

Conference Paper

Mother's Stress Experience towards Caring for the Children with Autism

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Abstract

Standard care guidelines for children with autism has not been established yet in Indonesia. This issue triggers inappropriate treatment for them. The previous grounded study conducted by the researcher with the purpose to develop the framework for taking care the autism children, revealed the new standard in taking care the autism children at home by the mother. One of the standard operating procedures is to reduces stress level of the mother as the person in charge for their child at home. This research aimed to explore the mother's stress experience towards caring for the children with autism. Formulated the information and phenomenon of mother's stress experience towards caring for the children with autism with case study. Data were collected in 2019 among 7 participants by utilizing observation, in depth interview, field recording, and literature review. The result revealed the early stress level of the mother in caring their children with autism. They reported the feeling of being disappointment, reject the reality, desperate, and negative stigma by the surrounding. Thus they always avoid to introduce their children. The mothers often feel scared and worried to bring their children in crowd area. This study provides the suggestion for pediatric nurses to improve their knowledge and skills in giving the support system to the parents of the autism children and promote the education regarding autism treatment and care and most importantly is the the establishment of standard operating procedures or guidelines in primary care of autism children at home by mother.

Keywords: Autism, Children, Experience, Mother, Stress

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1. Introduction

Standard care guidelines for children with autism has not been established yet in Indonesia since this case happened. This issue triggers inappropriate treatment for them. The previous grounded study conducted by the researcher with the purpose to develop the framework for taking care the autism children, revealed the new standard in taking care the autism children at home by the mother, but researchers have not discussed the stress of mothers in caring for children in depth. One of the standard operating procedures is to reduces stress level of the mother as the person in charge for their child at home. This study aims to explore the stressful experiences of mothers in caring for autistic children. All mothers have been counseled about the results of

previous studies conducted by researchers regarding a framework for treating autism children, one of which is coping with the stress of care.

2. Methods and Equipment

This research was administered qualitative design with case study approach. 7 participants are the mothers of autistic children in Banjarmasin. The data were collected through observations and in depth interview with observation and interview method. Observation was done in one month to observe the mother's stress experience towards caring for the children with autism. The observation is done when the participants were taking care of their autistic children, starting from when the children awake till they sleep. Another instrument that being used to collect the data is in depth interview. Data source from experience, knowledge, support, and social interaction of mothers in dealing with stress when Caring for Children with Autism.

3. Results

The results of the study identified mother's stress experience towards caring for the children with autism, such like:

3.1. Mothers's feeling of being disappointment, reject the reality, desperate, and negative stigma by the surrounding

"It I initially did not accept the condition of my child, I was sad, often cried, every effort I made was in vain. I was very sad with the negative views of my child, my child was considered like a crazy person. Sometimes I choose to try to avoid the community, rather than seeing my child in bully"

3.2. Lack of spirituality

"I was reluctant to pray to God. I once felt praying was futile. God is not fair"

3.3. They blame God and their religion

"sometimes I have the thought to change religion. sometimes I feel unsure of my religion"

3.4. Think to leave their husband and children.

“sometimes I want to leave my husband and child, when fighting with my husband. when I fight with my husband, I hate my child more. when I get angry with my husband, I hit my child.”

3.5. Hiding children from the community

“sometimes I am ashamed to bring my child to the public.”

3.6. Professional team and unprofessional team to reduce maternal stress

“I have been to a psychologist to discuss my problem and my stress. I once took my child to the doctor, to a therapy place and even a place for massage and herbs so that my child recovered and I was calm.”

3.7. Support from a husband, siblings, parents, and those around him has a major impact on reducing maternal stress levels.

“Support from my family. My husband provided me and my child with some needs... Some family members recommended that I stop giving therapy to my child because it separated me and my child, but I did not. My other children really helped me caring for my child with autism ”

3.8. Burden of child care

“I discussed it with my husband, but I take the most dominant role in taking care my child.”

