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Artikel Asli/Original Articles

Reframing Services for Malaysian Students in Schools: Time to Bring Occupational Therapy into the Classroom

Merangka Perkhidmatan bagi Pelajar Malaysia di Sekolah: Tiba Masanya untuk Membawa Terapi Carakerja ke dalam Bilik Darjah

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ABSTRACT

Autism spectrum disorder is a developmental disability that has gained increasing attention in Malaysia. Much effort is now being taken to include children with autism spectrum disorder in the school system, either in inclusive settings or in special educational settings. However, this endeavor raises many challenges for the children with autism spectrum disorder, their families and for service providers. The current study uses a qualitative approach to investigate parents' perceptions of problems faced by their children with autism spectrum disorder in issues related to academic skills. A face-to-face interview was performed with parents of children with autism spectrum disorders who were receiving occupational therapy services for their difficulties in academic related skills. Findings indicate that most of the difficulties faced by these children are related to skills needed to be accepted at school, such as ability to communicate and socialize and this often limit their performance at school. These findings not only raise and discuss important implications for service providers such as teachers, health care professionals and policy makers, but also lead to suggestions for future research.

Keywords: Autism spectrum disorder; academic performance; collaboration; service providers

ABSTRAK

Gangguan spektrum autisme merupakan gangguan perkembangan yang semakin mendapat perhatian semenjak kebelakangan ini. Banyak usaha telah dilakukan untuk membolehkan kanak-kanak yang mengalami gangguan spektrum autisme agar mereka dapat mengikuti proses pembelajaran sama ada secara inklusif mahupun di dalam pendidikan khas di sekolah. Walau bagaimanapun, usaha ini menemui pelbagai cabaran bagi kanak-kanak tersebut, keluarga mereka, serta pemberi khidmat. Kajian kualitatif ini bertujuan untuk memahami isu berkaitan skil akademik yang dialami oleh kanak-kanak tersebut daripada perspektif ibu bapa mereka sendiri. Temuduga secara bersemuka telah dilakukan bersama ibu bapa kepada anak yang mengalami spektrum autisme dan dirujuk untuk terapi carakerja kerana masalah berkaitan skil akademik. Dapatan kajian menunjukkan kebanyakan masalah yang dihadapi oleh kanak-kanak tersebut adalah berkaitan dengan kemahiran yang diperlukan untuk terus diterima di sekolah, seperti keupayaan untuk berkomunikasi dan bersosialisasi serta kerap juga, menghalang pencapaian akademik mereka di sekolah. Dapatan dari kajian ini bukan sahaja memberi implikasi penting kepada pemberi khidmat seperti guru, profesional sains kesihatan, dan pembuat dasar, malah mampu menyediakan ruang kajian yang lebih mendalam untuk masa akan datang.

Kata kunci: Gangguan spektrum autisme; pencapaian akademik; kolaborasi; pemberi khidmat

INTRODUCTION

With a total population of 28.3 million people living in both Peninsular and East Malaysia (Department of Statistics Malaysia 2012), Malaysia experienced a significant increase in numbers of people with disabilities according to the 2012 census. In the learning difficulties area which include the number of responses for people with Autism Spectrum Disorder (ASD), there have been 120,109 cases reported for this category of disability (Ministry of Women Family and Community Development Malaysia 2012).

Malaysia as a developing country, is ranked 64th on the human development index and is grouped in the

High Human Development category (United Nation Development Programme 2013). As a capable and resourceful country, Malaysia should develop its own practices in terms of health care and educational services for people with disabilities (Kadar et al. 2015). In order to achieve this, the potential stakeholders of these services should be actively involved in the development of such plan, especially in the areas concerning health care and educational services for children with ASD (Spann et al. 2003; White 2014).

