



Mothers' Experiences of Having a Child with Autism Spectrum Disorder in a Tertiary Care Hospital, Sri Lanka

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1 INTRODUCTION

Autism Spectrum Disorders (ASDs) is a growing problem worldwide and it was estimated that the global prevalence of ASDs to be one child in 160, which accounts 0.3% of the global burden of disease (World Health Organization-WHO, 2013). The children with ASDs encounter number of problems including restricted social, communicative and emotional competencies, uneven cognitive development and maladaptive behaviours and therefore, parents of these children have to face a unique set of challenges which in turn affects their psychological and emotional well-being (Meirsschaut *et al.*, 2010). Mothers appear to carry the large burden of care and may feel a need to be with their child always and experience stress related to coping with the heavy load of care giving (Davis and Carter, 2008; Meirsschaut *et al.*, 2010). Moreover, mothers were challenged with multiple reasons and therefore having suffered from deferent unpleasant experiences which are mostly remain unrevealed. Further, lack of published research studies were found in exploring mothers' experiences having a child with ASD within the Sri Lankan context. Hence, this study was conducted to explore the mothers' experience in parenting a child with ASD. The findings of this study will be helpful to aware relevant authorities, health care workers and the general public about the physical

and psychosocial problems the mothers of autistic children are facing and thereby to take necessary actions and facilitate them to overcome such problems.

2 METHODOLOGY

The qualitative exploratory research design was used for this study and the data analysis was done by the researcher using qualitative content analysis method described by Graneheim and Lundman (2004). Convenience sampling method was used to select participants of this study and sample size was determined as data saturation point is reached. Hence, for the study, a sample of 15 mothers a) who were able to understand and speak Sinhala or English languages and b) who were having a child aged between 3 years and 12 years with ASD were included from the Child Guidance Clinic (CGC) in the Lady Ridgway Hospital (LRH) of Sri Lanka.

Ethical approval for this study was obtained from Ethics Review Committee of LRH and the permission to conduct this study was taken from Director, Special Grade Nursing Officers and Nursing Officers In-Charge of LRH.

All the participants were provided with both written and verbal information about the purpose and the nature of the study. Voluntary participation to the study was



encouraged and from among those demonstrated the interest in participation, a written informed consent was taken prior to the data collection. All participants were informed about the right to withdraw from the study at any point of time without any sort of penalty. Researchers ensured the privacy and confidentiality of the participants prior, during and after the study and gathered data with tape recorders were protected with a password in a computer.

Data was collected using semi-structured interviews which usually lasted between 20-30 minutes. The interview guide for this study included demographic question about the participants and their children as well as 10 open-ended questions related to participant's experiences of having a child with ASDs in areas of a) the time of diagnosis of ADS, b) maintaining social and family relationships and c) own physical and mental well-being. Follow-up questions were included if clarity was needed in a particular area. All interviews were conducted in a confidential room at LRH by the research team members. The time duration of the individual interviews was ranged between 20-30 minutes.

All the interviews were tape recorded and transcribed in to verbatim. Then, the data were coded according to individual questions and patterns in order to make meaning of the participants' experiences. Coding continued until all possible option for themes had been derived and the interviews appeared to have been fully explored. The data was then organized thematically.

3 RESULTS AND DISCUSSION

3.1 Demographic Characteristics of the Participants

Mean age of the participants was 35 years the age was ranged between 28 to 41 years. Majority of the participants were Sinhalese (80%; n=12) and Buddhists (67%; n=10). Most of the participants had

studied up to O/L (67%; n=10) and many were unemployed (73%; n=11).

3.2 Mothers' Experiences of having a Child with ASD

According to the results, the major themes derived from this study were, a) Negative emotional reactions, b) physical exhaustion, c) financial problems, d) social withdrawal and e) coping with the autistic child.

a) Negative Emotional Reactions

Most mothers had negative emotional reactions when they first time heard that their children have ASDs. Feeling of sad: *"I have never heard the word autism here before. Once I heard that my child is having autism, I felt very sad"*; frustration: *"I got frustrated once my child was diagnosed with Autism.... and it took time to me to believe it and therefore, it was delayed to start treatments"*; and difficulty to tolerate: *"I felt a deep pain as I heard my child is having Autism. Actually I couldn't tolerate it"* were more common among participants. Similar to this finding, in a qualitative study done in UK found that parents had experienced distress and frustration when they were disclosed the diagnosis of their child's ASD (Abbott *et al.*, 2013). Also, the participants expressed uncertainty over their child's future: *"Anyone can't look after my child and they are not accepting my child. I think when I die; we both need to die together"*. In their study, Davis and Carter (2008) reported that parents undergo high level of stress and depressive symptoms when raising a child with ASD.

