

Qualitative Study of Families Resilience in Mothers with a Child with Autism Spectrum Disorder

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Abstract

To date, there is limited research focusing on positive aspect of family with a child with autism. This phenomenological qualitative study aimed to examine lived experience of family resilience in mothers with a child with autism. There were seven Thai mothers with a child with autism participating in this study. In-depth interviews were conducted. Interview scripts were analyzed using qualitative method.

Findings revealed six themes of experiences. First theme is family hardship such as situational and psychological hardship. Second theme is family resources including the love and care of parents, family bonding, emotional and morale support and useful information and services. Third theme is growing acceptance of their child with autism as well as having realistic expectation toward professionals who works with their child. Fourth theme is positive family development. Fifth theme is effective family functioning including family communication, family task allocation, and development in readiness to cope. Sixth theme is the happiness and personal growth such as happiness, and life satisfaction.

The study assists psychologists and mental health professionals working with family in particular the mothers to be cognizant of the possible influences of family development through positive aspects of having a child with autism

Keywords: Family resilience, Mothers with a child with autism, Qualitative study

ประสบการณ์การฟื้นคืนได้ของครอบครัวที่บุตรมีภาวะออทิซึม

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บทคัดย่อ

ในปัจจุบันยังมีงานวิจัยจำนวนไม่มากนักที่ศึกษาเกี่ยวกับประสบการณ์ด้านบวกของครอบครัวที่บุตรมีภาวะออทิซึม งานวิจัยในครั้งนี้จึงมีวัตถุประสงค์เพื่อศึกษาประสบการณ์การฟื้นคืนได้ของครอบครัวที่บุตรมีภาวะออทิซึม โดยผู้ให้ข้อมูลคือมารดาที่บุตรมีภาวะออทิซึมจำนวน 7 ราย มีการเก็บข้อมูลด้วยการสัมภาษณ์เชิงลึก และวิเคราะห์ผลด้วยการวิจัยเชิงคุณภาพแบบปรากฏการณ์วิทยา

ผลการวิเคราะห์ข้อมูล พบประสบการณ์การฟื้นคืนได้ของครอบครัว 6 ประเด็นหลัก ดังนี้ (1) ความยากลำบากที่ครอบครัวเผชิญทั้งจากสถานการณ์และภาวะใจ (2) ขุมพลังของครอบครัว ได้แก่ ความรักของพ่อแม่ การมีสายสัมพันธ์ในครอบครัวที่แน่นแฟ้น การได้รับกำลังใจจากคนรอบข้าง และการเข้าถึงแหล่งข้อมูลที่เป็นประโยชน์ (3) ความเข้าใจและการยอมรับลูกที่มีภาวะออทิซึมของครอบครัว (4) การพัฒนาวิถีครอบครัวพลังบวก (5) การจัดการในครอบครัวอย่างมีประสิทธิภาพ ได้แก่ การสื่อสารภายในครอบครัว การแบ่งหน้าที่ในครอบครัว และการพัฒนาความพร้อมในการเผชิญปัญหา และ (6) การมีความสุขในการดูแลลูกที่มีภาวะออทิซึม การตกผลึกการเรียนรู้จากประสบการณ์ และการมีความพึงพอใจในชีวิต

ผลการศึกษาครั้งนี้ทำให้เข้าใจประสบการณ์การฟื้นคืนได้ของครอบครัวที่ลูกมีภาวะออทิซึมและปัจจัยที่ทำให้เกิดการฟื้นคืนได้ และสามารถนำไปใช้เป็นแนวทางสำหรับนักจิตวิทยาและหน่วยงานที่เกี่ยวข้องในการให้ความช่วยเหลือครอบครัวเหล่านี้ต่อไป

คำสำคัญ: การฟื้นคืนได้ของครอบครัว, มารดาที่บุตรมีภาวะออทิซึม, งานวิจัยเชิงคุณภาพ

Introduction

Families with children with autism have been found to encounter a wide range of stressors including issues related to the child's delayed development and diagnosis (Lopes, Clifford, Minnes, & Ouellette-Kuntz, 2008), learning about and accessing the service system (Villeneuve et al., 2013) and managing behavioral challenges (Brown, McIntyre, Crnic, Baker, & Blacher, 2011). Another source of stress for these parents is also due to additional expenses from autistic-child care and strained relationships with their relatives and people around them. Other children in the family might also feel neglected, ashamed, or hurt. Even the marriage lives of parents can be put at risk from stress and high likelihood of divorce or separation, emotional disturbances, undesirable impacts on income and the whole family. Alienation from the society can be inevitable because of constraints on places to visit and activities to do, leading to loss of some friends and social life in addition to poor relations with those around the families of children with autism (Myers, Mackintosh, & Goin-Kochel, 2009).