The increased prevalence of children with ASD has been reported worldwide [(Center for Disease Control and Prevention [CDC] 2007)]. It is hopeful that the increased

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incidence of children with ASD could lead to increase in attention and funding supports needed in managing these cases from both the government and private sectors. According to the Diagnostic and Statistical Manual of Mental Disorders – 5th Edition (DSM-V), children diagnosed with ASD are typically presented with difficulties in social communication and interaction as well as in behavior (American Psychiatric Association 2013). The challenging behavior exhibited by children with ASD might be due to their difficulties in sensory processing, such as poor abilities in sensory modulation (Ben-Sasson et al. 2009; Schaaf et al. 2011; Tomchek & Dunn 2007). A study by Ashburner, Ziviani and Rodger (2008) found that the difficulties in aspects of sensory processing such as sensory-seeking and sensory-underresponsiveness behaviors could lead to academic underachievement in children with ASD. Given there could be many causal factors affecting children with ASD, they need to be carefully diagnosed. Efforts in managing problems faced by children with ASD and their families need to be appropriately channeled, so that problems of not being able to fully and actively participate in their life and community settings could be adequately addressed (Rodger & Umaibalan 2011; Spann et al. 2003)

According to a published preliminary study, there is generally low public awareness on the difficulties faced by children with ASD in Malaysia, with some participants having never heard of the condition (Md Shamsudin & Abdul Rahman 2014). This ignorance would help to explain the negative reaction and stigmatization placed on children with ASD and their families (Gray 1993; Woodgate et al. 2008), specifically, on those who exhibit challenging behaviors (Ashburner et al. 2008; O'Donnell et al. 2012; Schaaf et al. 2011). This stigmatization could increase psychological stress in parents or caregivers of children with ASD (Schaaf et al. 2011). It is therefore important to carry out a more comprehensive look at the needs of the children with ASD and their families if we are to understand their challenges.

In Malaysia, service providers such as teachers are generally aware on the positive benefits and gains that stem from an inclusive education for children with special needs (Mohd Ali et al. 2006). However, there are some teachers in Malaysia who were reported as being apprehensive in accepting children with ASD into their classrooms. This is mainly due to the fact that they have to teach in a less supportive environment and in addition, being puzzled by the complex characteristics shown by the children (Mohamad Razali et al. 2013). Some teachers, despite their willingness to accept children with ASD, have expressed a need for ongoing training before and during the period when these children are included in their classroom (Mohamad Razali et al. 2013). On the other hand, parents also often expressed concerns about the services that their children with ASD receive at school, including their unmet needs that are associated with the normal functioning of the school systems (Spann et al. 2003; White 2014).

The focus of this study is to understand the challenges faced by children with ASD in Malaysia, in terms of their academic-related activities, as perceived by their parents. A thorough understanding of parents' perceptions of the academic challenges experienced by children with ASD might create a platform from which service providers can equip themselves with necessary expertise to assist these children (Barnhill et al. 2010; Brantlinger et al. 2005; Nabors et al. 2008; Simpson 2004). Difficulties in academic-related activities exhibited by children with ASD should be countered as early as possible, preferably, before enrolling in school. Such strategy should help in increasing the chances of children with ASD of being accepted and nurtured in the school system.

METHOD

DESIGN

This qualitative research study involved face-to-face, openended interviews with the participants. A set of guiding questions was developed and thematic data analysis were employed. The primary questions guiding the interview process were: (1) What are the main difficulties experienced by your ASD child that hinder his/her academic performance in school, (2) What are other factors (not caused by your child's own ability or inability) that might influence his/ her academic performance in school and (3) How 'parentteacher communication' (if any) in regards to the academic performance of your child were carried out? These primary questions were basically used to help steer the interview process, but other questions which emerged during the interview sessions were also discussed (DiCicco-Bloom & Crabtree 2006). The qualitative research design adopted in this study was considered as appropriate and as the most suitable method for understanding the parents' perceptions of difficulties experienced by children with ASD in the school system (Brantlinger et al. 2005; DiCicco-Bloom & Crabtree 2006; Woodgate et al. 2008).

RESEARCH ETHICS

Ethical approval from The Medical Research and Innovation Secretariat, The National University of Malaysia, was obtained and allocated a project number: NN-005-2014. Ethical standards were carefully maintained throughout the study process and parents who agreed to participate were given verbal and written explanations of the study and asked to sign consent forms. The parents were also explained that the interview would be audio-recorded for analytical purposes only and consent to do so was also obtained from them. The parents were also advised that they could withdraw from the study at any time without jeopardizing the health care or educational services that they have been receiving for their children with ASD.

