

**PARENTS' EXPERIENCES IN RAISING CHILDREN WITH AUTISM:
A CASE STUDY IN KUCHING**

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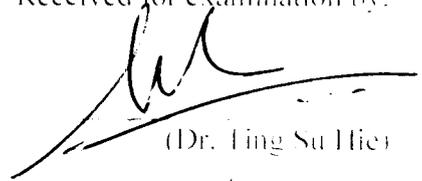
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ABSTRACT

PARENTS' EXPERIENCES IN RAISING CHILDREN WITH AUTISM: A CASE STUDY IN KUCHING

Chuah Heng Kiu

This study explores parents' experiences in raising children with autism in Kuching. Data were collected through in-depth, face-to-face interview which lasted for 1½ to 2 hours at parents' residence or at Sarawak Autistic Association (SAA). The results of this study showed that children with autism have problems in communication, social interactions and behaviour. They usually were diagnosed as autistic after the age of three. In addition, children with autism also had hyperactive behaviour and it was noticeable when they were four years old and above. Due to the loss of a normal child, parents went through various emotional stages, namely, shock, denial, guilt and grief before they actually accepted the child. When parents were no longer viewed their child's disorder as a crisis, they started to train their children to carry out the daily routines such as taking bath and using the toilet. The training was conducted by using verbal instruction and demonstration. In addition, parents also corrected the child's behaviour if he or she did something wrong. The child was punished physically (e.g. beating the hands, caning, flickering of rubber band and spanking) or verbally (e.g. giving command) in order to make them realised their mistakes. Some parents faced the problems in obtaining pre-school education or day care to place their autistic child. Overall, the relationships of the family members with the autistic were good as they have reached the acceptance stage at the time of this study. Raising and nurturing children with autism are a challenge for parents. They have to cope with the impact of the autistic child created in the family as well as the public views on their autistic child. The findings of this study highlight the importance of creating public awareness of autism and ways of providing support to those autistic children.

ABSTRAK

PENGALAMAN IBU BAPA MENJAGA ANAK AUTISTIK: KAJIAN KES DI KUCHING

Chuah Heng Kiu

Kajian ini mengkaji pengalaman ibu bapa dalam menjaga anak autistik di Kuching. Data dikumpul melalui temuramah secara mendalam dengan ibu bapa selama satu setengah jam hingga dua jam. Temuramah tersebut diadakan sama ada di kediaman responden atau di Persatuan Autistik Sarawak (SAA). Keputusan kajian ini menunjukkan bahawa kanak-kanak autistik menghadapi masalah dalam tiga aspek, iaitu masalah komunikasi, interaksi sosial dan kelakuan. Biasanya, kanak-kanak dikenal pasti mempunyai ciri-ciri autistik selepas umur tiga tahun. Di samping itu, mereka juga mempunyai sifat hyperaktif tetapi sifat ini akan menjadi semakin jelas apabila mereka berumur empat tahun ke atas. Disebabkan anak mereka mempunyai ciri-ciri autistik, ibu bapa mereka telah melalui beberapa tahap konflik emosi seperti kejutan, penafian, rasa bersalah, kesedihan dan akhirnya penerimaan. Semasa penjagaan anak, ibu bapa telah memberi latihan kepada anak mereka untuk melakukan aktiviti-aktiviti harian seperti mandi dan menggunakan tandas dengan cara yang betul. Di samping itu, ibu bapa juga disiplin anak mereka supaya berkelakuan baik. Ibu bapa juga menghadapi masalah untuk mencari tempat untuk pendidikan pra-sekolah atau pusat penjagaan kanak-kanak kepada anak mereka. Secara keseluruhan, hubungan kekeluargaan tidak terjejas selepas anggota keluarga dapat menerima anak autistik tersebut. Penjagaan anak autistik merupakan satu cabaran bagi ibu bapa. Ibu bapa perlu bersedia untuk menangani cabaran yang akan dihadapi kesan daripada kewujudan anak autistik dalam keluarga dan juga pandangan komuniti terhadap anak mereka yang mempunyai kekurangan diri. Oleh itu, kajian ini berharap dapat meningkatkan kesedaran masyarakat tentang kewujudan kanak-kanak autistik dan seterusnya masyarakat dapat memberi sokongan serta bantuan kepada mereka.

