

Perception of Family Burden Having Children with Mental Retardation

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Keywords: Burden, Family, Mental Retardation.

Abstract: Having a child with mental retardation who has a variety of dependence of parents, create a special burden for the family. The purpose of the study is to determine the perception of the burden which felt by the family in caring for children with mental retardation. The design of study was qualitative with phenomenological approach. Instrument derived from the researcher with the subject of research using purposive sampling. Data collection technique used interview and observation techniques. Data analysis techniques were done interactively or continuously. The validity of data used member check and triangulation. the result showed that the burden felt by the families who care for children with mental retardation was categorized into two classification, namely objective and subjective burden. Based on the above study showed that families with mentally retarded children made the most perceived burden was the economic burden (objective burden) felt heavier than the feeling or psychological burden (subjective burden) because of the objective burden as the effect was greater to the whole family members when compared to feelings of sadness, shame whose impact could only be felt by care giver only.

1 BACKGROUND

Mental retardation is an inability of intellectual function, with IQ is less than 84, before the age of 16, and is accompanied by obstacles in adaptive behavior (Pratiwi 2013). Children with mental retardation requires special care and full support from parents and family. The effectiveness of various programs for handling and upgrading the lives of mentally retarded children depend on the participation and support from families. Therefore, it takes a way to manage stress and optimizes the roles in parenting and optimizing the survival by mental retardation.

WHO data (World Health Organization) mentions that mental retardation experienced about 1-3% of the population in Indonesia. Mental retardation is 1.5 times mostly suffered women. The number of children with mental retardation in East Java are 6,633 people or 61.21% of all children with special needs in East Java, which numbered 10,836 children with mental retardation (Idris, 2014). From the previous research found the improvement of anxietas many as 21.4%, economic burden as many as 52%, physical retirement as many as 37.8% (Armatas, 2009). The impact of the limitations of children with mental retardation results in child

dependence on parents so that parents will feel more burden and exhausted in the process of parenting and more vulnerable to psychological stress.

The burden experienced by parents is caused by exhausted or the burden of caring for a mental retardation that takes extra time in caring for a child's mental retardation, a high level of patience, unlimited responsibility, the embarrassment the family has with the condition of the child and also the stigmatization effect of the community which affects the lives, emotions, thoughts, and behaviors of the family, in this case the parents (Yolanda, 2012).

Some problems that arise in the care of the child's mental retardation create tension for parents in caring for the child with the condition that significantly affect the family and its function. families lose a lot of function such as psychological function, caring function, education function, socialization function so that psychosocial problem must be handled appropriately (Bomar, 2004) The purpose of the study is to determine the perception of the burden which felt by the family in caring for children with mental retardation.

2 METHODS

The research design was qualitative with phenomenological approach, which was a research method based on postpositivism philosophy. Instruments in this study were researchers themselves. Sampling used purposive, with focus on the subject in this study in accordance with the background of this study. The subject of this study was family who care the children with mental retardation in her daily life. Data collection techniques used in this study were interview and observation techniques.

The study was conducted in the second week of December 2018 - the third week of January 2018, at noon at the informant's house, in *Sengon Village, Jombang* Regency, which was approved by the informant. To know the perception of the burden of families who have children with mental retardation, researchers used data analysis techniques: data reduction, presentation, and conclusion verification. In this research will use some testing techniques of data validity: member check and triangulation.

3 RESULTS

Description of the research first informant. First informant Mrs. R. 48 years old, as housewife, Mrs.R. has 3 children, the third child has mental retardation and attends state primary school. Mrs. R's husband is a helper whose income is uncertain. In everyday that cares for children with mental retardation was Mrs R itself, because husband Mrs R should work.

Second informant Mrs. J. 59-year-old housewife and food seller. Mrs.J has 2 children and the second child has mental retardation, from the interview Mrs.J had entered high risk age of pregnancy that is 42 years old. To care for her child Mrs.J was usually assisted by her mother. Mrs.J.'s husband worked as a pedicab driver and has just returned home at night.

Third informant Mr.B 69 years old a retiree has 4 children, the fourth child has mental retardation, this fourth child was unplanned and had wanted to be aborted by drinking herbal medicine. For caring the child was Mrs.B, because Mr. B feels incapable with his child.

The results of the study was divided in two main themes they are subjective and objective burden. We collect the burdens which could not measured such as feeling become a subjective burden, that provide an overview of the perceived burden felt by the family in caring for children with mental retardation. Then

the next theme which can be measured such as economic aspect, time to care and physical exhausted become to objective burden.

3.1 Subjective Burden

The interview on how family feelings had been so far in caring for children with mental retardation. Researchers difine into several sub them from the theme. The subjectives burden are :

- 1 Sad : the family feels unhappy because the children's disability
2. Shy : the parents shy cause of the
3. Anxiety : the parents feels anxiety about the future of children

Here's a brief answer from first informant which was conveyed to the researcher: *"ya lelah sekali mbak, merawat anak seperti ini, apalagi saya sendiri harus banyak-banyak sabar..."*

Translation : *" yes, I am very tired to cure this child, moreover I must have big patient..."*

Second informant said *"perasaan saya ya campur aduk mbak kalau ditanya, kadang sedih kadang jengkel, kadang cemas memikirkan masa depan anak ini"*

Translation : *"my feeling is terrible feels, sometimes I feel sad, anxiety to think the future of them"*