However, Myers et al (2009) found that some parents of children with autism viewed this experience as "my greatest pleasure and pain at the same time." On the positive note, parents reported that they had gained certain insights and accepted their children's disability, satisfied with what their children were without the desire to treat them to be normal: they still could lead worthy lives, appreciate and love their children with patience and perseverance, learn to be content with little mundane things, relish in mutual moral support within their families,

and find unexpected positive outcomes among their children, the siblings of their children with autism. These findings are well supported by a previous study by King, Zwaigenbaum, King, Baxter, Rosenbaum, and Bates (2009) that, when parents are informed of their children's autism, they will first see their lives change and dreams collapse, followed by adaption from awareness of their values - what is really important to them-, and recognition of hope and growth. This development can be reflected in their ability to enjoy little things in daily lives, greater tolerance, unconditional love, and change in attitudes: instead of focusing on treatment of the condition, they turn to develop their children's assets and capacities, enabling them to find balance in their lives

Few studies have in fact been carried out on lived experience of Thai family with autistic child. Therefore, it would be significant for understand experience of such families from their perspectives by using qualitative method. In order to meet the needs of study presented above, the research questions generated for this study are as follows: (1) what experience did families with a child with autism undergo during their hardship and resilience? and (2) what factors facilitated resilience among families with children with autism?

Literature Review

Literally, resilience is defined as the ability to persist and recover from crises, hardships, or challenges in life (Walsh, 1996, 2003), and specifically in the familial context, as the process in which the families can adjust and function well in the face of crises or

afflictions (Patterson, 2004).

In the Family Adjustment and Adaptation Response (FAAR) Model (Patterson, 2004), families engage in stable patterns of interacting as they try to balance the demands they face with their existing capabilities to achieve a level of family adjustment. However, there are times when family demands significantly exceed their capabilities. When this imbalance persists, families experience crisis, which is a period of significant disequilibrium and disorganization in a family. A crisis is very often a turning point for a family, leading to major change in their structure, interaction patterns, or both. A crisis can lead to a discontinuity in the family's trajectory of functioning either in the direction of improved functioning or poorer functioning. When the discontinuity is in the direction of improved functioning, that's the family resilience.

As families with children with autism are encountered with considerable ordeals on a regular basis, their experience of resilience is simply noteworthy. Research in other countries, Bayat's (2007) among others, found particular characteristics of the resilience process in families with children with autism: positive reframing of disabilities, securing support, family solidification, greater recognition of lives and individuals with special attributes, and spiritual strength. Furthermore, a mixed-method research by Greeff and Walt (2010) pointed out that family resilience is associated with ability to solve problems within a family.

King et al (2009) denoted positive outlooks of these parents, including optimism, acceptance, appreciation, and determination

to champion the proper environment for their children (King, Baxter, Rosenbaum, Zwigenbaum & Bates, 2009). According to King et al (2011), there are benefits that family can gain from having a child with autism: (1) for parents in that they can accept what their children are and overlook their children's limitation to promote what their children can do, (2) for the whole family as they become closer and more attentive to one another and learn to live, grow, and develop their strength, and (3) for the society to see potentials of the disabled and for other families with disabled children to be encouraged (King, Zwigenbaum, Bates, Baxter, & Rosenbaum, 2011). This constructive experience of families with children with autism is viewed by positive psychologists as an ability to snap back from critical life events, or resilience.

Methods

This phenomenology qualitative received the Ethical Review Committee for Research Involving Human Research Subjects, Health Science Group, Chulalongkorn University (COA No. 101/2556).

Participants. There were seven mothers of child with autism participating in this study. They were purposively selected under the following criteria: have an over-8-year-old child diagnosed with autism in all areas of autism spectrum disorder; be a major caregiver for at least 3 years; have scored at least 4 out of 5 on the Family Resilience Assessment Scale; and be willing to participate in this study. The demographic data of all mothers with a child with autism in this study are shown in Table 1.

