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STORIES OF MOTHERS WITH INTELLECTUAL DISABILITY CHILDREN IN WEST SUMATERA, INDONESIA

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ABSTRACT

Background: Children with intellectual disability are rejected not only by other individuals around them but also by their own family. Even though they need support from the mother to achieve accurate conformity. The form of mother social support can be in the form of emotional support, appreciation, instrumental and informative. However, the parents of Children with intellectual disability often refuse the presence of their children. The purpose of this study was to obtain qualitative data on the experience of mothers who have intellectually disabled children

Methods: This study is a qualitative research conducted by interview using the semi-structured interview method. The participants were selected by using purposive sampling technique. The data were qualitative analyzed by employing Collaizi model. The participants in this study were 6 mothers who have children with intellectual disability

Results: Participants have a positive perception about the educational needs of children with intellectual disability. However, due to financial issues, participants do not provide education for their intellectually disabled children. They mentioned that if their intellectually disabled children were properly, they would be able to take care of themselves and would no longer depend on others.

Conclusion: In this study, the researchers found five themes of mothers' stories with intellectual disability child in West Sumatera, Indonesia, including (1) their unawareness of their intellectually disabled children condition; (2) disappointment as the initial response knowing their children status; (3) anxiety and worry about their children future; (4) financial issues as a factor in obstructing education, and (5) religious worship as a source of strength. The results of this study can be used in nursing practice so that families can maintain the sources of strength to accept the fact that they have children with intellectual disability and that education is very important for children with intellectual disability.

Keywords: Intellectual Disability, Education, Mothers' Experience, Mothers' stories

INTRODUCTION

It is a desire of every parent to have children in their marriage because children are a gift for their parents. However, not all children are born into the world in perfect conditions; some are born with physical or psychological limitations, one of which is intellectual disability. Intellectually disabled children are children with special needs characterized by disorders in their intellectual function and social adaptability that are significantly below the average, which has been detected since their childhood [1]. The existence of intellectually retarded children in the family will become a separate stressor for each familys, It is causing parents refuse their child's presence [2]. Labelling and discrimination affect their lives making them withdraw themselves physically and socially from the surrounding community and environment [3]. In

addition to with drawing from the environment, the family also experience tremendous stress and burdens that can develop into physical and psychological tensions affecting relationships in the family environment and work [4].

The research conducted by Marlinda in 2011 about the experience of mothers in caring for children with special needs in Banjarbaru South Kalimantan. The results of this study show that mothers who have intellectually disabled children really need support from the surrounding environment, from family as well as local nurses. Parents with the experience caring for intellectually disabled children need to reduce the stress they face [5]. A similar study was also conducted by Marliyana in 2017, she stated that the lack of family's understanding of intellectually disabled children led to unpreparedness of parents and families to deal with the presence of children with this condition [6].

The data from the West Sumatra Central Bureau of Statistics in 2017 reveals that Agam Regency ranks 5th as the highest number of children with special needs, with the highest number being intellectually disabled, as many as 1,665 children and 935 of them still at school age. In IV Angkek area, there are 120 people with intellectual disability. Unfortunately, not all of them are given proper educational facilities. Based on the recapitulation of data from the special needs school of West Sumatra Province from the Office of Education and Culture of West Sumatra Province, there are 131 special needs schools in West Sumatra, 5 of which are in Agam regency. However, there are 246 children with intellectual disability recorded in special needs educational institutions in Agam regency [7].

The results of interviews with two informants who have intellectually disabled children reveal that education in intellectually disabled children is not important because they think there will be no changes that occur in their children. Sending them to school will not change their future because they will still be considered "idiots" by society. After conducting the preliminary survey, local village officials state that many children with intellectual disabilities are not provided with educational facilities by their parents. This study aims to obtain purely qualitative data on the experience of mothers who have children with intellectual disability.

