PARENTS' RECOGNITION OF AUTISTIC BEHAVIOUR AND THEIR COPING STRATEGIES: A CASE STUDY AT SARAWAK AUTISTIC ASSOCIATION

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Abstract

The paper reports the parents' recognition of autistic behaviour of their children and the coping strategies they used to handle their children's behaviour. The case study involved 12 parents with children registered at the Sarawak Autistic Association, Kuching. Semi-structured interviews revealed that more parents reported differences in social interaction patterns and physical behaviours than speech impairment when compared to children with normal development. The behavioural indicators of autism highlighted by the parents were stereotypic behaviour, sleep problems, hyperactivity and hypersensitivity to specific sounds. The autistic children also showed difficulty mixing with peers, liking to be hugged and lack of eye contact. However, it was the loss of speech ability and absence of speech development which alerted them to the possibility of autism. The study revealed that the parents handled their distress and anxiety mainly through religious means and family support. The findings suggest the need for support and services for autistic children in Sarawak.

Key words: autism, speech ability, social interaction, coping strategies

Introduction

Autism is a specific diagnosis as well as one of the sub-types included in the autistic spectrum disorders (Smith, 2004). According to the Medical Research Council (2001), the term spectrum implies that the disorders share problems in three areas of development: communication, social skills and range of interests, in which the developmental disorders vary from severe problems to above-average abilities. Apart from autism, childhood disintegrative disorder, Asperger's syndrome, Rett's syndrome, and pervasive developmental disorder-not otherwise specified (PDD-NOS) are also under the umbrella of autistic spectrum disorder. Although autism has its own specific diagnostic criteria as listed in the American Psychiatric Association (1994), the terms "autism" and "Autistic Spectrum Disorder" are often used interchangeably to refer to

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all the disorders and syndromes under the umbrella (Dunlap & Bunton-Pierce, 1999; Smith, 2004). Generally, autism occurs in approximately 5 to 15 per 10,000 births, with boys outnumbering girls by the ratio of 4:1 (National Information Center for Children and Youth with Disabilities, 2001).

There are indications that raising children with autism is more stressful than raising children with other childhood disorders such as Down's syndrome (Dumas, Wolf, Fisman, & Cullingan, 1991; Rodrigue, Morgan & Geffken, 1990; Sanders & Morgan, 1997). The level of stress and mental health is indirectly determined by the parents' use of certain coping strategies such as active avoidance coping, problem-focused coping, positive coping, and religious/denial coping (Hastings, Kovshoff, Brown, Ward, Espinosa & Remington, 2005). Mothers have been found to have a higher level of stress than the fathers but they have higher level of confidence in handling the autistic child's behavioural problems (Sharpley & Bitsika, 1997). Research has indicated that the parents eventually gain adaptive coping skills when raising a child with autism or disability in the family (Li-Tsang, Yau & Hon, 2001).

Research on autism in Malaysia has covered aspects such as clinical interventions (Jayachandra, 2005), description of autistic behaviour (Kasmini & Zasmani, 1995) and behavioural treatment (Nasuno & Yamamoto, 2003; Takeuchi, Kubota & Yamamoto, 2002; Tang & Shih, 2006), and the outcomes have benefitted the diagnosis, assessment, education and treatment for autistic children. However, public awareness of autism is still far from satisfactory (e.g., "Autistic kids," 2006; Khalid, 2008). The chairman of National Autism Society of Malaysia (Nasom) chairman, Teh Beng Choon, estimated that in Malaysia, there are about 3,000 cases of autism, with about 500 new ones diagnosed every year (see Khalid, 2008). In Malaysia, three different ministries provide services for autistic children: Ministry of Health in the identification and screening of autistic children; Ministry of Women, Family and Community Development in the provision of early intervention programmes and educational services; and the Ministry of Education in catering to the educational needs (See, 2005). However, the public may not be aware of the available governmental support and the associations providing assistance to autistic children (e.g. National Autism Society of Malaysia, Malaysian Care, Sarawak Autistic Association, Hua Ming Autism Society) are still putting in effort to create public awareness of autism. Studies on parents' reaction to indicators of autism and their coping strategies would provide input to develop counselling programmes and intervention services that are relevant to the local context.

