

## Having Children with Mental Retardation

Sri Endriyani, Yunike

Health Polytechnic, Palembang, Indonesia

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### ABSTRACT

Mental Retardation is a condition in which the intelligence function is under average, which began during the developmental period. Children with mentally retarded have limited mental function, communication skills, ability to maintain themselves and social skills. These conditions impact the mothers they responsible to train children's ability to be independent. The purpose of this study is to explore the mothers' experience having children with mental retardation at Special School for mentally retarded (SLB) of Karya Ibu Palembang, Indonesia. This is a qualitative research with phenomenology approach from five participants with indept interview. Five themes were get including can't accept reality, burden, the social stigma, need support from relatives, worry about the future, and admitting God's will. The Adaptation behaviors found in this study are the acceptance of children's condition, and loving the children thoroughly.

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### Corresponding Author:

Sri Endriyani,  
Health Polytechnic,  
Jenderal Sudirman Street KM 3,5 Number 1365,  
Palembang, South Sumatera, Indonesia.  
Email: sriendriyani@yahoo.co.id

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## 1. INTRODUCTION

Mental Retardation remains the world problem particularly for developing countries. It is Estimated that the incidence of severe mental retardation approximately 0.3 % of total population and nearly 3 % the Intelligence Quotient (IQ) is under 70. About 0.1 % of those children requires treatment, guidance and prolongs supervision throughout their life. Mental retardation remains a dilemma, leading anxiety for families and communities. The diagnosis, treatment, and its prevention for children with mentallly retarded are remains indistinct [1].

Mental retardation is a result of pathologic process in the brain that illustrates the limitations of intellectual and adaptive function, but it is not a disease. Mental retardation may occur with or without disruption of mentally or physical disorders [2]. Mental retardation classified into three groups including mild (IQ between 52-68 Binet scale), moderate (IQ between 36-51 Binet scale), severe (IQ between 20-30 Binet scale and <20 Binet scale) [3].

More than 120 millions people all over the world are expected suffering mental retardation [4]. Prior studies in many countries revealed that the prevalence of mental retardation among mild and moderate groups aged 15 to 19 years are 3 to 4 person per 1000 people. In United State of America, 3 % of the population having mental retardation, in Netherlands 2.6%, in Britain 1 to 8%, and 3 % of Asian population suffering mental retardation [5]. In Indonesia, of 222 millions of total population, 2.8 million people (0.7 %) are disabled. Among them 290,837 are children with mentally retarded (13.68 %), physical disabilities (33.74 %), and blindness (15.93 %) [6].

Mental retardation is a condition of disability characterized by limitations in intellectual function and adaptive behavior, especially in conceptual, social and adaptive skills. Children with mentally retarded have limited mental function, communication skills, ability to maintain themselves and and independence of children during the period of development [7]-[9].

Children with mental retardation require intensive care by parents to optimize their developmental stages such as conducting medical examinations, counseling and coaching. Old parents and other family members are the most important part for children with mental retardation to be able to live their lives well [7],[8],[10].

## **2. RESEARCH METHOD**

This study was a qualitative research. Qualitative research is a research which is conducted to study a natural object, where the researchers as the key instrument [11],[12]. This research uses qualitative research with descriptive phenomenology approach, depicting depth condition experienced by what it is. Triangulation technique is used to obtain validity and enrich data, which is utilizing something else in comparing interview result to respondent in the form of interview, observation and document [12]. The researcher uses triangulation of source and theory that is comparing data of observation result with result of interview and related theory.

Data analysis was conducted inductively and the result of a qualitative research emphasize the meaning rather than generalisation. This study applies phenomenology approach. Phenomenology approach attempts to explain or reveal the meaning of the concept or experience constituted by consciousness that occurred upon some individuals [12],[13].

The results showed that 5 participants are quite representing all informations needed by the researcher and the data saturation has been obtained regarding the parents' experience having children with mental retardation. This study was conducted at SLB of Karya Ibu Palembang.

## **3. RESULTS AND ANALYSIS**

### **3.1. Can not accept reality**

There are several characteristics of the children having mental retardation including limited of intelligence, social limitation, and the limitation of other mental functions. All of these limitations induce denial from the parents to accept the reality that their child is having mental retardation [4],[8],[10].

This study identified the initial response of parents as they notice that their child is mentally-retarded. The parent's psychological response is denial in which most participants feeling sorrowful for having a mentally-retarded child. It was illustrated by the criteria of the participants by feeling shocked, and miserable. Some participants revealed that they were disappointed having mentally retarded children, there also felt ashamed having children with special needs such as mental retardation.

This findings are similar with the explanation that knowing their children is mentally retarded, at first, many will reject it feeling incapable to grow and guide their children [4],[7]. Meanwhile, we assume that the first psychological response is difficult to accept the reality as they know their children were mentally-retarded. Initially, the parents did not believe about the condition of their children, feeling miserable and shocked is the impact of having children with mental retardation. They also feel sad, angry, guilty for not being able to bear a normal child [8],[14]. Having a child with mental retardation makes a mother feel that she has no self-esteem, uselessness and causes the disappointment of the couple and extended family by giving birth to a disabled child [14],[15].

