

A CASE STUDY OF MOTHERS OF CHILDREN WITH AUTISM: CHALLENGES IN HANDLING THEIR CHILD'S DAILY LIVING SKILLS

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Abstract: Most children with autism have deficits in their daily living skills that include dressing, self-feeding, and toileting. Because of their difficulties in performing these skills, they are dependent on their mothers or other members in the family. This case study paper explores the challenges faced by mothers of children with autism with regard to handling their child's daily living skills and their experiences in the family because of the child with autism. Three mothers of children with autism from three special schools in the city of Bangalore participated in the study. Information was collected based on narrative interviews and in-depth correspondence with the mothers of children with autism. This paper reveals that mothers of children with autism experience parenting related stress, psychological distress, and total exhaustion, and have less time to interact with others because of their child's inability to perform daily living activities. Therefore, there is a need to educate mothers of children with autism about the importance of training their child with autism in daily living skills in order to reduce their burden of care giving.

Keywords: Autism, Case study, Daily living skills, Psychological distress

Introduction: According to Hrala (2016), children with autism are those with conditions characterised by impairment in social behaviours, repetitive behaviours and abnormal reactions to sensory stimuli that are not merely the result of defects in brain development. At present, the prevalence of autism in India is 1 in 66, among children between 2 and 9 years of age (Deshmukh, et al., 2013).

Children with autism are also characterised by restrictive repetitive and stereotypical patterns of behaviours, interests and activities (American Psychiatric Association, 2013; MacFarlane and Kanaya, 2009; Cuningham and Schreiber, 2008). They have difficulty in communicating with others around them; they may communicate with others either verbally or non-verbally or a combination of both (Hartmann, 2012). These issues cause significant difficulties in performing their day to day daily living activities or daily living skills including brushing, toileting, self-feeding, etc. and make them more dependent on their mothers or other members in the family. Mothers should teach their child with autism basic functional skills especially the daily living skills which form the essence of their day to day life. According to Stabel (2013), "Daily Living Skills" (DLS), refer to a wide range of personal self-care activities across home, school, work and community settings. It includes personal hygiene and grooming, eating, and getting around the community. These skills form the core components for personality development and helps in the identity formation of the child. Functional skills help children with Autism be self reliant and productive.

When parents receive a diagnosis of autism for their child, they are affected differently. Some fathers blame their child's autism on their wives (Neely-Barnes, Hall, Roberts, and Graff, 2011). Fathers most

likely did not quit full-time employment to become the primary care-giver for children diagnosed with Autism. The problems at home caused them to work for longer hours so they were out of the home environment (Gray, 2003).

Mothers, on the other hand, confessed that their child's disability had significant personal effects on them. Mothers who worked outside the home often missed work, they were often required to accept part-time work or even give up on employment outside the home (Gray, 2003), to accommodate the needs of their child with autism (Montes and Halterman, 2008). Moreover, mothers of children with autism were found to be psychological distressed by their child's dependency. Psychological distress can be defined as a continuum in which an individual can move from experiencing wellbeing to distress and back, at various times throughout their lives (Horwitz and Scheid, 1999; Mechanic, 1999). Some mothers of autistic children experience higher risk of depression, deep sadness, social isolation, self-blame, guilt, helplessness, feelings of inadequacy, anger and shock (Gupta and Singhal, 2005).

This paper concerns the challenges faced by mothers of children with autism with regard to handling their child's daily living skills. It focuses on the mothers' experiences in the family with a child with autism.

Methodology:

Purpose: The purpose of this case study was to document the challenges faced by mothers of children with autism in handling their children's daily living skills.

Sample: The investigator conducted a qualitative research in the form of a case study on three parents of children with autism from different special schools in the city of Bangalore, who willingly shared the

challenges faced by them with regard to their child's daily living skills and their experiences in the family.

Methods: The investigator visited special schools and obtained permission from the principals to interact with the mothers of children with autism. The investigator collected data through narrative interviews and in-depth correspondence with the respondents. The investigator obtained information about the demographic details of the family, diagnosis of the child, abilities and behaviours of their child and their areas of struggle. According to Jovchelovitch and Bauer (2000), the narrative interview envisages a setting that encourages and stimulates an interviewee to tell a story about some significant event in their life and social context.