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TABLE OF CONTENTS

	Page
ABSTRACT	iii
ABSTRAK	iv
ACKNOWLEDGEMENT	v
LIST OF TABLES	x
LIST OF ABBREVIATIONS	xi
CHAPTER	
1 INTRODUCTION	1
1.1 Background of the research problem	2
1.2 Statement of the problem	7
1.3 Significance of the study	10
1.4 Operational definition of terms	11
1.4.1 Parent	11
1.4.2 Characteristics of autism	11
1.4.2.1 Impairment in social interactions	11
1.4.2.2 Poor communication abilities	12
1.4.2.3 Repetitive, restricted and unusual behaviour patterns	13
1.4.3 Pre-diagnostic process	15
1.4.4 Post-diagnostic process	15
1.4.5 Primary needs	16
1.4.6 Resources	16

2	LITERATURE REVIEW	17
	2.1 Historical view of autism	19
	2.2 Types of disorder	21
	2.3 Differences between autism and other disorders	24
	2.3.1 Autism versus mental retardation	24
	2.3.2 Autism versus schizophrenia	25
	2.3.3 Autism versus learning disabilities	26
	2.4 Family stress	27
	2.5 Family coping ability	36
	2.6 Family reactions to the diagnosis	41
	2.7 Routinisation	44
	2.8 Sibling's relationship with the autistic child	46
	2.9 Intervention services	49
	2.10 Summary	52
3	METHODOLOGY	54
	3.1 Research design	55
	3.2 Selection of participants	57
	3.3 Instrument for collecting data	59
	3.3.1 Validity of the instrument	63
	3.3.2 Reliability of the data collected	64
	3.4 Data collection procedures	65
	3.5 Data analysis	68
	3.6 Limitations of the study	70

4	RESULTS AND DISCUSSION	72
	4.1 Overview of participants' experiences	73
	4.2 Pre-diagnostic process	74
	4.2.1 Communicative ability	74
	4.2.2 Social interactions	79
	4.2.2.1 Hugging	79
	4.2.2.2 Preference of isolation	82
	4.2.2.3 Initiation of eye contact	85
	4.2.3 Behaviour	86
	4.2.3.1 Hyperactive behaviour	87
	4.2.3.2 Hypersensitive	90
	4.2.3.3 Stereotypic behaviour	92
	4.2.3.4 Sleep problem	95
	4.3 Post-diagnostic process	98
	4.3.1 Family reactions to the diagnosis	98
	4.3.1.1 Shock and denial	99
	4.3.1.2 Guilt and grief	101
	4.3.1.3 Acceptance	106
	4.3.2 Establishment of daily routines	111
	4.3.3 Behaviour management	120
	4.3.3.1 Physical punishment	120
	4.3.3.2 Verbal reprimands	127
	4.3.4 Problems in obtaining pre-school education or day care	129
	4.4 Relationships of the family members with the autistic child	136
	4.4.1 Parent-autistic child relationship	136
	4.4.2 Grandparent-autistic grandchild relationship	138
	4.4.3 Sibling-autistic child relationship	140
	4.5 Participants' primary needs and their hope for the autistic child's future	144

4.6 Discussion	150
5 CONCLUSIONS, RECOMMENDATIONS AND IMPLICATIONS	153
5.1 Summary	158
5.2 Recommendations	159
5.3 Implications	161
5.4 Conclusions	
REFERENCES	163
APPENDICES	
APPENDIX A	169
APPENDIX B	171
APPENDIX C	172

LIST OF TABLES

Table		Page
1	Summarised transcription key	68

LIST OF ABBREVIATIONS

P	Participant
SAA	Sarawak Autistic Association

CHAPTER 1

INTRODUCTION

This chapter begins with a general description of the background of autism and researches that have been conducted. This is followed by the statement of the problem and research objectives which further elaborate on the need to explore parents' lived experiences of raising children with autism in Kuching. Then it moves on to the significance of the study which focused on the practical applications of this study. Some operational definition of terms used to define the variables of the research objectives are also included.

1.1 Background of the research problem

The syndrome of 'early infantile autism' was first described by Kanner in 1943. Kanner viewed infantile autism as distinct from childhood schizophrenia and other clinical diagnoses based on his three observations (Mesibov, Adams & Klinger, 1997). Currently, autism is a specific diagnosis as well as one of the sub-types included in the autistic spectrum disorders (ASD) (Smith, 2004). Apart from autism, childhood disintegrative disorder (CDD), Asperger's syndrome, Rett's syndrome, and pervasive developmental disorder-not otherwise specified (PDD-NOS) are also under the umbrella of ASD. 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. 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).

Research has shown that families of children with autism face a number of challenges, yet they have gained unique experiences in bringing up the child. There are indications shown that raising children with autism is more stressful than raising children with other childhood disorders such as Down's syndrome (Dumas, Wolf, Fisman, & Culligan, 1991; Rodrigue, Morgan & Geffken, 1990; Sanders & Morgan, 1997). Sharpley and Bitsika (1997) further explained that even though mothers have higher level of stress than the fathers, they have higher level of confidence in handling the child's behavioural problems.

