



**EXPLORING EXPERIENCES OF MALAYSIAN
PARENTS IN RAISING ADOLESCENTS WITH
AUTISM: A CASE STUDY**

BY

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the degree of Master of Education**

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ABSTRACT

Parents of children with autism experience prolonged levels of stress and isolation. Thus, the present study is an attempt to explore Malaysian parents' experiences, coping strategies and their adjustments, and maintained stability in raising adolescents with autism. Semi-structured, in-depth interviews were conducted with three participants. Data were transcribed verbatim and analyzed using a thematic approach to the phenomenological analysis. A family resilience framework was used to interpret the process of positive adaptations that led to resilience. Four key themes around the challenges were identified, namely the challenges associated with autism spectrum disorder, challenges that arise from the lack of understanding and acceptance, challenges of interacting with health and education services, and challenges to family dynamics and work responsibilities. The discovered coping strategies were parallel with the theory, which are meaning making of adversity, positive outlook and transcendence/spirituality.

خلاصة البحث

يواجه أولياء أمور الأطفال المصابين بالتوحد مستويات من التوتر والعزلة قد تستمر لفترات طويلة. وبالتالي حاولت هذه الدراسة استكشاف تجارب أولياء الأمور المميزين واستراتيجياتهم التكيفية، وتعديلاتهم ، والحفاظ على الاستقرار في عملية تربية المراهقين المصابين بالتوحد. أجريت مقابلات شبه منظمة ومتعمقة مع ثلاثة مشاركين. تم نسخ البيانات حرفياً وتحليلها باستخدام الطريقة الموضوعية للتحليل. تم استخدام إطار مرونة الأسرة لتفسير عملية التكيفات الإيجابية التي أدت إلى المرونة الأسرية. تم تحديد أربعة مواضيع رئيسية حول التحديات، وهي التحديات المرتبطة بمتلازمة التوحد الطيفي، والتحديات التي تنشأ من عدم الفهم والقبول، والتحديات المتعلقة بالتفاعل مع الخدمات الصحية والتعليمية، والتحديات التي تواجه الديناميكيات العائلية ومسؤوليات العمل. كانت استراتيجيات التكيف المكتشفة موازية للنظرية المحددة، وهي معرفة المغزى من الشدائد، والنظرة الإيجابية والسمو أو الروحانية.

APPROVAL PAGE

I certify that I have supervised and read this study and that in my opinion, it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Master of Education.

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I hereby declare that this dissertation is the result of my own investigations, except where otherwise stated. I also declare that it has not been previously or concurrently submitted as a whole for any other degrees at IIUM or other institutions.

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CHAPTER ONE

INTRODUCTION

1.1 BACKGROUND OF STUDY

Autism is a developmental disability that increased in incidence over the past decade. Parents of children with autism experience prolonged levels of stress and isolation. Autistic spectrum disorder (ASD) is considered the fastest growing form of developmental disability. It is characterized by abnormalities in communication skills, social relationships, cognitive functioning, sensory processing, and behaviour. Research on the challenges of raising a child with autism is mostly reported from Europe, North America, and Australia, which revealed that parents have to come to terms with living with a child who has a lifelong developmental disability. In addition, parents are faced with numerous concerns, such as caring burdens, poor prognosis, and negative public attitudes. Other challenges include increased financial burdens, misconception of the nature of autism, and low levels of social support. Availability of services for treatment is limited, even when a proper diagnosis is done.

Lack of awareness limits the access to appropriate services that may improve the quality of life and prognosis in autistic children. In addition, parents of children with autism face several challenges, such as single parenting or divorce, childcare needs, and lack of financial resources, all of which have negative effects. Information on how these parents cope with these challenges is scant. The attitudes of parents of children with disabilities shape the strength and stability of family and social relationships. Previous research has implicated that if parents were given proper coaching and guidance, they could positively influence most areas of their child's

development (Jiménez, Lugo & Morales, 1999). Heward (2007) argued that active family participation is of vital importance in continuous educational planning, and further predicts that helping and coaching families will become key objectives in working with children with disabilities.