Purpose Of The Study

The paper reports the parents' recognition of their children's autistic behaviour and the coping strategies used to handle their children's behaviour. The aspects of the children's autistic behavior examined are speech ability, social interaction and other physical behaviours.

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body pressure and found positive effects (Edelson, Edelson, Kerr & Grandin, 1999).

The distinctive social interaction patterns reported by parents in this study are difficulty mixing with peers and preference of solitary play, lack of eye contact and preference for hugging by mother. Preference for solitary play was reported by seven out of 12 parents in the study. According to P1,

> *"It's very difficult. Sometimes M [autistic child] liked to be alone...he himself seldom mix with others, he doesn't like. [But] with the brother sometimes they played together."* (P1)

Although P1's child could play with his siblings, he still preferred to play by himself. For two of the children, it was their parents who isolated them from other children. For example, P3 said, "He didn't play with people because we don't really let him mix around...we were always busy, so no time to bring him out to mix with other children." P8 also seldom socialised with other parents after knowing that their son was autistic due to embarrassment and fear of negative reactions.

The lack of initiation and maintenance of eye contact was reported by four parents, two with twins (P2 and P10). The phrases used by parents to describe this deficit were "no eye contact sometimes" (P7), "not focusing" (P2) and "didn't want to look" (P8). The parents' descriptions corresponded with Smith's (2004) findings in which "eye contact is not initiated or maintained" (p. 430) by autistic children due to their indifference to others and shorter attention span. However, the parents in this study tended to attribute the differences they observed in their children's social interaction patterns to individual differences in sociability rather than signs of autism.

Other behavioural differences. The parents of autistic children in this study highlighted stereotypical behaviour, sleep problems, hyperactivity and hypersensitivity to sounds. Stereotypic behaviour alerted six of the parents to their child being different from others. P10 had provided a vivid description on her son's severe hand-flapping behaviour:

> *"He flap his hands and sometimes he like to play with his saliva also. Umm... it can be said that he 24 hours flap his hands, very serious, except for he really sleep already. Before and while he's going to sleep, he still flap his hands, you see."* (P10)

"Hand-flapping, a behavior in which hands rhythmically move up and down in association with the forearm with limp wrists as the elbows are repeatedly flexed and extended, is uniquely seen in people with autistic disorder" (Recio, Miguez, Buxton & Challet, 1997, p. 49). Hand-flapping is not as frequent as spinning and rocking based on the reports of the six parents with autistic children in this study. One child (P3's) had not exhibited stereotypic behaviour at the time of study.

Similar to what is documented in the literature, some autistic children in this study demonstrated abnormalities in the development of the normal sleep-wake cycle (see Recio, Miguez, Buxton & Challet, 1997). P3's account of her son's sleep problem during a holiday illustrates the severity:

> *"Sometimes he could stay up or awake the whole night. For example, the last trip we took him to KL. He didn't sleep the whole night, he was walking up and down the hotel room and then he knocked the TV down, we had to pay for the TV."* (P3)

Unlike P3's child who had problems going to sleep, P7's son slept according to his own timing even though he was already13 years old. Putting the child to bed was such a big problem for the parents that some had figured out triggers for the late hours, such as coke, coffee and tea.

In this study, five parents had hyperactive children. P1 pointed out that his son was "very hyperactive at about five years old. Sometimes when [they] went to the coffee shop, he couldn't wait for the food to come. He wanted to run here and there." According to P8, if the gate was open, her four-to-five year-old child would run out, and she had to chase him to bring him back to the house. Despite the hyperactivity, P12's son was able to concentrate on things that interested him for a long time, also referred to as sustained odd play.

Hypersensitivity towards auditory stimulation was reported by only three parents. For P4's child, it was the sound of the car engine, vacuum cleaner and musical instruments but for the children of P5 and P8, it was the radio and human voices respectively. The children usually reacted by screaming. In comparison, fewer autistic children in this study exhibited hypersensitivity to sounds than stereotypic behaviour, sleep problems and hyperactivity.