Besides that, there is an increase in the rates of developing psychiatric disorders such as depression and social phobia in parents of children with autism, which might be directly related to stress and the burden of living with and caring for an autistic child or adult (Lainhart, 1999). Nevertheless, Piven and Palmer (1999) disagreed with Lainhart's (1999) proclamation. They argued that the high rate of major depressive disorder (or social phobia) might not be due to the stress of having an autistic child or children in the family. The parents might only have the risk to experience it.

Although parents of children with special need experienced much stress, research has shown that they eventually gained adaptive coping skills when raising a child with autism or disability in the family (Li-Tsang, Yau & Hon, 2001). Furthermore, Hastings, Kovshoff, Brown, Ward, Espinosa and Remington (2005) elucidated that the use of certain coping strategies (active avoidance, problem-focused, positive or religious) by parents of autistic children would indirectly determine their level of stress and mental health.

In fact, before the parents of children with special needs or disability can effectively deal with their sons or daughters, they actually have gone through several emotional stages. As parents, they would have grief reaction because of the loss of a normal child (Spidel, 2000; Tommasone & Tommasone, 2000). They might go through stages of shock, guilt, anger, resentment, grief and eventual acceptance (Tommasone & Tommasone, 2000). In addition, one might also go through the denial stage when the diagnosis is confirmed (Larry & Silver, 1992).

After experiencing the stages which are intensely distressed the parents, they endeavoured to train their autistic child to carry out the daily routines. According to Larson (2006), training has become the focus of daily efforts for

parents in fostering the child in the development of skill acquisition. To ensure the sustainability of the daily routines, one of the strategies used by parents is through instructions. The success of using instructions in training could be due to the nature of the autistic children who prefer to engage in repetitive actions and ritualistic routines (American Psychiatric Association, 1994, in Larson, 2006).

Subsequently, having an autistic brother or sister in a family is difficult for some siblings although parents have accepted the presence of the child. According to Kaminsky and Dewey (2001), siblings of children with autism were characterised by less intimacy, less prosocial behaviour and less nurturance than those Down syndrome and developmentally normal siblings. On the other hand, Pilowsky, Yirmiya, Doppelt, Gross-Tsur and Shalev (2004) explained that siblings of children with autism could also be well-adjusted socially and emotionally towards the presence of the autistic sibling in the family

Research was also conducted to document the importance of having educational services or vocational training for children with autism. According to Boyd (2002), a lack of social support might affect mothers' emotional

well-being such as the exacerbation of stress level if necessary support were not provided for their autistic child. Little (2003) also noted that certain services such as the educational training (e.g. pragmatics training) and educational resources (e.g. trained assistant in the classroom) were not available for children with AS [Asperger's Syndrome] or NLD [Nonverbal Learning Disorder].

Much published studies to date have focused on parental stress by comparing the levels of anxiety and depression from parents of children with autism to parents of children with Down syndrome and developmentally normal children. Some researchers have also addressed the coping skills used by parents of children with autism in parenting their autistic children. Some studies also examine the perceptions of parents of children with autism regarding the services provided to autistic children. Nevertheless, there is a lack of comprehensive study in investigating the aspect of relationships of the family members with the autistic child and whether the availability of resources and support systems (formal and/or informal) fulfill the needs of parents of children with autism.

Therefore, the researcher of this present study is not only looking at the experiences of parents of children with autism in the aspect of parental stress (raising and parenting the autistic child from birth to diagnosis process of autism), family's coping ability, the availability of intervention services, but also the relationships of the family members with the autistic child, their primary needs that are not attended by the resources available at present as well as their concern towards the autistic child's future.

1.2 Statement of the problem

Parents of children with autism usually obtain information about autism and services (e.g. Early Intervention Programme) from the non-governmental organisation in Malaysia as well as the local parent support groups. This includes The National Autism Society of Malaysia (NASOM) which provides parents of children with autism the latest approaches in diagnosis, assessment, education and treatment for their autistic child. Besides, parents of children with autism also obtain information about autism and services from the local parent support group such as Sarawak Autistic Association (SAA). However, there are very few local parent support groups providing junior and senior vocational and pre-vocational program, speech and music therapy.

With the establishment of such centres for individuals with autism, it is hoped that the awareness of the public towards individuals with autism would increase. As what has been pointed out by Datuk Dr. Ng Yen Yen, the Deputy Finance Minister of Malaysia, “many cases of child abuse stemmed from a lack of understanding about autistic children” (*The Star*, 2006). Parents are frustrated in handling the ‘naughty’ child’s behaviour as they do not understand why the child behaves strangely. Thus, raising and nurturing an autistic child become a difficult journey that challenges the parents emotionally.