PROCEDURES

In the effort of understanding the difficulties experienced by children with ASD, parents are considered as legitimate informants that could most appropriately provide valuable information about their children. Because of this, the study recruited parents of children with ASD from those who receive occupational therapy (OT) services in the Pusat Perubatan Universiti Kebangsaan Malaysia (PPUKM) located in Kuala Lumpur, Malaysia. PPUKM is one of the most significant teaching and reference hospitals in Malaysia, as it receives referrals throughout the country, including referrals of children with ASD. Children with ASD are often referred for OT services for various intervention needs, including those related to academic difficulties (Ashburner et al. 2008; Schaaf et al. 2011). All referrals of children with ASD aged between 3 to 12 years by pediatricians or child and adolescent psychiatrists, to the OT services in PPUKM received between July and December 2013 were screened. This was to identify children that were referred for school or pre-school assessments and interventions and/or those that were referred due to academic difficulties. After the identification, parents were approached and then invited to the study. To be eligible for the study, the children with ASD must not have been diagnosed with any other known physical disabilities or intellectual difficulties.

A total of eight parents of children with ASD agreed to participate in the study. They were six mothers and two fathers. The parents ranged in age from their early 30's to mid 40's. All parents held a full-time paid job, except for two mothers who were full-time housewives. The six boys and two girls with ASD were aged between 4 and 8 years old. These children received OT intervention and were referred for OT due to their difficulties in academic-related skills. All children involved were reported by parents to have various levels of severity in terms of communication abilities, social participation skills and behavior. Table 1 shows the demographic characteristics of the parents and their children with ASD involved in this study.

TABLE 1. Demographic characteristics of the	ne parents and their children with ASD
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Parents' code	Relationship with the children with ASD	Parents' age (years)	Parents' occupation	Gender/Age of the children with ASD (years)
P1, M, 4, G	Mother	30 years	Post-graduate student	Girl/4 years
P2, M, 3, B	Mother	20 years	Executive officer	Boy/3 years
P3, M, 8, G	Mother	41 years	Lecturer	Girl/8 years
P4, M, 5, B	Mother	38 years	Housewife	Boy/5 years
P5, F, 7, N	Father	37 years	Project manager	Boy/7 years
P6, M, 4, B	Mother	39 years	Administration officer	Boy/4 years
P7, M, 8, B	Mother	43 years	Housewife	Boy/8 years
P8, F, 4, B	Father	40 years	Businessman	Boy/ 4 years

DATA COLLECTION AND ANALYSIS

Prior to the interview sessions, parents were asked to complete a brief demographic form. This activity was used as a platform from which rapport with the parents could be established (DiCicco-Bloom & Crabtree 2006). Each interview was carried-out in a vacant room located in the OT department in PPUKM to prevent the conversation from being overheard (Liamputtong 2009). Data collection were done over a 3-month period. All interviews with parents, performed by the third author, were audio-recorded. The face-to-face, open-ended interviews gave parents an opportunity to explain their concerns in their own words, as well as providing the researchers with an opportunity to clarify any information provided. All interviews were carried out with only one parent in each session and they lasted between 1.5 and 2.5 hours. Questions that asked to the parents include:

1. What are the problem/s faced by your child that might hinder their academic performance at school?

- 2. What are the external factor/s (other than the child own abilities and/or disabilities) that might influence their academic performance at school?
- 3. What are your perception/s regarding to the problem/s faced by your child that might hinder their academic performance at school?
- 4. How do you reflect the relationship and communication between teachers and parents regarding to the problem/s faced by your child at school?

In order to ensure accurate interpretations of parents' perspectives were made, at the end of each interview, preliminary data interpretations on the main issues parents have discussed were also being performed by the third author. This *member checking* procedure would ensure accurate interpretation of data and correct identification of issues in the data analysis process (Liamputtong 2009). All interviews were transcribed verbatim using *Microsoft Word 2008* on a password protected computer. All data transcription was performed by the third author and data were analyzed concurrently with data collection. The transcribed data were reviewed sentence-by-sentence

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repeatedly in order to understand its meaning and to identify the issues that were raised. In order to maintain trustworthiness in the data analysis, an *audit trail* (Liamputtong 2009) was performed with the first author. To ensure correct interpretations were being made, any discrepancies in the data interpretation were confirmed by referring back to the transcriptions (Liamputtong 2009). The identified issues were considered to be saturated when issues recurred during the analysis process.

For de-identification purposes, all parents were coded by numbers (p1 to p8), their role (M for mother and F for father), followed by the age of their child with ASD and the child's gender. For example: p3, M, 8, G means participant number 3, mother, child age is 8 years, girl with ASD.

