as the interventionist can learn and better understand their strength and capabilities so that information can be delivered based on their understanding. In addition, to providing information to the families directly during the intervention session, the parents were encouraged to acquire information and knowledge through another medium, such as the center's Massive Open Online Courses (MOOC) called iKurnia. These online platforms offered for free and suitable in providing information and contents for various backgrounds of individuals (Petronzi & Hadi, 2016).

Education and seminars on weekends held by the centers may also justify parents' greater satisfaction. The topics delivered during the workshop series aimed at enhancing knowledge and skills in managing and educating children with ASD, which include topics on understanding ASD and sensory issues, behaviour management strategies, toilet training and adaptive skills, early communication skills, work task system and social stories, pre-writing and stimulation, play and social skills, and many other relevant topics. Besides providing information to the parents, these trainings and seminars have supported the public and raised awareness of disabilities among people in community.

Conclusion

Early intervention services play a fundamental role in supporting families of children with disabilities. Our study focused on early intervention, especially among children with ASD and the parents' satisfaction. Therefore, family-centred practices in the early intervention program may become a model for other early intervention services in Malaysia. For example, the results suggest that the service providers in early intervention may need to pay particular attention to meeting the child's and family's holistic needs, facilitating parents active involvement in their child care, and providing information about disabilities, community services, and sources of information.

Future research is needed to explore other variables such as the severity of the diagnosis, behaviour of the child and child's skills development and their link with parents' satisfaction. It is essential to explore how attrition or wear related to parental resistance can affect the implementation of the intervention, thereby reducing the development of their children with ASD. Moreover, incorporating qualitative methodologies such as interviews in addition to the rating scales in measuring parental satisfaction were also recommended, as it will provide more information on the parental ratings about the early intervention services.

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Conflict of Interest

The authors declare no conflicts of interest.

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