The impetus for this study is because the local families may have different experiences in raising the autistic child as none of the medical professionals are easily available in Sarawak to provide advice to parent. This is because most medical professionals in Sarawak are ‘flying’ doctors. Due to such constraint, parents have to seek help from other parents who have autistic child or to rely on religion as coping strategy to bring up the autistic child. Besides that, the local families may have limited opportunity to access to information about autism, support and services for autistic children in Sarawak before the establishment of Sarawak Autistic Association (SAA) in 1998. In addition, not many parents can afford the cost for therapy treatment such as the

occupational therapy (OT) or speech therapy because it is costly.

Therefore, the purpose of this study is to explore and describe the parents' experiences in raising children with autism. In order to examine parents' experiences, the following questions are addressed:

1. How do parents of autistic child experience the pre-diagnostic process, which is before the age of 3, regarding the child's communication ability, social interactions and behaviour?
2. How do parents react towards the diagnosis of autism?
3. How do parents train the child to carry out the daily routines, discipline the child's behaviour and problems that the parent encountered in obtaining pre-school education or day care during the post-diagnostic process?
4. How do parents experience the relationships of the family members (parent-autistic child, grandparent-autistic grandchild and/or autistic child-siblings relationships) arising from the presence of the autistic child?
5. What are the parents' primary needs that are not attended by the resources available at present and their concern towards the autistic child's future?

1.3 Significance of the study

This study aims at exploring and describing the parents' experiences in raising children with autism. Working with children with special needs normally involves doctor-patient or medical relationships. The belief in professionals 'as experts' in our society is rooted in most of the parents' mind. As a result, "[t]he view, feelings and wishes of the parent are not necessarily consulted" (Dale, 1996, p. 8). Moreover, it is easier for the professionals to view the child with a disability objectively than it is for the parents.

Due to such circumstance, it is hoped that this study could offer insights to all parties (professionals, special education trained teachers or the community) about parents' views and feelings of having children with autism. Some practical applications could be derived from this study. The professionals could use the data to develop counselling programmes and intervention services that are sensitive to the unique needs of the culturally-diverse families. In addition, to work effectively with families with autistic children, the professionals have to recognise their feelings and be willing to honour them (Chinn, Winn & Walters, 1978; Chinn, 1984, in Spidel, 2000). Besides that, the special education trained teachers could use the data to learn more about the parent's perspective through negotiation by exchanging views on the autistic

child's development and areas of improvement. For the community, perhaps people could be more sympathetic by showing their supportive attitude when the children are in contact with people outside the family.

1.4 Operational definition of terms

1.4.1 Parent

The term 'parent' is referred to the biological parents who have "full legal responsibility for the child's [day-to-day] care and upbringing from birth until legally defined adulthood" (Dale, 1996, p. 5). In this study, the parents are those who have children with autism in the family.

1.4.2 Characteristics of autism

In this study, autistic children are categorised as having the following characteristics:

1.4.2.1 Impairment in social interactions

The following are signs of impairment in social interactions:

- Normal attachments to parents, family members, or caregivers do not develop.
- Friendships with peers fail to develop.

- Cooperative or peer play is rarely observed.
- Emotions, such as affection and empathy, are rarely displayed.
- Nonverbal signals of social intent (smiling, gestures, physical contact) tend not to be used.
- Eye contact is not initiated or maintained.
- Imaginative play is seldom observed.
- The lack of social communicative gestures and utterances is apparent during the first few months of life.
- Preferred interaction style could be characterized as “extreme isolation”.
- Understanding of others’ beliefs or motivations is greatly impaired.
- Joint attention deficits (not being able to cooperate or share interest with others in the same event or activity) impair normal social reciprocation.

(Smith, 2004, p. 430)

1.4.2.2 Poor communication abilities

The following are signs of poor communication abilities:

- Functional language is not acquired fully or mastered.
- Content of language is usually unrelated to immediate environmental events.
- Utterances are stereotypic and repetitive.
- Gestures, facial expressions and nonverbal cues are poorly understood.

- Conversations are not maintained.
- Spontaneous conversations are rarely initiated.
- Speech can be meaningless, repetitive and echolalic.
- Many fail to use the words / and yes and have problems with pronouns in general.
- Both expressive and receptive language are extremely literal.
- Verbal turn-taking, choosing a topic and contributing properly to conversation are rare.

(Smith, 2004, p. 430)

1.4.2.3 Repetitive, restricted and unusual behaviour patterns

The following are signs of repetitive, restricted and unusual behaviour patterns:

- Marked distress is typically experienced over trivial or minor changes in the environment.
- Aspects of daily routine can become ritualized.
- Obsessive and compulsive behavior is frequently displayed.
- The need to complete self-imposed, required actions is intense.
- Stereotypic behaviors (rocking, hand-flapping) are repeated in cycles difficult to stop.