



Counseling intervention for native mothers with autism spectrum disorder (asd) children

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ABSTRACT

The purpose of the study was to explore the experiences of native mothers with autistic children in Kuching, Sarawak. The research focused on the challenges faced by native mothers with autistic children, their coping strategies, and participation in counseling intervention. This is a qualitative-based research with three native mothers with autistic children, employing approximately 30 until 45 minutes semi-structured interview sessions. Outcome of the interview sessions were categorized into four major themes and nine sub-themes. Recommendation of counseling intervention include psychoeducational, which aim to provide information to native mothers with regards to autism-related knowledge, skills, and techniques to handling autistic children.



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Introduction

Statistic showed that estimated one out of every 600 children in Malaysia is born with autism (Lee, 2016). Children with Autism Spectrum Disorder (ASD) faced difficulties in social interaction and sensory processing. They are unable to use verbal and non-verbal communication effectively (American Psychiatric Association, 2013). Mental, psychological, and biological development of autistic children are different with typically developing children. According to Piaget's Theory, cognitive development in early childhood consists of four stages, which are sensorimotor, pre-operational, concrete operational, and formal operational stage. On the other hand, autistic children are unable to perform cognitive tasks such as reasoning, decision making, numbering and so on. Vikram, Nameera, and Jacob (2016) found that typically developing children performed better in reasoning compared with autistic children. However, cognitive ability of autistic children could not be examined by intelligence test because impairment of brain in autistic children did not affect their cognitive ability, but it impacts their social interaction ability. For typically developing children, quality of social interaction depends on active dialogue between their parents and children (Tordjman, Davlantis, Goergieff, Goeffray, Speranza, & Anderson, 2015). Limitation in social interaction cause autistic children unable to develop relationship with others such as family members, friends, teachers, and so on (Autism Spectrum Australia, 2008). Opposite with autistic children, typically developing children tend to share their interest and enjoyment with others. Biological development among autistic children is different with typically developing children. Autistic children are weak in activities that

required used of small-muscle coordination and used of eye-hand. In addition, they are over-sensitive to light and sound so they usually faced sleeping problem. Tordjman et al. (2013) found that abnormalities of circadian rhythm cause autistic children poor in adapting to internal and external environment changes. Thus, there are more challenges and difficulties faced by mothers with autistic children.

Autistic children required excessive care and support from caregivers due to poor social interaction, self-care, and behavior problem. Majority mothers with autistic children experienced rigid family schedules, social isolation, heavy child care duties, discrimination, and lack of social support and awareness of society (Divan, Vajaratkar, Desai, Strik- Lievers, & Patel, 2012; Hoefman, Payakachat, Exel, Kuhlthau, Kovacs, & Pyne, 2014; & Myers, Mackintosh, & Goin- Kochel, 2009). In Malaysia context, there is more than half (53.8%) of parents with autistic children experienced disturbance in psychological well-being (Nikmat, Ahmad, Oon, & Razali, 2008). Lee, Ong, Lee, & Fairuz (2017) found that parenting stress among parents with autistic children is higher than parents with typically developing children. Negative psychology development affects behavior and interaction patterns between caregivers and their children. Beurkens (2010) found that severity of autism symptoms and parent-child relationship are highly associated. Result showed that scores of parent-child interaction decrease when the scores of autism symptoms increase (Beurkens, 2010). Parenting training (PT) is a treatment provided by counselors or therapist for mothers with autistic children in western countries. On the other hand, Program PERMATA Kurnia was established by Yang Bahagia Datin Paduka Seri Rosmah Mansor to help autistic children and their parents in Malaysia. It aimed to educating autistic children to become more independent and empowering parents in raising up autistic children. Seminar, weekend parent training, and public talks are the services provided by Program PERMATA Kurnia to caregivers of autistic children.

Quantitative approach using questionnaire or instrument is commonly used in previous research. Majority researchers more likely to study about the impact of having autistic children toward caregivers instead of exploring about their experiences in raising up autistic children. Besides that, target participants of the autism-related research in Malaysia mostly focus in West Malaysia. Therefore, the objectives of the research were 1) To explore the challenges faced by native mothers in dealing with Autism Spectrum Disorder children; 2) To explore their coping strategies in raising up Autism Spectrum Disorder children; and 3) To suggest appropriate counseling interventions to assists native mothers in raising up Autism Spectrum Disorder children.

