



THE MEANING OF PRIMARY CAREGIVER FOR MENTALLY RETARDED CHILD: MOTHER PRESPECTIVES

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ABSTRACT

Background: Children with mental retardation will have development problems of their mind, so that they experiencing disability in their intellectual and social function. As many as 73.4% of the parents who have kids with mentally retarded have experienced stress in taking caring of their kids compared to parents who have normal kids. **The objective:** The aim of this study was explored the meaning of mother's experience as primary caregiver in taking care of kids with mental retardation. **Methods:** Mythology of this research used qualitative design with interpretive phenomenology and involved six participants of mothers who have children with mental retardation and they were attended at school in SLB Dharma Asih Kraksaan Probolinggo East Java. The data collected by using in-depth interview with semi-structured questions by using recorder. **Results:** The findings of this study obtained two themes that describe the mother's experience as the main caregiver for children with mental retardation and they feeling tired and they want to make their children to be autonomous for their life. **Conclusion:** Mothers who taking care of the children with mental retardation will feels tired and try to make their children to be autonomous for their life.

KEYWORDS: Mental retardation, child, mother, Primary Caregiver.

INTRODUCTION

Children who experienced mental retardation will have development problems of mind, in the end they will get disability in intellectual and social functions, moreover, decreased intelligence is the main symptom of the mind problem.^[1] Problems in learning process will occur among children with mental retardation because the lower of mental levels and in daily activities will have a lack of capability.^[2]

Mothers who have children with mental retardation will be brought into a stress situation, isolated and frustration.^[3] Mothers with retarded children are more susceptible to have psychological problems such as stress when knowing and diagnosed that their kids are mental retardation compared with mothers who have normal kids.^[4] A stressor of mother who have kids with mental retardation are more have high stress level and it can make mental burden for the mother.^[5,6]

As many as 73.4% of parents who have kids with mental retardation experienced stress while taking care of their

mentally ill children compared with the parents who have normal kids.^[7] Some studies mentioned that various stresses was related with how to taking care of people with mental retardation, this also will give low spirit and increasing depression than general population.^[5,6]

Researchers have identified family conflicts, fatigue, guilt, financial tension, and limited social life as a negative impact of parenting^[8] and have identified support, sufficient care, and future planning as key areas of family concerns.^[9]

Mothers who have kids with abnormalities feel not confidence and unbeliefs that happened to their children.^[10] Mothers who have kids with mental disorders will experience exhaustion such as feelings of guilt, fear of other people's reactions, and uncertainty about the child's future.^[11] Therefore the aim of this study was to explore the meaning of mother experience as the main caregiver in caring for children with mental retardation.

LITERATURE REVIEW

The ability of children with mental retardation will have a sharp decline, it mostly at below of the average to be able to react to their environment and it also will have problem to learn something and practice new skills. The lower level of maturity of the child's mental retardation was related with the higher of level mental retardation.^[12] Commonly, the mothers expect that their children to be able to independently and grow optimally.^[13] The mother will embed independence to the child and it will make their parents happy. When the parents are able to appreciate the child in family life then the parents will be more prosperous.^[15] Acceptance of parents to children with mental disorders will bring the parents in to prosperity and happiness.^[14] Mostly, the mothers get support from other families so she can be stronger in becoming the main caregiver for their children with mental retardation.^[16]

MATERIALS AND METHODS

Study design

The research design in this study used qualitative research design with interpretive phenomenology, it mean that gives the meaning of a phenomenon not only by describing the phenomenon but also the result of the interpretation of the experiment¹⁶. This study aims to explore the meaning of mother experience as the main caregiver in caring for children with mental retardation.

Setting

This research was conducted in SLB Dharma Asih Kraksaan Probolinggo East Java.

Research subject

Respondents used in this study were six participants, it is the mothers who have kids with mental retardation and they has taking care the kids and had provided fulfillment of daily needs of children with mental retardation and also were attended school at.

Instruments

Instruments in this study used semi-structured interview guidelines, MP3s, and researchers. Semi-structured interview were used to guidelines for researchers in interviewing participants so the questions are consistent with research objectives, MP3s are used to record the conversations during interviews, and the researcher was a investigator in this study.

Ethical consideration

Ethical approval was obtained from Health Research Ethics Committee POLTEKES KEMENKES in Malang at December 29, 2017 (No: 227 / KEPK-POLKESMA / 2017).

Data collection

The data collection procedure in this research used phenomenology approach and using in-depth interview

technique (in-depth interview) with semi-structured questions.