Table 1 The demographic data of key informants

Key Informant	Child Information	Description of the Family
Kaew ^a Age : 44	Saw ^a Gender : Boy Age : 10 Birth Order : 2 of 2 Onset : 2 years old	Kaew has two children: the elder is a daughter and the younger is a 10-year-old son with autism. She knew of her son's autistic condition when he was two years old diagnosed with moderate Autism Spectrum Disorder (ASD). The family consists of Kaew, her husband, the elder daughter (Khima), and the younger son old (Saw) and grandma. Now she is a housewife, looking after her two children, grandma, and all house chores.
Wi ^a Age : 40	Pete ^a Gender : Boy Age : 8 Birth Order : 1 of 1 Onset : 2 years old	Wi has an only 8-year-old son with autism, Pete. She knew of his deficits of moderate ASD when he was two years old. Now he has been learning at Special Children Development Center for four years. After finding out her son's condition, Wi resigned from her work in order to take care of him as he had been neglected when he was with a hired babysitter.
Na ^a Age : 49	Ni ^a Gender : Boy Age : 11-8 Birth Order : 2 of 2 Onset : 4 years old	Na, has two sons, the younger of whom, Ni, 11 years old 8 months, is autistic. He was diagnosed with moderate ASD at four years old and now has been studying at a special child development center in a prep class for elementary levels for two years. Na comes from a close-knit extended Muslim family. She has been trying to make all her relatives to understand and accept her son so as to make them support her and help her take care of her son, with major support from her own husband.
Por ^a Age : 39	Nil ^a Gender : Girl Age : 8years old Birth Order : 2 of 2 Onset : 3 years old	Por has two daughters. The younger one, Nil, has ASD. Por knew of his deficits of severe ASD when he was three years old. Por had lived with the extended family of her husband before the birth of Nil. After that, the discovery of her younger daughter's severe physical problems with the incomplete function of inner organs caused them frequent visits to hospital and later resignation of Por from her work to provide intimate care for Nil. When Nil was allowed to leave the hospital, Por and her husband decided to settle by themselves as a nuclear family so as to be able to set up the equipment and facilities needed for Nil's treatment program. The elder daughter, however, continued to stay with the grandparents during school days but would stay with her parents at weekends.

Table 1 The demographic data of key informants (cont.)

Key Informant	Child Information	Description of the Family
Nid ^a Age : 43	Shid ^a Gender : Boy Age : 11 Birth Order : 2 of 2 Onset : 2 years old	Nid has two siblings, an older daughter and a younger son with autism, who is now 11 years old called Shid. Shid was diagnosed with high-function ASD at the age of two. At present, Nid, is a housewife taking care of both children and earn some extra income from selling things. Nid is one of the founders of Parent Club providing support to families with children with autism and also a volunteer to help any activities concerning with children with specific needs.
Da ^a Age : 54	Dol ^a Gender : Boy Age : 13 Birth Order : 2/2 Onset : 2 years old	Da, has two sons. The younger, Dol, aged 13, was diagnosed with moderate autism at the age of two. Now he is studying in Grade 6 in a school providing mainstreaming classes in the conventional school system. Da quit working to be a housewife since the birth of her first son. Her main responsibility concerns taking care of both son: driving them to and back from school, and now she also has to wait for and take care of Dol at school every day.
Jom ^a Age : 58	Earth ^a Gender : Boy Age : 22 Birth Order : 2 of 2 Onset : 3 years old	Jom has two sons. The older, Earth aged 22 years old, was diagnosed with high functioning ASD when he was three years and six months old. Jom herself have been taking care and teaching Earth since his condition was aware and has been suffering a great deal, physically and mentally, from bringing him up, but she has endured all hardship for him. Her family consisted of father, mother, two sons, and grandmother. Jom had been working and taking care of her children until Earth was 7 years old when she quit her job to accompany her son at school because his assistant teachers couldn't control his behavior. After that she could look after him closely, resulting in his much improved development.

^aSubstitute name

Procedure. After receiving the approval from the Committee for Human Research, Chulalongkorn University, the researcher contacted the gatekeepers to recruit the qualified mothers. Then, the appointments with the mothers were made to provide them with information about the study and their rights to

participate in the study. Those who were willing to participate in the study were asked to sign the consent form and complete the Family Resilience Assessment Scale that was developed from the definition and research about resilience (Patterson 2004; Sixbey, 2005). It contains five questions in which both the gate keeper and the

participants must reach four points out of five. Afterwards, the participants who passed all the selective criteria were in-depth interviewed with details from the interview outline. The questions refer to personal experiences on raising a child with ASD and the daily living of families with a child with ASD. The interview was focused on the emotions of the participants.