1.2 PROBLEM STATEMENT

The number of children diagnosed with Autism Spectrum Disorder (ASD) is increasing at an alarming rate (Rice, 2009). Although numerous studies have been published on family functioning and coping strategies in general, none were specific to the Southeast Asian population. Malaysia as a multicultural country presents unique characteristics, challenges and perhaps coping styles. Traditionally, Malaysian families live in clans and depend on each other for all the needs of the family. Therefore, this study intends to explore and understand how parents of adolescents with autism prepare in raising children, how they cope and how they adjust and maintain the stability in raising autistic adolescents.

The Ministry of Health Malaysia (2011) has urged that more studies should be conducted on children with disability and their caregivers. Some recent qualitative studies have reported a number of themes faced by parents of children with ASD in different regions globally (e.g., Cridland, Jones, Caputi & Magee, 2014; Griffith, Totsika, Nash, Jones & Hastings, 2012; Jardine, 2008; Phelps, Hodgson, McCammon & Lamson, 2009; Swanepoel, 2003), however, limited qualitative work has been conducted in Malaysia (Ting & Chuah, 2010). Given the limited ASD research in South-East Asia and particularly in Malaysia, researchers have noted that there is a tremendous need for more investigation (e.g., Clark et al., 2012; Golden & Liaw, 2015; Ilias, Ponnusamy & Normah, 2008; Neik et al., 2014).

1.3 RESEARCH OBJECTIVE

The purpose of this study is to explore the experiences of Malaysian parents in raising autistic adolescents, to describe the challenges of Malaysian parents in raising autistic adolescents, to examine the preparedness of Malaysian parents in dealing with challenges in raising autistic adolescents, as well as to identify the coping strategies in dealing with challenges in raising autistic adolescents.

1.4 RESEARCH QUESTIONS

Considering the factors that contribute to the challenges faced by Malaysian parents with autistic adolescents and to explore how the challenges are coped with, the study attempts to address the following research questions:

1. What are the challenges of raising autistic adolescents faced by Malaysian parents?
2. How do Malaysian parents cope with the challenges of raising autistic adolescents?
3. What are the coping strategies to deal with the challenges of raising autistic adolescents?

1.5 SIGNIFICANCE OF THE STUDY

In Malaysia, studies pertaining to issues of rising autistic children are increasingly carried out. It is important that a study on the challenges and coping strategies is conducted to better understand the situation of parents in Malaysia for a better preparation in raising autistic children.

The results of this study will be useful for other parents to learn the necessary strategies to cope with autistic children, and special education teachers to prepare

themselves in teaching autistic children, i.e. what to expect and how to deal with autistic children. Moreover, it will be useful for the Ministry of Women, Family and Community Development, as well as the Department of Social Welfare to support Malaysian parents in raising autistic children.

1.6 LIMITATIONS OF THE STUDY

The current study was only limited to Malaysian parents with autistic children and it was conducted in selected areas, considering the availability of Malaysian parents with autistic children.

1.7 DEFINITION OF TERMS

There is a need to interpret some terms related to this study to provide a basic understanding for the readers. Therefore, the following terms in this study will be interpreted.

Parents

For the purposes of this study, the term “parents” refers to the mothers and fathers of children with autism who serve as their primary care provider and are responsible for the maintenance of these children.

Adolescence

Adolescence is commonly understood to define the period of life between childhood and adulthood (Kaplan, 2004, p.1). This critical developmental period is conventionally understood as the years between the onset of puberty and the establishment of social independence (Steinberg, 2014).

Adolescents

Adolescents are any persons between the ages 10 and 19. This age group falls within the group of young adolescents, which refers to individuals between the ages 12 and 20, which is roughly equivalent to the term teens.

Autism Spectrum Disorder (ASD)

This disorder is characterized by abnormalities in communication skills, social relationships, cognitive functioning, sensory processing and behavior (American Psychiatric Association, 1994).

Parental Experiences

Parents of children with Autism experience significantly longer delays and greater frustration searching for a diagnosis compared to parents of a child with autism (Howlin & Asgharian, 1999). The factors that can contribute to these prolonged delays include a lack of professional awareness, knowledge and training, a 'wait and see' attitude, misdiagnoses, excessive financial costs, and the length of time for the majority of the child's difficulties to become apparent (Inglis, 2006; Shacar, 2006).