METHODS

This type of research is qualitative using a phenomenological descriptive approach. The researcher wants to find out more about how the mother views about the educational needs of children with intellectual disability. This research was conducted in the IV Angkek Agam Regency. The participants of the study were selected by using a purposive sampling technique. In this study saturation data of the participants was reached in 6 mothers who have children with moderate mental disabilities who are not sent to special needs schools, and no participants dropped out during study. The criteria for participants in this study are: (1) A mother who has a moderate intellectually disabled child who is not provided with special needs; (2) An intellectually disabled child at school age but not send to school; (3) A willingness to be a respondent with the ability to communicate and cooperate. Previously participants had given informed consent to express their willingness to be participants in this study.

The procedure for data collection consists of:

1. Preparation Phase: Preparation phase the researcher meets with prospective participants according to the research criteria.
2. Implementation Phase: At the implementation stage researchers conduct interviews in three phases, (a) Orientation Phase pay attention to the condition of participants physically and psychologically. (b) Working Phase, The work phase begins with in-depth interviews with participants where the researcher begins with the question "Can you tell me about how the experience of mothers caring for children with

intellectual disability?". Researcher attention to participants' nonverbal responses and their suitability with verbal responses. At Nonverbal response the researcher focuses on symbols, facial expressions and body movements. such as nodding the head to express approval, smiling to express a friendly, respectful, and polite attitude towards others, frowning when the partisipants do not understand the research question, or tone of the voice to assess the emotional condition of the respondent who was happy, sad, angry or disappointed. And for verbal responses researchers used a voice recorder to recorded the conversations of researchers and participants (c) termination phase was termination is carried out after all the complete data and data depth are in accordance with the research objectives.

For suitability of verbal response researcher used Collaizi (1978) model that explained the stages of the qualitative data analysis process. The reason for choosing this analysis is because it provides differences compared to other models, namely in the final stage of analysis. Collaizi adds final validation for participants. This stage aims to ensure that the results of the research represent participants' feelings according to their life experiences. The stages of the Collaizi model analysis are;(1) Acquiring a sense of transcript; (2) Extracting significant statement; (3) Formulating Meaning; (4) Organizing formulating meaning into Cluster of themes;(5) Exhaustively describing the investigated phenomenon;(6) Describing the fundamental structure of the phenomenon [10].

RESULTS

Respondent characteristics are; the first Participant (EM) was a 55 years old, she was the housewife with a widow status and had 6 children. Child of the participant (ID) who had 13 years of intellectual disabled was the third child of 6 siblings; **The second Participant (DS)** was a 42 years old as a trader who was married and had 3 children. Child of the participant (RS) who experienced 11 years old of intellectual disabled were the second child of 3 siblings; **The Third partisipan (PY)** was a 39 years old, she was housewife who was married and had 4 children. Children of participants (SL) who experience 14 years old of intellectual disabled were the second child of 4 siblings. SL has never taken an education level; **The Fourth Participant (LM)** was a 36 years old as a housewife who was married and had 4 children. Participant's child (ZK) who experienced 13 years of intellectual disabled were the third child of 4 siblings. ZK had never taken an education level; **The Fifth Participant (MR)** was a 40 years old as a housewife who was married and had 3 children. Partisipan's children (AZ) who experience 9 years old of intellectual disabled. He was the second child of 3 siblings. AZ had never taken an education level; **The Sixth Partisipan (NW)** was 49 years old as a housewife who was married and had 5 children. Participant children (AR) who experienced 14 years old of intellectual disabled were the 4th child of 5 siblings. AR has never taken an education level.

According to the Colaizzi method, the results of the study was found 5 themes: (1) unawareness of their intellectually disabled children condition; (2) disappointment as the initial response knowing their intellectually disabled children; (3) anxiety and worry about their children future; (4) financial issues as a factor in obstructing education; (5) religious worship as a source of strength.