Data Analysis. Data analysis applied a phenomenological qualitative. After interviews, the data collected were transcribed verbatim and re-listened to check the accuracy of transcription. The transcribed dialogues were re-read several times to make sense of the overall picture, together with interview notes recorded by the researcher. Key messages and sentences concerning experience, thoughts, and feelings of each informant were elicited and encoded. The encoded information was then associated and grouped into meaningful topics and themes to construct the conclusion from all the main selected themes. Peer debriefing was arranged with the research advisor to prevent the analytic results from blinded with the researcher's bias and presumption and to ensure the maximum accuracy with the original interview scripts.

Results

The results of the data analysis reveal six main themes of resilience experience among families with children with autism, as follows.

1. Family hardship

There were 2 aspects: situational and psychological hardship that encountered by the families, as follows.

1.1 Situational hardship. Key inform-

ants identified threatening situations toward peace and harmony of the families. Those include hardship during treatment, hardship during childcare, clashes of opinions, hardship from other problems in the families, as can be seen an example in the following sample excerpts.

"In the past, he would break nearly everything. In the house, there were no picture frames. Dad disposed them all. I kept telling dad it was not the right solution, and he would suddenly lose his temper that I didn't follow his idea to prevent our son from getting hurt. I thought that if so we had to indulge our son's every whim, which is not possible in the real life. What if he had to stay at others' places? We needed to teach him it was not right: we needed to take him out of that situation, frequently, telling him "no" frequently, maybe 100 times. For five forbidden things we may need to tell him 100 to 500 times each, but if it needed to be so, we had to." (Por)

1.2 Psychological hardship. This caused by the process emotional adjustment to accept their children's condition, including denial when first learning of their children's diagnosis of autism, negative feelings from hardship in childcare, as shown below.

"I eat with tears every time I see his behavior. At first I was so happy seeing my son so cute. Nothing hinted anything wrong. But when I knew from the doctor, misery arrived. The world shattered. It was such a great agony. And when the doctor told me when my son was 5 that he couldn't speak. He was mute. My suffering doubled. This condition can't be cured (crying). I didn't know what to do. My money couldn't help anything." (Jom)

It can be seen that prior to families of children with autism could adjust the balance and have adapted until becoming a resilience family, the informing families were confronted with various difficult situations and faced numerous mental difficulties. However, the mental experiences that the informant families faced, both in real life and in the mind, until they're gone away are essential experiences that the families have been through. They are learning, adjusting, and adapting to become a resilient family.

2. Family resources.

There were four salient resources that the mother mentioned as the narrative below.

2.1 Love and care of parents. Key informants reported that their love and care of their children with autism made it possible for them to do whatever that help best supports their families, as follows

"I had to devote to my child. I had to think that way as mom, I couldn't think of hiring someone to look after my child for a day so that I could take a day out. I cannot enjoy doing other things because of the concerns about how my child would be or eat. He is my baby and I have been with him from the start." (Kaew)

2.2 Family bonding. This strong familial tie can be sense of love, warmth, care, and support, and encouragement that family have together or parents have together, as an example below

"At first, I was upset, but my husband soothed me. He could accept and so we learned to do so together...He calmed me down, telling me it was alright. At first I cried, but he comforted me, saying, "It is alright." He said that even a

monkey could be trained to do human things. What's that monkey's name? Pang Kung, isn't he? He said a monkey could be trained and how couldn't our child, a human? He said so (laughing)." (Da)

2.3 Emotional and morale support.

Key informants told that the supports usually came from people around, including relatives, friends, doctors, teachers, physiologists, and other families having children with special needs, via speech and acceptance of their children with autism and families, as show in the following excerpt

"So does his uncle. His uncle understands, asking my son to kiss him and hug him. At 10 or 11 p.m. if his uncle is still awake, he will come downstairs to play with my son first. Sometimes to feed the child milk or anything he could get. When the uncle travels, he usually brings something back for his nephew, knowing what favors his nephew likes. His grandmother also never gets angry or crossed with him, sometimes my son is at home, but he will run to his grandma's house to play water there, a bucket full of water. Grandma never complains. Sometimes she stays with him to watch, afraid that he will be drowned or something happens. Grandma is already 78 but still she sits watching him. Tell him, "Go up, kiss your granny first." He does. Tell him to hug her, and he does as well." (Na)