RESULTS

Six main issues that hinder the academic performance of children with ASD involved in this study were identified by their parents.

ISSUES IN SOCIAL RELATIONSHIP SKILLS

Difficulties in social relationship occur in all children with ASD involved in this study. Parents reported that their children with ASD do not seem to be able to wait for their turn, are not willing to share their belongings and do not know how to socialize with their peers at school. Parents expressed this as follows:

He plays quite rough. When there are other children trying to approach and play with him, he will push them away and prefers to be alone... he always refused to do activities in groups at school... (p4, M, 5, B).

My daughter cannot wait for her turns when playing with her siblings and also with her friends at school... sometimes she can play with them, but the way she plays looks weird to me and it does not seem like she is playing together with them... (p3, M, 8, G).

I did mention to her teacher that she does not like to play with other children, there are also some other children with autism in that school, so her teacher understands her behavior and why she does not like to play with others... (p1, M, 4, G).

My son does not play with other children. He can rarely share his belongings with others, but most of the time he will simply grab things that he wants from others... (p8, F, 4, B).

ISSUES IN SOCIAL-COMMUNICATION SKILLS

Communication difficulties mentioned by parents among the children with ASD involved in this study consist of an inability to establish eye-contact, an inability to follow instructions and limited and/or no verbal communication abilities. For example: She does not have any eye-contact with us... she simply ignores us when we call her name... her teacher tells me that she can says a few words, but we are not aware of that because we never heard she is saying it at home... (p3, M, 8, G).

Whenever she wants something from her teacher at school, she will pull her teacher's hand to get to the things that she wants. If her teacher calls her name, she will rarely respond to it... the way she does things is by getting close to her teacher, looking at the teacher's face, or usually she will simply ignore her teacher... (p1, M, 4, G).

ISSUES RELATED TO ACADEMIC SKILLS

Difficulties related to academic skills involved an inability to write, copy, or focus during lessons. All the children with ASD involved in this study were reported as only able to scribble and they had poor attention spans, as some parents expressed:

She still cannot write...she cannot do it when we instructed her to do it, for example, when we asked her to draw a circle... if she feels like doing it, she will do it... she is not disruptive in the classroom, she will not disturb her friends, but she will make some kind of noise [that will disturb others]... (p1, M, 4, G).

My son's ability to focus on his lesson is really bad... he kept wandering around in the classroom... he cannot stay and sit still during lessons... (p7, M, 8, B).

ISSUES RELATED WITH CHALLENGING BEHAVIORS

All the children with ASD in this study were reported as having behavioral issues that can be described as harming others and tantrumming, as reported by some parents:

Sometimes, my son hits other students at school. When there is something wrong that makes him unhappy, he will cry and start to hit others... (p6, M, 4, B).

She will show her bad tantrum at school because she does not like to do her mathematics... sometimes she will pretend to fall asleep during mathematics lessons... she hates it except for arts classes. Other than that, if the school gates are still closed when the bell already rings for time to go home, she will show her tantrum... she will not wear her shoes and simply run barefooted... (p3, M, 8, G).

DIFFICULTIES IN PERSONAL CARE ACTIVITIES

In terms of personal-care skills, the issues mentioned by parents in this study involved toileting, eating and dressing. The children either cannot go or cannot indicate their need to use the toilet, cannot clean themselves after toileting, have to be fed and some children with ASD refused to wear their school uniform.

ISSUES RELATED TO THE SCHOOL SYSTEM

Regarding other factors that hindered the performance of children with ASD in school, the parents involved in this study were mainly concerned with the quality of services given by service providers. Some parents reported lack of experience and expertise among the teachers in managing children with ASD. Some parents said that they stopped sending their children with ASD to school because they do not feel satisfied with the services their children have received. Some parents mentioned:

The teacher is very reluctant to accept my daughter in her class because she is worried that my daughter will make noise... climbing... so, what the teacher does is, she gives my daughter TAB [Tablet] to keep her quiet. That is all. If that is all that the teacher does, I can also do that at home... just give her TAB to keep her quiet... (p1, M, 4, G).

Previously, I am having problems finding a nursery for him. When I mentioned that my son is an autistic kid, they said that there is no expert in their centre... they said that they do not have a teacher that is specialized in that area to manage such kids... such as my son... (p3, M, 8, G).