At the first theme, all the participants did not know that the differences seen at the beginning of birth are the first sign of intellectual disability. After the participants knew that the child had intellectual disability, they took care of them just like other normal children. There is no special treatment for them. Participants did not know how to properly care for children with special needs. The expression of the ignorance was expressed by participants as follows:

"At first, I didn't know that RS had intellectual disability. When RS was 3 months old, he gave a slow response when I called. He did not give a good response like his brother. I thought it was just a normal delay experienced by children his age." – (The second Participant (DS), 42 years old)

The second theme is obtained when all participants expressed a sense of disappointment with the reality that they had to accept their children condition being different from other children. The disappointment arose when participants took their children to the doctor to ascertain the condition of the child, then the doctor said that the participants' children experienced intellectual disability and had to get special therapy. The disappointment was expressed by participants as follows:

"At first, I often isolated myself, this situation quite hit me. It is very difficult for me to accept this fact ... "(The Fifth Participant (MR), 40 years old)

The third theme is anxiety and worry about the future of their intellectually disabled children is obtained when all participants share their experiences at the beginning of the child diagnosed with intellectual disability they feel anxious about the future of their children. This anxiety occurs because participants are worried about who will take care of their children later after they are gone. They worried about who would take care and help all activities carried out by the children. These feelings of anxiety and worry were expressed by participants as follows:

"Of course. I feel sad, I'm worried how she will grow up ..."

"... I can't imagine how the future of RS will be like..." (The first Participant (EM), 55 years old)

The fourth theme is financial issues as a factor in obstructing education is the main factor for all participants not to provide education for their children. Before participants have children with intellectual disability, they did not have jobs to provide income to meet family needs. Participants' income is reduced because they cannot work and must take care of children who experience intellectual disability. This has an impact on the family economy where only husbands work to meet family needs. Participants do not have sufficient funds for children's education. The cost of education for children with special needs is quite expensive. Therefore, the participants decided to take care of children at home. The expression of limited income was revealed by participants as follows:

"I can no longer work because I have to take care of the SL all day long, so the family income is reduced. Then, SL can't do anything. I must always help him " (The Third Participant (PY), 39 years old)

The fifth theme is religious worship as a source of strength is obtained from all the participant's expression that praying to Allah can calm and strengthen them in their living life. It is carried out by participants in the form of *tahajud*, *dhikr*, and praying to Allah. The following is the participant's expression related to the worship he performed:

"Every prayer, I pray to Allah so that the RS will recover soon, and may He lift up all the illnesses and he can be normal like the other children ..."(The second Participant (DS), 42 years old)

DISCUSSION

Unawareness of their intellectually disabled children condition

In the beginning, participants had a suspicion that something was wrong with their children when they saw their child experiencing developmental delays. All of them realized their children had developmental delays in motoric and communication skills. However, the participants did not know that the delay would have a

negative impact on their children. They did not know what to do to provide care for children with special needs. then the theme appears Unawareness of Their Intellectually Disabled Children Condition

The participants who have intellectually disabled children should have had the knowledge and understanding of this condition, so they can act in the right way when raising and educating their children. Knowledge in educating children with special needs aims to improve the abilities and skills of their children, so they can be independent in carrying out their daily lives and face the life of the social environment. Children with special needs such as intellectual disability must be treated specifically because of their limitations. Good knowledge of the specific characteristics of the children can help mothers prepare appropriate care to maximize child development [11].

The participants' ignorance in caring for children with mental disabilities is certainly a problem in taking care of the children. The difficulty and stressful situations experienced by mothers with intellectual disability children makes them stress as the children still needs continuous guidance and training from parents. Intellectually disabled children have limitations in all areas of development, so they have difficulty in meeting their own needs and tend to depend on the environment, especially in their parents and siblings [12].