Methods

Qualitative approach was utilized in the research to explore challenges faced by native mothers and their coping strategies in the process of raising up autistic children. Face-to-face interview session using semi-structured interview questions was conducted to collect data. It consists of four parts, included demographic data of participants, challenges faced by native mothers, their coping strategies, and counseling intervention needed by them. Semi-structured interview question was designed and adapted according to the research objectives, with the references of interview question of previous research and suggestion of supervisor. Informed consent was provided to every participant in order to protect their welfare. Interview session took approximately 45 minutes. Five native mothers with at least one son or daughter diagnosed as autistic children were recruited by program coordinator of Kuching Autistic Association (KAA). Three native mothers were involved in the interview sessions, two native mothers withdraw from the research, and one native mother was participated in pilot study. Pilot study took times for approximately 25 minutes and participant was capable to understand and answer all the semi-structured interview questions correctly. Thematic analysis was used to analyze collected data (Braun & Clark, 2016).

Findings

The result of the research was categorized into four major themes and nine sub-themes emerged.

Table 1. Research findings

Themes	Sub-themes
Experiences of native mothers	-
Challenges faced by native mothers	Children's condition Family's acceptance Lack of Autism-related resources and support Low awareness of society
Coping strategies	Self-commitment Assistance of family Assistance of agencies
Participation in counseling intervention	Mother's experiences Mother's expectation

Theme 1: Experiences of native mothers

Based on interview sessions, experiences shared by participants consists of positive and negative experiences. All participants had shared meaningful experiences in the process of raising up autistic children.

...I feel satisfy every time when there is improvement in my son... (Madam A)

...I consider him as gift...I never considered his condition like illness... (Madam V)

...She teaches me to become more patient... (Madam L)

However, experiences shared by Madam L and Madam I illustrated some negative experiences;

...It is so hard to guess what they are thinking about... (Madam L)

...Some autistic children fear of fire, some of them fear of the sound, some of them have diet problem, they have various problem, so it's very hard in raising up an autistic child... (Madam I)

Theme 2: Challenges faced by native mothers

Children's condition. Communication and behavior patterns of autistic children are different with typically developing children. All participants agreed that children's condition is one of the challenges they faced in the process of raising up an autistic child. However, two native mothers claimed that their schedules become more rigid.

...Last time, we can't even go to supermarket, can't even put him inside the trolley, he just can't go anywhere... (Madam V)

...In the past, she was afraid of strangers. She will cry when other people come to my house... (Madam I)

Family's acceptance. Family members of all participants responded differently toward the diagnosis, which included positive, neutral, and negative responses.

...To be honest, actually we had been mentally and physically prepared... (Madam L)

... They do not have any special reaction toward the diagnosis because they don't know what it is... (Madam I)

...It was really tough at first, we were in denial stage especially the father. Very hard to convince him about A's condition... (Madam V)

Lack of autism-related resources and support. All participants claimed that resources related with autism were limited in Kuching area.

...Lacking of well-trained kindergarten for autistic children is one of the issues in Kuching... (Madam L)

...A has not received any allowance from the government... (Madam V)

...This is because only have KAA in Kuching, we do not have any other organization that cater for autistic children... (Madam I)

Low awareness of the society. Two participants mentioned that low awareness of society toward autism had caused some harmful events toward autistic children and their family.

...I feel hurt when people right in front of my eyes, people treat my son like that... (Madam V)

...It is impossible for me to hope for assistance from the society, because they don't know what autism is... (Madam I)

Theme 3: Coping strategies

Self-commitment. Two participants were willing to get more knowledge, skills, and information about autism through internet and reading while one participant had put a lot of efforts in convincing her husband regarding her son's condition.

...I search information about autism in internet, go through group of autism to search for information and search for research related to autism... (Madam L)

...I have joined a WhatsApp group. In the group, all parents with autism children will share and exchange their experiences... (Madam I)

...I asked him to add the post or Facebook of autism Malaysia...I asked him to go, to get use to this kind of thing...get him familiar to therapy thing... (Madam V)

Assistance from family. All participants had stated that support and help given by family members especially husband could reduce their stress level and care duties.

...I gave birth to my baby, so my mother-in-law helped me to take care of my children for few weeks...support from my husband is very important to me... (Madam L)

...for wife, the closest is the husband...so husband and wife have to work together... (Madam V)

...at least my husband can help me to bring N to go to therapy... (Madam I)

Assistance from the agencies. All participants agreed that there are improvements in their autistic children after attending treatment or therapy.