4. Discussion

The early stress level of the mother in caring their children with autism. They reported the feeling of being disappointment, reject the reality, desperate, and negative stigma by the surrounding. Thus they always avoid to introduce their children to the environment. The mothers often feel scared and worried to bring their children in crowd area. There

are mothers who experience lack of spirituality. They blame God and their religion regarding their circumstances handle the children with autism. There are mothers who were reluctant to worship, because they did not accept the conditions given by God to him, even mothers had thought to leave their husbands and children. The mothers manage their negative emotion and change it into positive emotion. The positive way can be expressed by these kind of acts: Take enough rest while they have a time, Consulting with the expert, Fulfill their mental and spiritual health, Having a me time to do their hobby. The support system to reduce the stress among the mothers in caring their children is natural support by professional team and unprofessional team. The support from husband, the siblings of the child with autism, parents, and people surrounding have a great impact to reduce the stress level of the mother.

Excessive behavior shown by children with autism when taken to public places often cause others disturbed, this makes the mother feel afraid or anxious when bringing autistic children, as well as when going to certain events. In this study also identified that children with autism are unpredictable, tend to be angry, and unable to control emotions, which according to American Psychiatric Association it becomes an obstacle for the mother, because the mother feels rejected when what has been done to try to understand the child Ignored by the child, but on the other hand the mother also does not want to ignore child [1]

Mothers' dominant role in taking care autistic children from the treatment actions they performed consistently, just as the child understood the rules clearly. This is in line with the statement from which is a consistent environment is the best tool for children with autism to learn [2]. Consistency in daily routine, discipline, communication, social interaction, and experience all contribute to strengthening their learning environment. Children with autism more often have difficulties in transferring what they learn from one experience to another. There are several things to consider such as child's temperaments, individual needs, schedules and commitments. Routines in children with autism provide them the opportunity to predict everyday events that can make them feel safe. Consistency in this research is very beneficial by participants when they see their children able to be given roles and responsibilities in accordance with its ability. The behavior or closeness of the mother-child relationship and the competence of the child is one of the goals of the "becoming mother" model according to Mercer. Another purpose is the cognitive or mental development and child health [3].

This is partially similar to Koesomo research findings which suggest that social support as a form of family needs in caring for children with autism comes from parents and children. Support comes from the Family, friends and neighbors. Other sources of

support authors identified in this study were caregivers, teachers and autism education foundations [4].

Mother must always have enough stamina, because caring and accompanying children with autism will drain physical energy. Effective treatment takes a lot of time and energy [5].

Father's less concern according to because the father often hide feelings, anxiety and bury anger and avoid problems that are in the house so choose to work longer and outside the home environment. The support gained from the participants is more than the other children, siblings, cousins and parents. This is partially similar to [4] research findings which suggest that social support as a form of family needs in caring for children with autism comes from parents and children. Support comes from the Family, friends and neighbors. Other sources of support authors identified in this study were caregivers, teachers and autism education foundations.

Having a child with autism produces the care burden and many assumptions or refusal from other people. The attitude towards children with autism in family has a great impact to determine the success of care planning among them. Response from the parents including the father and relatives could become a support system to reduce the mother's stress level during taking care the child with autism.

5. Conclusion

The result revealed the early stress level of the mother in caring their children with autism. They reported the feeling of being disappointment, reject the reality, desperate, and negative stigma by the surrounding. Thus they always avoid to introduce their children to the environment. The mothers often feel scared and worried to bring their children in crowd area. The support system to reduce the stress among the mothers in caring their children is natural support by professional team and unprofessional team. The support from husband, the siblings of the child with autism, parents, and people surrounding have a great impact to reduce the stress level of the mother. In early stage they mostly feel the pressure and tend to overcome it with negative coping mechanism, however in the acceptance stage the mothers have adapted with their circumstance change their mechanism coping to become more positive. The mothers manage their negative emotion and change it into positive emotion. the positive way can be expressed by these kind of acts: take enough rest while they have a time, consulting with the expert, fulfill their mental and spiritual health, having a me time to do their hobby.

This study provides the suggestion for pediatric nurses to improve their knowledge and skills in giving the support system to the parents of the autism children and promote the education regarding autism treatment and care and most importantly is the the establishment of standard operating procedures or guidelines in primary care of autism children at home by their mother.

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