Social phenomena still show that some people still look down on intellectually disabled children. They are often ignored, ridiculed, and considered useless. Some mothers even feel embarrassed and depressed by the social stigma about intellectual disability. They also believe that such condition is punishment from God, so they feel inadequate, inferior as well as lost and avoid or withdraw themselves from their surrounding environment. Intellectually disabled children are not only rejected by other individuals around them but also by their own family [2]. The presence of intellectually disabled children in the family environment can be a stressor for each family member causing parents to reject them. Various stressors affect each other and can worsen stress levels in the family. Family concerns about the future and recovery of their children are often the main reasons for stress in the family. In addition, parents' level of knowledge and education, their care for their children, and their acceptance for their intellectually disabled children greatly influence the level of stress they will feel. Financial needs for the cost of medical treatment and care for intellectually disabled children will also add to the burden on the family [3].

Disappointment as the initial response knowing their intellectually disabled children

At the second theme, Participants were very disappointed when they found out the children were born with intellectual disability. The children they are waiting for were born with limitations, both physically and mentally. The participants' thoughts of their ideal child are those with good physical and mental healthy. These thoughts will influence the participant's reaction to the children. There are two possible responses from family members to individuals who experience intellectual disability, namely accepting or rejecting.

The presence of intellectually disabled children is often considered troublesome and a burden by other parties. Mothers sometimes do not accept the condition of their children who were born disabled due to social or personal pressure [11]. The reaction of mother's rejection of intellectually disabled children is in accordance with the research conducted by Hendriyani in 2006 about the acceptance of families who have children with intellectual disability. Excessive burden will be felt as a manifestation of the demands in treating intellectually disabled children. Besides, there is a social stigma about the intellectually disabled children, dependence of children on the family, extra patience, and decreasing family productivity. This lack of family acceptance eventually raises negative attitudes and treatments for the children, such as by covering or hiding children from other people, minimizing children involvement in various family activities etc. [13]. In fact, it is not infrequent that sometimes mothers feel decrease in self-esteem caused by the birth

of a child who is out of their expectations. This situation creates a heavy burden and can impact the family [14].

One of physical burdens causing disappointment is related to children inability manage their daily activities, making parents, especially mothers, always help and assist their children. It absolutely causes physical fatigue. Meanwhile, the psychological burden was also felt by parents related to the acceptance process starting from shock, disappointment, guilt over the condition of the child, and the presence or absence of support from the family [15]. Children with intellectual disorder are more likely to have other medical conditions, including cataracts, vision and hearing impairments, congenital heart disease, constipation, obesity, and sleep disorders, which may prompt additional referrals. Such comorbidities not only impact overall function and quality of life, but can also increase challenging behaviors [16].

Based on the coping theory from Lazarus in 1984, the participants in this study have positive coping in which they can reflect the acceptance of reality which they initially rejected. Coping is an act of changing cognitive and behavior to overcome internal and external demands that are considered burdensome or exceed the resources that an individual has. Coping requires effort that is obtained through the learning process. Coping is seen as an attempt to master a depressed situation, but not as a whole [17].

Participants using coping on problems accept the fact they are blessed with children with mental disability. Participants are able to pass the inner shock, a sense of shock and disappointment that can cause stress. This can be done by participants because they have a good coping mechanism for a stressor. Coping mechanism is an effort made by individuals to cope with the stress faced. In this study, participants carry out adaptive coping mechanisms because they are able to solve problems due to negative and adverse stressors, namely having children who are different from other children. Participants have good self-coping to accept the children condition. The coping strategy used is to increase worship to God, such as by increasing dhikr, prayer, and praying for inner peace. Participants feel more calm when they finish praying.

Anxiety and worry about their children future

The theme Anxiety and Worry of Children Future, Participants in this study experienced psychological problems in the form of anxiety and worry. This anxiety occurs because participants feel worried about the children future. Children who experience intellectual disability must get special attention and all their needs and activities must be helped due to their limitations. The participant's statement regarding maternal anxiety and worry is supported by Bitsika, Sharpley & Bell (2013) who state that mothers are more prone to having problems in nurturing intellectually disabled children than fathers because they have more contact with children. Mothers are the main caregivers for children in the family. The mother's responsibility in caring for children is greater, so they will be more susceptible to problems than fathers [17].