2.4 Useful information and services.

Key informants mentioned that accessing to helpful information and aiding sources, such as hospitals and other parents, due to the families' attempt to gain knowledge regarding autism help them to increase their

understanding and possibilities to help their children, as shown below

“About training regarding his specific conditions, we have teachers who can see the areas my son is deficient teach him that way, for example, SI right?, or physical therapy activities, exercising, systematic playing and thinking, among others. There are teachers responsible for that areas. For behavior modification, we have teachers specialized in this. And I, too, have to help with my son’s behavior modification.” (Kaew)

In order for the family to overcome the difficulties, the family must possess the powers which are parenting love, a strong relationship with the family, encouragement from those around them, and access to useful resources and assistance which is a resource that the family can rely on. These will act as a powerful resources in their daily lives, as the center of mind, as a driving force, as a shelter, as an encouragement to be helpful, as a knowledge that is a part that helps the parents to gain the strength to face difficulties from various challenges, problems or obstacles that comes into life, including the correct direction and method to overcome each problem.

3. Growing autism understanding and acceptance

Key informants reported their growing autism acceptances in two areas: within their family and toward professionals, as shown here.

3.1 Acceptance of their children with autism by having realistic expectation of these children and not feeling ashamed of having them, as reflected in the following excerpt.

“Depending on his potentials. We keep

training him, but if he happens to improve much, we considered ourselves lucky (laughing). We don’t have much expectation, just some goals. But never expect him to be able to do this or that, just aiming at encouraging him to try this and that. Just try anything that seem helpful, keep trying.” (Da)

3.2 Understanding towards professionals working closely with their children, especially teachers who take care, modify behaviors, and teach their children, sometimes, simultaneously with other children with special needs. Therefore, some informants tried to have empathy with them despite problems arising with their children, as demonstrated below.

“I told her, with me, she could tell everything truthfully. I sent my child here, and I knew teachers wanted to teach children, not having a trouble with parents. I never viewed teacher negatively, but just wanted her to tell the truth about my child’s conditions and behavior. She said, “Oh, do you suspect that I am too strict? The child refuses to get off the car?”... I am open and understanding teachers. No offense, just tell me the truth, don’t lie to me.” (Na)

The resilience of the informant family begins with understanding and accepting the autistic condition of the child first. With the expectation of the child in accordance with reality as well as the understanding of teachers or experts, which must be a caretaker whose children developed autism as well.

4. Positive family development.

Key informants identified positive family development such as the family put their efforts

in childcare and development training. They also adjusted their daily activities to fit the caregiving style of children with autism for achieving the best and nearest possible normal development of their child, as seen in an excerpt

“We visited the hospital once a week, where we got some advice. We took Pete for speech therapy and tried to find more chances for him to receive this training. On Saturday, there was a special speech-training clinic, for both normal children and those with special needs, to correct speaking.” (Wi)

The mothers also mentioned that there was growing strength within the family that helped them to best cope and face any challenge and hardship undauntedly

“We need to try, to adjust ourselves, to make peace with our minds that our child is like this. We must not be down, must not whine, we must be strong and try to find ways out. We must not be ill, too, must be healthy. We must take good care of our health so that we are fit enough to take our child everywhere and take care of him.” (Kaew)

Regarding the information providers and families have progressed or developed ways of living in the family, which is a way that is contributory to the resilience and makes every family member to live together in a balanced way, the parents also have a way of life and a way of thinking that makes them have the strengths to do things for their children, and their children are fully taken care of and have good lives and development. At the same time, informants and families have a strong mind with a positive perspective and possess a strong inner strength can, therefore, be called the families

with “Positive family trajectory”.