Data analysis

Data analysis in this research used thematic analysis. Thematic analysis is a method for identifying, analyzing and reporting patterns (themes) of data.^[18]

RESULTS AND DISCUSSION

Results

Characteristics of Participants

Six participants were mothers who taking care of their kids who have mentally retarded and also attending school at SLB Dharma Asih Kraksaan Probolinggo. Four participants were aged 40-49 years old and two participants were between aged 50-59 years old.

Thematic analytics

Two themes were described mother's experience as the main caregiver in taking care for children with mental retardation, they were feeling tired and also they want be able to independence of the children.

Theme of feel the exhaustion was formed from two sub themes, it are sub themes of difficulty feeling and sub theme of unbelieve of reality as the participant statement as follows:

P3: Yes, it was different feeling with other people feeling, Sir! And then I feel like suffering, Sir!

P4: Yes it is difficult, Yes, how to get a guidance.

P1: At first, yes do not believe it yes, it is real that I have kids like that? I am still thinking about that!

P5: In my family member and from the family history, my family did not have a family member who have illness like this, so why my kids like this? No have like this before in my family.

The theme of wanting children's independence was formed from two sub themes, it are sub seeking help and training children ability such as participant statement as follows:

P3: Yes, I brought she/he to religious leader (Kyai), than Kyai had spread some water and give it to my kids and ask my kids to drink that water.

P6: When she/ he was kids, she/ he had seizures in every month and already come to the doctor and also a shaman

P1: Just an especially, the kids had joined a course and come to school at SLB

P2: Learn by myself! Every day, I try to giving lesson and learn together.

P1: Just, when clean their butt always used this than use soap to prevent bad smelling.

P3: Yeah, while teaching how to grasp of a scoop than how to use the soap.

DISCUSSION

Theme 1: Feeling Tired

Mothers who have children with mental disorders will feel exhaustion such as feelings of guilt, fear of other people's reactions, and uncertainty about the child's future.^[11] Parents who have children with abnormalities feel unbelievers at the first time and following with rejected attitudes of the reality that happened to their child.^[10] As many as 73.4% of parents who have children with mental retardation experienced stress while taking caring for their mentally ill children compared with the parents who have normal children.^[7]

Feeling overwhelmed because the mother are a person who often stay together with children and have close relationship with the child. Anything that occurs to their children will give big impact to the mother because the mother has an important role in taking care process of the child. General reactions when the child has mental retardation is commonly the mother will reject the state of the child, feels sadness, disappointment, annoyance, suffering, despair, and feel tired. Mother who have child with mental retardation will feels sad, disappointed, and suffering because there is a loose of mother hope of her child. Moreover, the mother also feels upset because she doesn't know how to handle child with mental retardation. Mothers will feels difficult in treating mental retardation children in their daily lives because children with mental retardation were require special attention both in terms of activities daily living (ADL) and learning process in their school. Difficult feeling will appear to the mother such as feel annoyed, suffer, feel tired and feel desperate.

Theme 2: Expect to children independence

Generally, the parents were expected that their children to be able to independently and grow optimally.^[13] Families will give support to mentally vulnerable members to be able to independent during their lifetime.^[19] The main task of a mother is taking care of their children including children with mental disorders. The main task as a caregiver are follows; a) Identify health problems, b) Make appropriate decisions for health child status, c) Providing a care when the child getting sick, d) Maintain or create a healthy home atmosphere, e) Maintain relationships by using public health facilities which aimed to be enable to children independently.^[20]

Mostly, the mothers really want their children to be independent so the children will be able to stand by their own and not suspended with others person. Children with mental retardation have low self-reliance so they often need some helps from their mothers or other people to do their daily activities. The high level of dependency of childhood will make mothers think to find some solutions to make the children become more independent.

Some efforts to make the children more independent will lead the mothers to find helps from other people who are experts in the field or who can provide alternative solutions to their problems. Another effort that is carried out by the mother is increasing the independence level of their children by giving training related with daily activities, review school lessons, giving motivation and support to children. These efforts are still done by the mother and she always giving help everytime to her children until the children able to do by their self. Providing help is always done by the mother to the child while they have difficulties to doing daily living and learning activities process.

CONCLUSION

In taking care process of children with mental retardation, at the first the mother will feels tired.

Mothers in the process of caring for children with will initially feel tired. The tired feeling experienced by the mother will encourage the mother to get independence of their child.

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