A comparison of the parents' reports of their children's speech ability, social interaction and behavioural patterns showed that more parents reported differences in social interaction and physical behaviours but it was speech differences that made them suspect that their child was different from children with normal development at about two years old - although there was one case of the late onset of autism at five years old. It is then that they sought professional advice from general practitioners and child specialists. The interviews revealed that it is usually about 1.5 to 2 years later before autism was confirmed. The diagnosis of autism is late compared to Giacomo and Fombonne (1998). From a study of 82 consecutive referrals to an outpatient diagnostic service, Giacomo and Fombonne found that the first symptoms to arouse parental concern are speech and language development, followed by abnormal socio-emotional response, and medical problem or delay in milestone. When the parents first became concerned, the mean age of children was 19.1 months (SD=9.4), and the first professional advice was sought when children were 24.1 months old (SD=11.7). In the context of the present study, there was a time lag before parents acted on their suspicion that their child was not normal and brought the child to see a doctor, and another time lag before the child was diagnosed with autism, usually after a series of visits to different doctors. In many of the cases, the diagnosis of autism was made by specialists in Kuala Lumpur hospitals. Studies on the medical personnel's willingness to alert parents to possibility of autism would shed light on why children's symptoms of autism are not picked up by qualified medical personnel in initial visits.

Coping strategies of parents

From the interviews, it was found that the two main parental coping strategies were through religious means and family support. Five of the parents reported that they learnt to accept their autistic child as a gift from God:

"... every child is a gift from God, no matter what. It's a challenge when we are able to manage. I take it as a challenge from God, may be will make us better people." (P7)

Among the five, three were Christian (P1, P3, P7), one Muslim (P8) and one Buddhist (P9) but they expressed similar beliefs in there being a divine reason for them to have the autistic child. Some reached this stage of acceptance more easily than others such as P10 who went through a stage of blaming God for treating them unfairly by giving them the autistic child. Other parents such as P11 blamed themselves for bringing about the abnormality:

"Of course, I blamed myself. You will think back during your pregnancy, "Did you do anything? Adakah you buat salah? Adakah saya salah makan ubatkah?" Banyaklah, dari segi pantangkah,d ari segi medication kah, that you take. All these and may be genetic problem." (P11)

Hastings et al. (2005) also found religious/denial coping in their study on the coping strategies in mothers and fathers of pre-school and school-age children with autism. Unlike Hastings et al. who equated religious coping to denial coping, the parents' religious coping was not a denial strategy, but more of seeking divine strength to manage their child's condition.

Four other parents relied on the social support, mainly from their family, but P2 also talked about how her friends provided encouragement for her to be strong in handling her child who was diagnosed with autism at five years old. P11's parents-in-law were a great help because they also had children who had disability, and they were thus able to offer appropriate emotional support, advice and practical assistance in taking care of her child. One parent (P4) whose child was 8 years old at the time of the study was different from the others as she learnt to cope with her child's condition through a better understanding of the developmental disability, by reading books and attending talks. Many of the parents admitted that they knew very little about autism when they first observed different behavioural patterns in their child. Information on the coping strategies of two participants (P6 and P12) was not available from the interview data.

As the parents talked about how they coped with their autistic child's condition, they also stressed that it would have been easier for them to handle the situation if not so many factors were against them. For example, parents who blamed them for their child being autistic, negative reactions from people around them, lack of information on autism, lack of understanding from day care centres which refused to accept their child, and lack of speech therapists in Kuching (or Sarawak for that matter). One parent (P1) reported that she had to spend RM10,000 so that her child could see the speech therapist for a month in Kuala Lumpur. Due to the parents' concern for their autistic child's need for assistance in self-help skills and prospects for independent living, the following emerged as some forms of support and services that would help parents with autistic children cope better:

1. Availability of more speech therapists in Sarawak
2. Vocational school for autistic children
3. Government-funded autistic association

In fact, two of the parents in this study were involved in setting up Sarawak Autistic Association and the Sibu Autistic Association as they saw the need for a formal support group for parents of autistic children and to provide the intervention and educational services for their children. The concerns of these parents provide insights into the areas needing attention where services for autistic children are concerned.