While the third informant told me *"saya kadang sedih lihat anak saya, mau jadi apa anak saya kalau besar nanti, apalagi kalau saya dan istri saya sudah meninggal. Nanti siapa yang akan merawat.."*

Translation : *"sometimes, I feel sad to see my son, how about his future, though when we have died, who will care him"*

Furthermore, the researcher asked, from the feeling that was delivered was whether it was felt heavy by the family

First informant said *"berat mbak, karena saya kadang jenuh dengan keseharian merawat anak saya ini"*

Translation : *"Its hard, because I feel saturated with the daily of caring my child"*

Second informant said *"ini mungkin ujian saya mbak, yang harus saya terima dengan keluarga saya. Saya juga agak menyesal karena sebenarnya kehamilan anak saya ini tidak kami inginkan karena usia saya sudah tua. Akhirnya saya melahirkan anak seperti itu. Malu sebenarnya tapi bagaimana lagi..harus diterima. Bagaimanapun dia anak saya".*

Translation : *"This is my problem of life and I must received with my family , I regret it, because this son is not wished by us because of my age. I feel shy actually, but I ust receive it, though he is my son"*

Last informant explained “*berat mbak, apalagi kalau harus kumpul dengan keluarga rasanya malu*”.

Translation : “*Its so hard, even I gather with family, I feel shy....*”

3.2 Objective Burden

The burden of the family felt not only in terms of feelings but also the discomfort conditions that affect other family members. Researchers also ask whether the only burden of feeling that is felt heavy by the family or are there something else?

Finally researcher define into sub themes included:

1. Economic aspect : the children with mental retardation needs more financial aspect to cure the disability.
2. Time consuming : parents will get a lack of time to take the rest because they cares the children and give big attention to them
3. Physical condition : the parents feels tired during the process of curing the children.

First informant explained “ *selain perasaan jenuh, saya juga memikirkan biaya untuk anak saya mbak, sekolahnya, makannya dan banyak yang lain. Sementara hidup saya sendiri kekurangan*”

Translation: “*beside the saturated feeling, i also think the financial support of my children, her education, and so on. While my life is deficiency*”

Informants 2 and 3 also said the same thing that economic conditions become a burden also in caring for children with mental retardation. Informant 3 also said that caring for children with mental retardation took a lot of time and was physically exhausting.

The objective burden most often felt by respondents was the economic condition. This was in accordance with the research Khamis (2007) which stated that the most severe burden felt by the family was the financial burden. The impact of burden that is not managed would affect the productivity, quality of life and family functions.

The researcher also asked which of the two burdens felt the most. First and second informants explained that the most perceived burden is the economic burden compared to the feeling. Third informant recounts “*jelas lebih berat beban ekonomi, apalagi saya seorang pensiunan. Sementara anak dengan kebutuhan khusus membutuhkan banyak biaya dan lebih sering sakit*”

Translation : “*the bigger is economic problems, though i am a retirement while my child need more financial support and health*”

4 DISCUSSION

4.1 Subjective Burden

Families were faced with many problems that result in heavy burden in the family. The number of limitations possessed by children with mental retardation was a stressor for the family. The burden faced also varies depending on several factors: community stigma, knowledge, family emotions (Parish *et al*, 2012). The impact of the burden itself varies depending on the family coping mechanism that manages the burden. The subjective burden felt by family can affect the family welfare. Which affects the relationship between family members, until made the family's disharmony. Beside that, feeling of shame also causes psychosocial problems in families with disturbed social relationships.

Anxiety to the family especially mother was frustrated so bad impact on each members especially the function of family care. Family anxiety is not enough just lowered level but there should be enough exercise so as to maintain the psychosocial condition of the family. If unstable family conditions will affect the atmosphere and comfort of the family, as a family system consists of family members who interact and depend on each other. Living together in a physical, psychological and social environment. In a system the form of behavioral disorder and child dependence with mental retardation will disrupt all systems or family circumstances (Friedman, 2010).

4.2 Objective Burden

Some respondents complained that the burden felt most heavily is an economic problem, because the dependence of children made the parents could not work optimally. Children with mental retardation required a greater cost to their lives. This was consistent with the study that absolute burden was a difficult economic constraint because of the lack of family income, while children with special needs required more facilitation than normal children (Parish *et al.*, 2012).

In this study the average of other family members could not help earn an extra living because they have to wait and care for the child's mental retardation at home, while the average family income was below the UMR. Another study was conducted by Gonzales *et al* (2010), said that the objective burden was more felt than the subjective burden. The subjective burden only affected the care giver and usually tries to be suppressed, while the objective burden would have an

impact on the quality of family life ranging from decent food, shelter and child education.

Treatment in children with mental retardation was also time-consuming because of the high dependence of children and many care giver was less concerned with his own physical condition that eventually leads to physical exhausted and susceptible to disease. From some studies corroborated there was no significancy between the perception of the burden that allowed the subjective burden was not very meaningful compared with the objective burden.

5 CONCLUSIONS

The conclusion was that the objective burden such as economic aspect, time consuming and phisical condition felt heavier than the subjective burden such as sad, shy, anxiety. Families feel more influence and have negative effects on the whole family.

Families with children with mental retardation may share the appropriate role with the whole family in the care of children with mental retardation, to manage the burden and stress management. Next schools more often conduct counseling programs to ease the subjective and objective burden. The last Recommended for families who have children with mental retardation to follow health insurance programs organized by the government (BPJS) as an alternative decrease the objective burden.

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