Coping Strategies

Coping strategies refers to the efforts by which an individual manages personal or environmental demands that are perceive as stressful (Lazanis & Follanan, 1984). Moreover, coping strategies is a scheme a person adopts in order to cope with some specific stressful event. Problem-focused strategies are more probable when it is perceived that the problem is amendable to change (Folkman & Lazarus, 1980).

1.8 CHAPTER SUMMARY

Due to the increasing prevalence of ASD, and the necessity to work collaboratively with parents, it is imperative to understand the unique needs of the parents. Stuart et al., (2006) identified that learning about parents' past experiences is an important factor to build functional relationships. Through the current study, the uniqueness of the experiences and coping strategies in rising adolescents with ASD were presented with insight. A transcendental phenomenology design was employed to provide a voice to the participants and understand the essence of their shared experiences.

CHAPTER TWO

LITERATURE REVIEW

2.1 INTRODUCTION

Various issues were raised in previous studies. This chapter will discuss the theories of parental experiences and coping strategies and the findings of previous studies that are related to raising adolescents with autism and its challenges to parents.

2.2 THEORETICAL FRAMEWORK

For this study, experiences of parents raising children with autism spectrum disorder (ASD) and their positive adaptation were informed by a family resilience framework. This theory is based on the premise that parents know their children best and are intrinsically motivated to help their children reach their full potential. A focus on the talents, skills, resources, life experiences, and unmet needs of the parents and families is gaining more attention for the assessment of strengths and resilience to guide interventions (Tedeschi & Kilmer, 2005, p.230). The expertise and experiences of parents in raising children with AS can subsequently be used as a foundation for support (Altiere & von Kluge, 2009a; Bevan-Brown, 2004; Bromfield, 2011; Knafl & Deatrlick, 1987; Oprea & Stan, 2012; Summers et al., 1989). Boss (2002) asserts that “only after we see through a family’s eyes (and each member’s eyes) can we learn how to assess, support, and intervene without prejudice” (p. 26).

In the current study, positive coping efforts were considered within a family resilience framework (Walsh, 2006). A resilience framework shows how parents cope, adapt, and gain competency against significant adversities (Blacher & Hatton, 2007).

A focus on positive adaptation “engages distressed families with respect and compassion for their struggles, affirms their reparative potential, and seeks to bring out their best qualities” (Walsh, 2003c, p.14). Furthermore, a resilience perspective provides opportunities to acknowledge family strengths and is respectful of the perceptions and knowledge of the parents (Bayat, 2007; Summers et al., 1989).

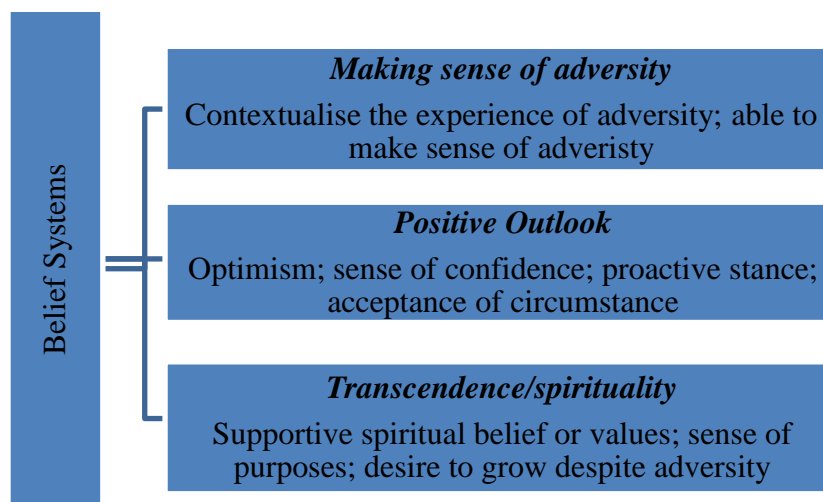


Figure 2.1 Key Processes in Family Resilience. Walsh’s (2006)