b) Physical Exhaustion

The participants' normal day today activities were drastically affected by having a child with ASD and caused them physical exhaustion. The participants reported that there is a heavy work load for them: *"I get up early in the morning and do everything for my family"*, *"I have to do lot of work due to my child's*



condition". On the other hand, they had missed their leisure time since they had to devote much more time and attention for their autistic child: *"Now I haven't freedom like earlier, it is zero"*. Supporting this result, another study also revealed that mothers reported difficulties in engaging with normal family activities such as going to a playground with the children, going on vacation, visiting friends, etc. (Meirsschaut *et al.*, 2010).

c) Financial Problems

Most mothers of this study expressed that they had to give up their career to give full time attention for their autistic child. Many mothers stayed at home and looked after the child thus father being the only breadwinner for the family: *"I had a dress making shop. Now I can't run it with this situation"*. Therefore, these families had to face financial difficulties since they had to spend considerable amount of money on expensive treatments of ASDs: *"We spent much money for the child's treatment. We can't save money. We are in rental house"*. In their study, Meirsschaut, *et al.*, (2010) also reported that it was impossible for mothers with autistic children to engage in full-time jobs due to their child's condition.

d) Social Withdrawal

In this study, mothers had to face many difficulties with their child's difficult behaviours. Some participants reported that their child demonstrated aggressive or violence behaviours towards parents, siblings or friends: *"he throws house hold items away and hit those on the floor"*; *"he always quarrels with friends at pre-school"*. In align with this result, other studies found that dealing with challenging behaviours (temper tantrums, repetitive behaviours and aggressive behavior) of children with ASD as stressful for parents (Ludlow *et al.*, 2011). Also, the participants experienced isolated feelings due to social stigma: *"I will be laughed at by others when they get to know my child's condition"*, *"we don't like to go to weddings, parties or*

restaurants because he (autistic child) runs here and there", *"I never go out of the home with this child alone"* and similar findings were reported by Nicholas, *et al.* (2016) and Hsu, *et al.* (2017).

e) Coping with the Autistic Child

Though initially mothers got delayed in accepting their child's condition, later they have accepted it: *"I made my mind to bare it...."* and turned to further improve their knowledge on ASDs by searching internet, watching television or reading newspaper articles (knowledge seeking behavior): *"I searched the internet and watched several videos regarding Autism and attended for a speech therapy class"*. A study done in Netherland found that parents of children with ASD showed high levels of acceptance and active adaptation to their child's recent diagnosis of ASD (Poslowsky *et al.*, 2014). This study found that most of mothers received help from their family members in looking after this child as well as the other children. Mothers had positive experience with paternal care and had support from their husbands. Also, the extended family become more helpful for those mothers: *"My younger sister looks after my child as she finished her school life...."* Mothers valued this support as a thing that helped them to cope with the situation. However, different results revealed by Meirsschaut *et al.*, (2010) since they found lack of understanding about ASD among relatives impacted on their relationships with the extended family members. Further, most of mothers got social support to care of their child, especially from health professionals like doctors, nurses and other therapists. Some mother got help from neighbors, head of the working place etc. However, lack of external support with lack of friendship and peer connection was reported in the study of Nicholas *et al.* (2016).



4 CONCLUSIONS AND RECOMMENDATIONS

This study explored mothers' experiences with their child diagnosed with Autism Spectrum Disorder and the major themes derived were negative emotional reactions, physical exhaustion, financial problems, social withdrawal and coping with the autistic child. Mothers had significant emotional challenges when it disclosed the news of the diagnosis. Mothers carried out intervention at home in the role of a full time therapist for their autistic child. It caused to increased level of stress and impacted upon their daily lives. Although a little number of mothers adjusted and were able to cope with daily activities with the diseased child, others were not fully adjusted. By revealing the challenges that the mothers faced of having a child with ASD, the authorities need to take actions to facilitate these mothers and strengthen their capacity to cope with and adjust with the condition. Further, awareness of the public regarding this disease is crucial since it helps to minimize social stigma that facilitates mothers to receive appropriate emotional and psychological support from the society at large.

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