...KAA has tried to help my son to speak by active communication between teacher and students... (Madam L)

...Yes, KAA is a good center...so the support system is KAA... (Madam V)

...Kuching, Sarawak only has KAA, special organization for autism... (Madam I)

Theme 4: Participation in counseling intervention

Mother's experiences. All participants mentioned that they didn't have any experience in counseling service or counseling intervention.

...No, usually I counseling myself... (Madam L)

...No, I am a full-time house wife... (Madam V)

...No, never... (Madam I)

Mother's expectation. Two participants mentioned that they wish to obtain more knowledge and skills regarding autism and techniques in handling autistic children.

...I need someone who can provide or share his or her idea with me in helping my children... (Madam L)

...I want to gain more knowledge in how to improve A's speech... (Madam V)

Discussion

The research focused on exploration of experiences of native mothers by understanding the challenges, their coping strategies, and their participation in counseling service or intervention. Children's condition is one of the challenges faced by native mothers because some autistic children were hypersensitive to light, sound, and fear to being in social environment (Stein, Plido, Najera, & Cermak, 2013; & Tordjman et al., 2013). Family's acceptance level influenced the quantity of support and helping that provided by family members toward autistic children and their caregivers. Some family members especially husband were being in denial stage when their children were diagnosed as autistic children. Ilias, Liaw, Cornish, Park, & Golden (2017) found that five out of seven mothers reported that their husband is denial with regard to the condition of their autistic children. Low awareness of society toward autism could lead to harmful events and affect the psychology well-being of mothers with autistic children. Discrimination toward autistic children and their parents had occurred due to low awareness of society (Divan et al. 2013). Ilias et al. (2017) found that professional organization that provided special treatment for autistic children was limited in Malaysia. As the result, majority family with autistic children needs to seek help from private agencies with high treatment fees. In order to overcome all the challenges, high self-commitment is needed among native mothers with autistic children. Participants reported that they were willing to search for autism-related information through internet and reading, seek help from other parents with autistic children, and help their family members to participate in the process of raising up autistic children. Eventually, autistic children had improved gradually from time to time could reduce the stress level among native mothers with autistic children. Ilias et al. (2017) supported that well-being of mothers with autistic children could be fostered by self-initiative and self-engagement in children's training or treatment. Appropriate counseling intervention was suggested in the research based on the findings. Another interesting finding was participants of the research had low stress level, which means the finding was contradicted with literature. One of the reasons that lead to this phenomenon is due to the sufficient of support system. Assistance and support from family members and professional agencies had reduced the feelings of stress among mothers with autistic children indirectly (Ilias et al., 2017).

All native mothers did not have any past experience in counseling service or intervention. It showed that demand for counseling service and intervention was low among native mothers since they had sufficient support system in the process of raising up autistic children. In addition, they did not have extra free time to attend counseling session since two participants were full-time housewife and another one was working woman. All participants mentioned that they usually obtained psychological support from their husband by sharing their negative feelings and thought. Therefore, face-to-face conversation and discussion with husband was the first option for participants instead of seeking help from counselors. However, they hoped to obtain more knowledge and skills in dealing with autistic children if they were given the opportunity to attend counseling session or counseling intervention. As the result, psychoeducational was the most suitable counseling intervention for native mothers with autistic children based on the research findings. Counselors will play a role as educator or teacher in sharing information, knowledge, skills and techniques in handling autistic children. Individual and group counseling can be conducted to help mothers with autistic children.

Conclusion and Implications

All native mothers in this research perceived raising up an autistic child was a wonderful and challenging journey in their life. External aspects such as children's condition, family's acceptance, lack of autism-related resources, and low awareness of society were challenges faced by native mothers in the process of raising up autistic children. However, high self-commitment and assistance from professional agencies and family helped and supported native mothers in terms of training, babysitting, and financial. Indirectly, it could reduce the stress level among native mothers in raising up an autistic child. Psychoeducational was the most counseling intervention for native mothers to help them in dealing with autistic children.

Implication from the research can be seen from developing deeper understanding regards challenges faced by native mothers in raising up autistic children among registered counselor and trainee counselor. Therefore,

counselors can design and develop counseling intervention that match with the needs of native mothers with autistic children.

Based on the research, it is recommended that future researchers to explore about the experiences of caregivers, which means include mothers and fathers in the data collection. Challenges and coping strategies might be different between mothers and fathers of autistic children. Mixed method is highly recommended for future researcher since it could

examine the stress level among native mothers based on validated instruments while exploring their own unique experiences.

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