Participants feel anxious because children who experience intellectual disability have a high dependence on them. All children's activities are assisted by participants every day. Hence, they feel worried about the lives of their children after they grows up especially when the participants die. Participants also stated that they feel anxious about children financial in the future because children who experience intellectual disability are unable to do anything and always depend on participants [18].

Participants' anxiety about the future of children is also supported by research conducted by Kosasih with the title of family experience in caring for intellectually disabled children in special needs schools C. She mentions that the anxiety experienced by mothers with intellectually disabled children is caused by limitations and obstacles experienced by children in fulfilling their daily needs. The anxiety also comes from worry about the future of their children. This anxiety is related to the mother's pessimism towards the

potential for children's independence in the future, protection of children's lives, future care, work and support for children [3].

Financial issues as a factor in obstructing education

The results of the interview about education for children with intellectual disabilities reveal that all participants agree that education is very important for children with mental disability. Participants hope that with the education children will be able to help themselves in everyday life. However, they said that the factor that causes of not sending the children to special needs education is financial issues. Most people with intellectual disability are financially disadvantaged. Meanwhile, the therapy requires a considerable amount of money. Given the economic inability, many families allow their children to grow without care and without optimal therapy. Many families do not understand how to treat intellectually disabled children. There are still many parents and families who hide these children [4]

Participants in this study are in the middle to lower class economy. Before having children with intellectual disability, they worked to help their husbands to fulfill their household needs. After the participants had children who were diagnosed with intellectual disability, they left their jobs because they had to take care of their children. Participants no longer work so income is reduced. Participants only expect income from their husbands. Decreased income causes a decline in the family economy, so participants are unable to provide education for children. The income earned by the husband is only enough for meal and household needs.

Contextual factors such as poverty, health, and culture may affect not only the resources available to families but also the ways in which parents think about disability. Several studies contributed further to the understanding of the impact of children with intellectual disabilities on parents by examining parental beliefs and coping styles. Sara Green, a sociologist and mother of a child with multiple disabilities, set out to examine feelings about control over matters of health and health care. She used narrative accounts and interactive interviews to study health related beliefs and wellbeing in 81 mothers of children with disabilities. Mothers with a high internal locus of control who also believed in chance reported less subjective burden of caregiving, causing researchers to suggest that these mothers used belief in chance as a way to avoid blaming themselves for their children's problems. On the other hand, belief in chance without a strong internal locus of control related to increased subjective burden, as mothers may have felt overwhelmed by the uncontrollable nature of life events [19].

Religious worship as a source of strength

The last theme is Religious Worship as a Source of Strength, Participants get closer to Allah by increasing their worship, such as reading the Qur'an more often and reciting dhikr to get inner peace. Five of the six participants said that they became calmer when they finished worshipping. Day after day, participants always improve their in the hope that Allah will provide healing for their children. The participant said that they get closer to Allah even when He gave them a child with special needs.

The participants also stated that Allah created man in the best form including children who with intellectual disability. They also believe that there is a meaning behind all of these shortcomings. The complex pressure felt by parents who have intellectually disabled children needs to be overcome one of which is by getting closer to Allah through living and practicing religious values. Someone who has a good value of religiosity will have a good attitude in facing reality.

Participants increasingly improve their worship to get to Allah. By getting closer to Allah, they find peace and calmness. This is supported by the results of a study conducted by Sapuan (2014) with the title of the

relationship between the level of religiosity and coping of mothers with intellectual disability in the SDLB Yogyakarta saying that the higher the level of maternal religiosity, the better the level of maternal coping [15].

CONCLUSION

In this study, the researchers found five themes, namely unawareness of their intellectually disabled children condition, disappointment as the initial response knowing their intellectually disabled children, anxiety and worry about their children future, financial issues as a factor in obstructing education, and religious worship as a source of strength. The results of this study can be used in nursing practice so that families can maintain the sources of strength to accept the fact that they have children with intellectual disability and that education is very important for children with intellectual disability.

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