2.3 AUTISM SPECTRUM DISORDER

Autism is a brain disorder that affects an individual’s ability to learn, communicate, socialise and develop normally, and results in having repetitive behaviours and narrow interests (Jasni et al., 2011). Autistic spectrum disorder (ASD) is diagnosed where a triad of behaviour patterns, namely including delayed or atypical social interaction and communication (verbal and/or non-verbal) and rigid, ritualistic behaviour is observed over a prolonged period of time (APA, 2000). The number of children diagnosed with ASD is rising and is now estimated to be as high as 1:100 (Knapp, Romeo & Beecham, 2007). Causes are thought to include genetic factors, as well as

environmental factors, although the exact an etiology is not yet established (Szpir, 2006).

The National Research Council in the United States (2001) stated that autism affects children throughout the world, regardless of race, ethnicity, and socio economic background. Autism occurs on average four times more often in boys than in girls (Mash & Wolfe, 2005). Autism Spectrum Disorder (ASD) is a pervasive developmental disorder that is generally recognised and diagnosed between the age of 18 months and three years (Troy et al., 2007). As articulated in the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2000), typical problems that are observed in individuals who are autistic include limited eye contact and the absence of appropriate facial expressions and gestures. Children with autism experience challenges in developing appropriate peer relationships and show a lack of emotional or social reciprocity.

Children with autism typically maintain restricted or repetitive behaviours and interests. They show an inflexible adherence to non-functional rituals; some children maintain stereotypical and repetitive movements, e.g. flapping of hands, also known as 'stimming'. They are most comfortable with, and may insist on, routine and they show resistance to trivial changes (Mash & Wolfe, 2005; Carr, 2006). According to Hillman (2006) no one behaviour serves as a definitive diagnostic indicator for children with autism as they present with a variety of symptoms across cognitive, emotional and behavioural domains, with language and non-verbal communication skills either absent or significantly delayed (Carr, 2006). Thus, autism is on a spectrum of disorders that affects each individual differently, and with varying degrees of severity.

Children with autism process sensory, motor, and perceptual experiences differently to neuro-typical children. “The way in which they register, modulate and integrate environmental stimuli by means of seeing, hearing, and smelling, tasting, moving around or touching may be affected” (Koudstaal, 2005, p.315). Their senses appear to be so sensitive, thus, it is hard for them to be in places with loud noise, strong smells, etc., such as in a supermarket. This could then result in an unexpected, negative behaviour (Koudstaal, 2005) by the autistic child. Some autistic children will try to regulate or escape the sensory input by covering their ears with their hands, walking on their toes, flapping their hands or jumping up and down (Koudstaal, 2005).

Behavioural problems exhibited by children with autism are among the most challenging and stressful issues faced by parents. The problematic behaviours that many autistic children display form significant barriers to effective social interactions as well as to educational placement and development (De Boer, 2009), but the undesirable and challenging behaviour of children with autism must be judged as secondary consequences, rather than as a feature of autism. Difficult behaviour such as socially embarrassing actions, temper tantrums, aggression, destructiveness, screaming, and running away are often associated with autism (De Boer, 2009). Challenging behaviour in most cases is a direct result of a lack of understanding. Children with autism in general are resistant to transition and change, because “sameness provides security”, order and predictability (Koudstaal, 2005, p.316; Mash & Wolfe, 2005).

Young children with autism have a higher than expected incidence of upper respiratory infections and gastrointestinal symptoms, which cause a lot of discomfort in their bodies. This could also lead to excessive burping, constipation and loose bowel movements (Sadock & Sadock, 2003). The discomfort experiences and the lack

of communication skills can also be a reason for showing disruptive behaviours. Furthermore, some children with autism have very fussy eating habits, which restrict their diets; while others will compulsively eat anything, even materials like paper, and play dough (Sadock & Sadock, 2003).