Case 1: MM is a 35 years old mother of two sons. Her first son is 12 years old and the second is 8 years old. She lives in a joint family in the city of Bangalore. By the age of 4 year her second son was diagnosed with Autism. MM described that her autistic son does not have a clear voice, he communicates with others through incomplete sentences mixed with gestures. He can copy and write the same word. He lacks daily living skills. She assists him for his day to day living activities such as toileting, brushing, eating, bathing, etc. He shows inappropriate behaviours in public places. He occasionally hits and bites other children including his own elder brother.

MM's second sister is also a physically challenged person. So, her mother-in-law blamed her as the main cause for the grandson's diagnosis. MM's relationships with her in-laws were not good. Her mother-in-law said to other members in the family to kill her autistic son by giving him poison when his mother is out. MM fears to leave her autistic child with other members in the family, except with her husband and first son. She would cut and kept the fruits or vegetables such as apple, cucumber, carrot, etc. in the refrigerator so that he can eat from the refrigerator when he feels hungry. She usually takes him along when she goes to the market. He can identify vegetables and point to them when asked. If MM lists down a couple of items like milk, banana or bread and asks him to buy it from a nearby shop, he is able to bring the items.

MM does not share about her child's behaviours and problems with her in-laws. Most of the time, she does all the household chores by herself, and also provides assistance for her son's day to day living activities. She says "I woke up early in the morning to get breakfast ready for all the members in the family. I am the solely responsible to assist my child with autism for his day to day activities such as brushing, toileting, eating, etc." She mentioned that sometimes, she shared her autistic son's behaviours and problems with other parents of children with similar challenges

but never about the stresses she is facing in the family.

Case 2: SM is a 34 years old mother of a 5 years old male child. He was diagnosed with autism at one and half years of age. In SM husband's family, there is a history of developmental delay. Her son has poor speech, he communicates mostly through gestures, and he also has poor eye contact. He has difficulty in eating soft food like rice but can eat medium size cut fruits and other finger foods. She must help him eat chapattis by tearing it into tiny bite sized pieces. He likes to use gadgets and play video games. Although he does not read aloud due to speech problems, he can recognise alphabets as well as three and four lettered words. When asked he can point to an alphabet a word correctly. She is worried for her son's future and frightened that her son won't be able to read aloud and dress himself. Her husband supports her financially but not in taking care of the child. When her son was at school, she stayed at home and takes care for the household chores such as washing clothes, cleaning and mopping, etc. She found very difficult to handle her son on holidays.

She described that her son has sensory issues so she must assist her autistic son in performing daily living skills like brushing, toileting, eating and bathing. At home, he can indicate when he wants to use the washroom, by pointing towards the toilet; but when in public places he does not indicate his need to use the toilet and wets his pants. He is now being trained to use Picture Exchange Communication System (PECS) to communicate his needs. He can identify his own belongings. On some days he dislikes wearing clothes, so she would force him to wear it. He cannot tolerate certain sound, especially the sound from ceiling fans. He closes his own ears and screams when he hears loud sounds.

She also mentioned that her son has sleeping problems; he does not sleep in time. He wants her to be awake and sing for him at night. If she dozes off, he cries, and wakes her up to sing again. Now, the child is going to a special school and also receiving speech therapy. The mother frequently goes through phases of depression and is undergoing treatment for it.

Case 3: DM is a mother of a 6 year old boy diagnosed with autism. Her son has difficulty in communicating with others. He has the ability to understand what is being said (receptive language) but is unable to express himself in a coherent manner. He can't frame sentences. Her son was enrolled into a regular early childhood education program but it did not help in his development. She noticed that her son's interaction with other children was poor. She was not happy with his behaviours and moved to a special school and started speech therapy for him. When her son was at school, DM had to stay at home to look

after the household chores. Her husband earns money for the family, so he does not take care of the child. Her son's behaviour at home is very difficult for her to manage, usually she finds little time to take rest. She says, "Sometimes I feels very confuse and alone but I tried to keep my emotions under control; if am sad and depress I may not be able to help and support my son's needs as well as the household chores".

She explained that her son has sensory dysfunction which causes delays in his ability to participate in daily living skills such as toileting and grooming independently. He would also manifest repetitive behaviours. DM described her son as a playful and energetic boy. He rarely makes eye contact with other people around him; he would not look at people when called. DM worries thinking about her son's future since she is looking after his day to day living activities and meeting all his necessities. She said "everyday I'm struggling with my household chores along with the need of extra attention and care that my son requires".

She had little contact with her relatives and friends. Sometimes she shares her struggles about her son's behaviours with others parents of children with autism in her son's special school. She says she is always stressed, depressed and exhausted due to the amount of care required by her son.

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