5. Effective family functioning

There were four effective family functioning such as family communication, family task allocation, and development in readiness to cope, as follows

5.1 Family communication, for instance communication with children with autism, communication between parents, parents-siblings-children with autism communication, and communication within the entire extended family, all of which reflect the perseverance of the families to communicate with their children with autism despite the latter’s inability for verbal expressions

“Every day, we have to observe his behavior. How is he today? What does he like or dislike? Is he agitated? Everything we observes, sleepy or not, when we are about to go out. When his dad took him out for a motorcycle ride for half an hour. Coming back, his dad had rested for just about 10 minutes, our child fretted to go out again. My husband refused, saying that his back ached, but I told him, “Please go. It must have left him suspended. He must have not be satisfied with it.” My husband complained, but finally yielded. This time our son came back happily.” (Na)

5.2 Family task allocation - Commonly, father is a breadwinner, while mother is a home and children caregiver. But in low-income families, mother also has to help her husband make money. It is found that these resilient families rarely suffered intra-family management despite mother’s working outside as resilient mothers could manage time and responsibili-

ties effectively. And fathers, in free time, would help taking care of and play with children, alleviating their wives' burdens, as expressed below.

"Dad never gets involved with childcare. He works, comes back home, and his only duty is playing, just playing with our children. No need to help with our children bathing and brushing teeth, never teach them to do so. I never mind this. I talked with him from the start when I left my job that he didn't have to worry himself with childcare because his responsibility as a sole breadwinner was already hard. Coming back and preparing milk for kids was not necessary. I could manage to do all. It's much easier and more comfortable form staying home. I am just physically tired from taking care of kids, but not stressed out. But he is stressed mentally." (Kaew)

5.3 Development in readiness to cope that might arise in the future, with confidence in ability to cope while staying with the present with courage - no negative anticipation- and proper family adjustment to enable effective management and balance within the family

"It's funny that each day can bring unexpected surprises, so we have to get prepared, prepare our feelings. As when once my child arrived at home, a lot of blood on him, you see what I felt, but I had to remain strong. Screaming wouldn't help. I had to think of a way to help him." (Kaew)

Families of children with autism have to face various situations which require a lot of adaptation due to autism. Family management is expected in order to be more effective in

accordance with the changing situation that is affected by the child. Information providers and families must, therefore, communicate and divide their duties within the family and develop a readiness to face any challenges so that they can adjust the balance of the family and lead to a resurgence of strength in the family.

6. Happiness and personal growth.

The mothers reported that they were happy and satisfied with their life. Their happiness from raising a child with autism including contentment when seeing better development of one's child, affection for the child, pleasure when seeing the child's happiness, as shown in the following excerpt

"Just a little thing my child could do, just an utter of a word, can make this mom happy. That my child can dress himself, I am so happy. It's like walking from zero to one. That's good enough. Once he loved playing with a bubble blower designed after cartoon characters. I bought him one, but there were no bubbles out from the blower, maybe because no shampoo inside, I don't know. But he poured some dishwasher liquid in the bottle and shook it, and then blew bubbles. He had seen me washing dish with soap suds. He could figure this out. Many things I have never thought, but he could. There are funny things in the family. Although very little, just a bit improvement can make me believe he is better." (Na)

Other aspect of happiness and personal growth included contentment with what one has, being proud and feeling good with oneself, viewing the experience as a luck in life. The

following excerpt show contentment in what one has.

“Because of warmth from the time we had been living together, as I have told, and my husband started to accept, adjust what to do with our child. When Saw has learnt what he has to do in his daily life, eating, stooling, bathing and grooming, sleeping, adjusting himself to fit with others to a certain extent, that is acceptable. That’s to say, we are happy with where we are now, satisfied. We can say we have no problems now.” (Kaew)

Personal growth included their crystallization an experience of raising children with autism, including temper control, letting go, sacrifice, sharing, patience, hardiness, openness, positivity, among others. Also, there was feeling empathetic and desire to share good things with other families facing the same situations that derived from experiencing hardship and adjustment because of having a child with autism, as expressed by some informants

“Having Earth now as a son is like having him as a teacher too because he has taught me to be patient, open to the world, sharing. I am already a sharing person, but only to a certain point. Now I am as generous as a big river. Whatever I can do or have a chance to do, I won’t hesitate. I raise fund for School B (a mixed school for children with special needs) every year. Even now that Earth graduated, I still do so.” (Jom)

We pass to others by being volunteer telling stories I used with my child. I can tell them my past experience of reading books to my son and how I raised him up. I can share my experience, what lessons I have learnt. It’s

like we increase their knowledge, which makes me happy. Happiness for me is when I can help others.” (Nid)

The experience of having children with autism of the informants and their families starts from going through various difficulties. Still, there is the strength of the families that have faced such experience of caring for children with autism until they become understanding of their children and the people around them, developed a style that fits the family lifestyle, and having effective family management.