I am now searching for another school that is more suitable for my son because his teacher said that my son still cannot talk and does not know how to write... It is quite difficult to teach him how to write... (p4, M, 5, B).

DISCUSSION

Findings of this study note that parents of ASD children involved in this study are more concerned with their child's ability to socialize and communicate with their peers, rather than emphasizing on lack of basic academic skills, such as ability to read, write and count. It can be assumed that this major emphasis on a child's ability to control their behavior might be related to the need of keeping their child accepted at a school and stay comfortably in the school system.

The findings also support that characteristics of ASD exhibited by the children could limits their academic performance in school, despite the fact that parents were more concerned with their child's ability to socialize with peers and ability to cope with school activities and routines. It seems that parents mainly considered their child's challenging behaviors such as tantrumming and inability to stay focused and follow teacher's instructions as factors that cause academic skills issues. In fact, these challenging behaviors have been widely reported among children with ASD (Ashburner et al. 2008; Ben-Sasson et al. 2009; O'Donnell et al. 2012; Schaaf et al. 2011; Tomchek & Dunn 2007) and have been found to affect academic achievement among these children (Ashburner et al. 2008). It should also be noted that none of the parents involved in this study mentioned any concerns regarding their child's ability to perform basic academic skills such as holding

a pencil; recognizing alphabets, numbers and shapes; and being able to read.

The ASD child's inability to stay focused and concentrate during lessons makes classroom management difficult for the teachers. Behaviors, such as making noise, tantrumming and wandering around the classroom, were among the disruptive behaviors reported by parents in this study. Those disruptive behaviors might lead to teachers' decisions of not wanting to accept them in their classroom (Mohamad Razali et al. 2013; White 2014).

Findings of this study lend support to the study by Barnhill et al. (2011) and Mohamad Razali et al. (2013) that suggest the need for ongoing in-service training among teachers who have children with ASD in their classroom. In order to improve the educational services for children with ASD, multidisciplinary team approaches involving teachers and therapists, especially occupational therapists who are skilled in managing children with ASD, is highly recommended (Schaaf et al. 2011). Keeping these two services separate, i.e., educational services at school and OT services in the clinical settings, which is how these services are currently widely practiced in Malaysia, does not seem to be significantly helpful in interventions for children with ASD. These two services should be implemented in a collaborative fashion in the child's natural settings, such as in the classroom, where the educational-related issues usually occur. In this way, occupational therapists can assist in managing functional problems exhibited by children with ASD. This can be done through adaptations and/or modifications to their environment, while teachers can concentrate on delivering the academic contents to the children. Indirectly, the teachers/therapists collaboration will help to improve the quality of services received by children with ASD and their families in school settings. This collaboration can also enhance teachers' knowledge regarding the characteristics shown by children with ASD, as well as assisting teachers to become better informed in how to manage these children.

CONCLUSION

Given the qualitative nature of this study and the implementation of careful procedures, smaller samples could sometimes explore a deeper and broader range of issues indeed (Russell & Gregory 2003). It is essential for teachers to be fully equipped with the required knowledge and proper training in the management of children with ASD (Barnhill et al. 2010; Spann et al. 2003). It is noted that parents' concern on the issues regarding teachers' expertise in the services for their children is somehow consistent with expression made by parents in the Spann et al. (2003) study. This concern should be taken seriously by service providers and their respective professional bodies, so that suitable measures in enhancing the professional development of their staff could be taken. To ease the classroom management process, fostering close collaboration between

teachers and occupational therapists is essentially needed. Apart from delivering academic contents, teachers should be given easy access to occupational therapy services in their classroom. Such arrangement should help to alleviate the heavy workload commonly encountered by teachers.

Further studies should include teachers' perceptions of the challenges that they face in teaching children with ASD, along with the supports and training that they need in Malaysia. This information can be used to aid in developing curriculums that are more beneficial for the teachers in their services (Spann et al. 2003; White 2014). It has been unclear in this study how parent/teacher communication works in Malaysian school system. Future studies could also investigate parent/teacher communication. This investigation would help to understand the extent of parents' involvement with their children with ASD at school as well as their contributions towards the child's achievement and educational planning. A close collaboration between the parents and teachers and/or school management would definitely help in improving the quality of services received by children with ASD (White 2014).

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