Conclusion

The study reveals to us that the parents from the Sarawak Autistic Association who participated in the study observed behavioural differences exhibited by their children but did not initially recognise them as symptoms of autism. The children liked to be hugged, had difficulty mixing with other children and showed lack of eye contact. They also showed other behaviours such as stereotypical behaviour, sleep problems and hyperactivity. Hypersensitivity to certain sounds was limited to a few children. Although more of the parents reported behaviours characteristic of autistic children, it was impairment in their child's speech ability which alerted them to the unusual development of their child, and which led to visits to medical personnel later. The impairments of speech ability which indicated clearly to the parents that something was amiss was the loss of speech ability, more so than lack of speech development which was initially attributed to deafness and dumbness or individual differences. Echolalia was not common among the children in this study. In order to manage their autistic child, the parents mostly sought religious help and social support from their family. While the autistic behaviours of the children are similar to those documented in the literature on autism, the contribution of this study is in highlighting the lack of parental recognition of autistic behaviours which resulted in a delay in seeking intervention and treatment for autism. The study also revealed the inaccessibility of information on autism to parents encountering the developmental disability for the first time and the lack of medical services, especially speech therapists, to assist their child. Although Sarawak Autistic Association and Sibu Autistic Association provide intervention programmes, the study points to a need for more government-supported services for autistic children and their parents.

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Endnote:

[1] The autistic spectrum disorder includes:

(1) Autism or autistic disorder significantly affects a child's communication, social skills, and patterns of behavior and generally emerges before 3 years old (Bergeson, Heuschel, Harmon, Gill & Colwell, 2003; Hornby, Atkinson & Howard, 2000; Howlin, 1997; Individuals with Disabilities Education Act, 1997);

(2) Childhood Disintegrative Disorder refers to children whose development appears normal until they are 5 or 6 years old at which age regression begins with the loss of expressive or receptive language and social skills (Dunlap & Bunton-Pierce, 1999; Smith, 2004);

(3) Asperger's syndrome refers to children who exhibit autistic characteristics but do not demonstrate cognitive delays (i.e. normal intelligence) and language delays (Medical Research Council, 2001; Smith, 2004), "although there may be deficits in the practical use of language and social-communication skills" (Bergeson et al. 2003, p. 8);

(4) Rett's syndrome is a genetic disorder commonly found in girls. It is defined by "normal development, at least until age of 5 months, followed by head growth deceleration between 5 and 48 months of life, loss of purposeful hand skills that were previously acquired and poorly coordinated gait and trunk movement" (Mesibov, Adams & Klinger, 1997). The characteristics include repeated, stereotypic hand-wringing, impaired expressive and receptive language development but less severe social impairment compared to children with autism (Mesibov, Adams & Klinger, 1997; Smith, 2004);

(5) Pervasive Developmental Disorder-Not Otherwise Specified refers to a collection of characteristics similar to autism but the children may have mild problems in communication, social skills and stereotyped behaviours and interests or they do not meet the criteria of other disabilities (Bergeson et al. 2003; Smith, 2004).

Appendix 1: Interview Questions

Experiences of bringing up the child until the diagnostic process

1. Could you please tell me your experience with (child's name) when he/she was a baby?
2. What kinds of things did (child's name) like to do at that time?
3. When did you notice something was "different" or "not quite right" with (child's name)?
4. What makes you say (child's name) is different from the other normal children (e.g. the child's social ability, speech and behaviour)?
5. How did you first learn that (child's name) had autism? How old was he/she?
6. Could you please describe your reaction(s) when you first learned that (child's name) was diagnosed as an autistic child?
7. How do you try to understand (child's name) condition (e.g. reading more books on autism, searching information from the internet)?
8. What difficulties did you face at that time in order to raise (child's name)?
9. Have you ever thought that you lack of parenting skill because the child did not response to you? Why?
10. What were your causes of stress?
11. How did you deal with your stress?
12. What kinds of advice have been given to you by the doctor?
13. In what ways has the advice been helpful or not helpful to you? Why do you say so?
14. Did you accept the diagnosis of autism or did you disagree, challenge or seek other diagnosis? Why?
15. Have you ever got angry when the doctor told you that you have an autistic child?
16. Was there a time you blamed yourself?
17. What kinds of advice have been given to you by your family members and relatives?