Ultimately, these families have regained their power which gives the informant and family the happiness and growth with the maturity of the family. This hence is the happiness caused by the child having autism and from personal satisfaction in the life of their own family and eventually learned after going through various experiences.

In summary, all of this is the experience of the restoration of the family in which the child has autism, which they have adapted through difficult times until they find happiness in life. The result found the factors that contribute to family resilience include family resources, growing autism understanding and acceptance, positive family development, and effective family functioning.

Discussion

Results of the present study showed that mothers of children with autism experience similar difficulties. All families reported that they had overwhelming stress. Besides, difficulties such as complications in treatment process, childcare hardship, opinion dissension, hardships

from other problems in the family- are also in the same line as the results from the study of Myers et al (2009) has found that parents with children with autism experienced stress, obstacles, and difficulties in managing the behavior and needs of children. Also, experienced negative emotions such as grief, depression, and guilt. However, it has been found that parents that develop an understanding and respect in the world of disability will feel welcome about what the child's condition is without wanting to cure the child. Living a life of appreciation and love for children, with patience, perseverance, and being happy with small things. According to FAAR Model (Patterson, 2004), the demands and difficulties force families to respond in a way that leads to a balance, but if families cannot make it, they enter a crisis, which requires adaptation period to create a balance and, thus, resilience. With regard to family resource, there were love and care of parents, family bonding, emotional and morale support and useful information and services. This concurs with the study on families with children with autism by previous studies (Myers et al, 2009; Greeff & Walt, 2010) that support from relatives and friends can predict adaptation of a family and that social support from families, friends, communities, and other parents of children with autism can be part of resilience experience of a family.

In this study, the mothers reported that their families developed positive aspects as acceptance of their child with autism as well as having realistic expectation toward professionals who works with their child. There are positive family development and

effective family functioning that mentioned by the mothers. This positive family development and effective functioning could have either alleviated stress or caused other forms of stress, or both. Family functioning styles after a crisis in the family stress theory of resilience is comparable to coping styles in Patterson (2004) with respect to family protective process. A study on resilience of families with disabled children found that families had strategies and coping styles as their protective factor, by creating a balance between illness and other necessities in the family, maintain clear boundaries of the family, developing effective communication, and participation in proactive problem management (Patterson, 1991). Myers et al (2009) found same result that personal factors as devotion and patience are part of resilience experience of families.

Interestingly, the families in this study believed that their children could learn and develop. This positive viewpoint is adaptation of family functioning that exemplifies both maintaining the existent functioning in families which already possessed positive outlooks and transforming the functioning to be positive or more positive regarding care given to children with autism. This concurs with the study of Greeff & Walt (2010). Bayat (2007) also found that families gave positive meanings to hardships or view them as learning, changed the view of the world, and understood philosophy and existential meanings. Mireau (2008) also discovered that such families viewed themselves and others in a positive light and have strong faith.

Finally, the result demonstrated in this

study that, among resilient families with children with autism, happiness and maturity of the family come from 4 sources: (1) contentment in raising children with autism derived from gladness to see their improvement, affectionate towards them, and happiness from seeing them happy, (2) life satisfaction, including satisfaction with what one has, pride and confidence in oneself, and viewing one's experience as fortunate, (3) crystallization of childcare experience, and (4) empathy and desire to share good things with other families. According to family stress theory of resilience, happiness and maturity growth of a family are the outcomes of successful adaptation. It was found in this study that families gain their happiness from raising their children with autism and satisfaction with their family lives, as well as crystallization of learning from past experience, which contributes to empathy, sympathy, and desire to share good things they have with other families with children with autism or children with special needs. This is in accordance with previous studies (King et al, 2009; King et al, 2011; Bayat, 2007)

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Conclusion

In conclusion, the resilience experience of families with children with autism in this study consists of critical period and adaptation period. The critical period included "hardships encountered by families." If families failed to adjust with the hardships, then the families entered the adaptation period, which required alteration of family functioning shown in the theme "development of positive families," while the social support backed up the previous process can be found in the theme "family resource" and situational appraisal is themed under "developing of understanding." The issue of coping in this study is under the theme "effective management within families," which leads to successful adaptation, called in the finding part as "happiness, growth, and maturity of the families."

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