In the early part of the last century autistic children were often misdiagnosed as being schizophrenic (Grinker, 2007). Based on the study done by Altieri and Kluge (2009), males suffer from the condition four times than females. Autism is becoming more prevalent and it has been found in children aged 18 years of age and under; the prevalence of autism ranges from five cases for every 10,000 individuals to 60 cases for every 10,000 individuals. Another study done by the Autism Developmental Disabilities Monitoring (ADDM) Network indicated an overall prevalence of ASD to be 9 in every 1,000 children (Rice & CDC, 2009). Findings from a recent study indicated that ASD is affecting 1 in every 110 children with a growing rate of 10% to 17% every year. Due to the growing prevalence of ASD, interest in autism and its effects on families is present (Meadan et al., 2010).

2.4 PARENTS' EXPERIENCES IN RAISING AUTISTIC ADOLESCENTS

A diagnosis can signal “an official loss of normality” and the resulting expectations (Russell & Norwich, 2012, p.237). According to a research done by Blacher and McIntyre (2006), it was found that no ethnic or cultural differences that relate to stress levels when caring for a child diagnosed with ASD. There seem to be gender differences with regard to the impact of parenting a child diagnosed with ASD, with mothers generally reporting more stress and depressive symptoms than fathers (Hastings, Kovshoff, Ward, Espinosa, Brown & Remington, 2005).

Besides this, Fombonne (2003) found that two of the respondents' children with ASD had experienced epilepsy when they were 1 year old; connoting that epilepsy is also associated with autism. This finding supports Gillberg and Cederlund (2005) who discovered that epilepsy in childhood is significantly associated with severe mental retarding and autism. Individuals with ASD can also have a secondary diagnosis, such as epilepsy or intellectual impairment, which can pose parenting as a challenge and render experiences across parents highly variable.

A number of studies that involved parents of children with ASD have also reported higher levels of stress in mothers in comparison to fathers (Baker-Ericzen, Brookman-Frazer & Stahmer, 2005). Most research have focused on mothers of children with disabilities because they are in constant interaction with the child, their role as primary caregivers, and due to the gender stigmas that are applied in the society (Caples & Sweeney, 2010; Espina & Ortego, 2003; Núñez, 2008). Rowbotham, Carroll and Cuskelly (2011) stated that mothers provide 40% more care for children than fathers do; thus, parents frequently question the role of genes in autism if a child is diagnosed with autism and they look at themselves and their partners. Parents blame themselves or their partners, and in whereby it was shown in Gray's (1995) study, which found that parents expressed a sense of guilt for possibly having passed on genes that caused their child's disability (Gray, 1995). Parents also experienced blame from people outside of their family, including health care professionals (Desai et al., 2012; Hutton & Caron, 2005).

The degree of explanation offered by the diagnosis helps parents accept that they are not to blame for their child's disorder (Mansell & Morris, 2004). According to Smith and Daughtrey (2000) diagnosis is a key stage in the lives of parents of children with disability, and the details and shock of the first diagnosis can affect

parents for years. Parents may experience an increase in stress, depression, anxiety, financial difficulties, relationship problems, as well as decreases in self-competence and self-confidence (Fitzgerald et al., 2000; Symon, 2001). Moreover, Osborne and Reed (2008) stated that initially parents experience a sense of relief when their suspicions have been confirmed and that there is a name for their child's condition.

Parents are reported to be more stressed when having a child diagnosed with autism as opposed to parents with children diagnosed with Down syndrome and parents of typically developing children (Meadan et al., 2010). Moreover, a study reported that mothers face more stress than fathers following an autism diagnosis as mothers are usually the primary caregivers of the children and since they are more active in the child's education (Dabrowska & Pisula, 2010). Some parents were devastated as they worried about the long-term impact of the diagnosis (Altiere & von Kluge, 2009; DeGrace, 2004). For other parents, the devastation was so overwhelming that it was equated to a death in the family (Altiere & von Kluge; Gray, 2003; Hutton & Caron, 2005). Furthermore, parents experienced feelings of anxiety, stress, and confusion as the problems of the condition became prominent, in addition to the difficulty of understanding the child's development (Gray, 2002).

2.5 CHALLENGES THAT PARENTS FACE IN RAISING A CHILD WITH AUTISM

ASD

According to UNICEF Malaysia (2014), children with autism suffer from learning difficulties and abnormalities in development. This description is similar to Jasni et al. (2011), who found that children and adults with autism have problems socialising with their peers, therefore affecting their learning, communication, and socialisation.