The parents wonder if they did something wrong, during the course of the pregnancy or after birth, while taking care of the child. They wonder if God is punishing them for their sins [16],[17]. Conscience, parents will question why I have to face such a situation, why me and why my child, did I do something wrong. This is the consequence of the unexpected children by the family [15]. The parents were definitely difficult to accept those conditions.

### **3.2. Burden**

The presence of mentally-retarded children impact the parents and their family and can be a source of burden for family. The burden experienced is subjective and objective. The objective burden includes economic issues (cost of treatment and maintenance), job loss, limited and loss of opportunities for social activities and interaction with family and the environment. The subjective burden experienced is the psychological problems of parents and family in caring for family members with mental retardation, especially the special needs different from other family members in the form of feelings of guilt, shame, uncertainty and depression [8],[14],[18].

Limited ability experienced by children with mental retardation causing problems or conflicts in the family, blaming, and accusing. Consequently, the retarded children are much more complicated to develop. This condition makes parents feel stressed even at risk of depression when they realize that their child is suffering from mental retardation [18],[19].

Children with mental retardation experience limitations in communication, self-care, social and interpersonal skills. They have difficulties in meeting the needs of daily living and functioning in society because of their intellectual abilities, limited motor skills and adaptation to the environment [8],[10]. Other studies have suggested that parents feel ashamed of having children with mental retardation because of difficulties in overcoming behavior problems like screaming, crying, inability to concentrate, aggressiveness, stubbornness etc. Often, the child might not understand how disruptive his/her behavior is to others and why they get angry. This problem makes parents even hiding children from their community and environment. Children's mental retardation needs to be specifically considered, making parents and other family members difficult to divide their time and care for their child with a maximum [16],[17]. This becomes the burden of parents in raising and having an impact on family activity in seeking income [16],[18].

There is no doubt that mental retardation is a life-long disability with a major impact on the lives of the children and their families. Caring child who are mental retardation is often itself stressful as caregiving affects several aspects of caregiver's life negatively including poor physical and emotional state. More specifically, mothers of children with MR displayed lower physical health, impairment in social relationships, in their psychological state and poorer perception of their environment. Mothers, experience more burden than parents of typically developing children. The possible reasons for this could be that a mothers spent more time with the children while caring for them; most mothers were home-makers without additional help and also were restricted to home with no time or provision for leisure activity [7],[19],[20]. All of these situations make parents and families feel a heavy burden in caring for children with mental retardation. Makes them feel tired and feel this burden never ending [18],[19].

### 3.3. The social stigma

Stigma is a negative attitude of a group of people who cause prejudice and discrimination against the subgroup. Stigma includes the cognitive, emotional, and behavioral aspects of prejudice, and discrimination. Stigma affects not only individuals who carry stigmatization labels, but also others who directly interact with them [16].

Problem isolation and rejection of society to mental retardation made families feel increasingly heavy burden feel very hard to live life. Cultures that developed in the community, that each individual is somewhat different from the normal state will determine the extent to which the individual was accepted by the people around him. A person with mental retardation is not just isolated environment, but also they experience ridicule and rejection from their own families [8],[14],[20].

They also often get insults and rejection of the neighbors and the society around. Results from this study that individuals with mental retardation obtain stigma verbal and nonverbal, as expelled by the local community. They often get unpleasant treatment and discrimination in social interaction and daily activities. Some participants expressed their child can not freely play and get together with friends their own age.

The rejection of others will make them feel inferior, withdraw from the environment and be afraid to interact with others. People in the neighborhood often give negative responses to mental retardation children such as, underestimating, insulting and excluding children with mental retardation and their families, especially mothers who feel the impact of stigma. Negative impact experienced in the form of feeling uncomfortable, depressed, and insomnia. They find it difficult to interact and maintain social relationships in society [16],[19],[20].

Stigma happens because of misunderstandings and ignorance related to disability arising from an illness or event that results in worse treatment, rejection, and an impaired role in society. When society does not give a chance, they really feel a limited social life, affecting their personal, emotional and physical life [16]. The findings of this research indicate the importance of information dissemination efforts and the improvement of public knowledge about mental retardation diseases, impacts and ways of caring also the participation of the community in achieving health and wellbeing degrees both physically, psychologically and socially.

### 3.4. Need support from relatives

The presence of mentally-retarded children in the family needs supports from the family or surroundings. While doing their duty as parents, participants were assisted by family (both core and big family), and also from surroundings e.g. neighbors and special groups in the community.

The findings showed that emotional supports were gained from the big family and from other family members which manifested in the form of attention and compassion, as well as from community social support such as support from the neighbors and the community. We assume that support related to nurturing and training the mentally retarded children is inescapable. If the support is not existed leads to the emotional alteration such as anger, depression, and maladaptive behavior.

The results show that social support provided by families and the environment can help overcome stress and be able to see positive aspects of the life they live in by having a child's mental retardation. The support provided makes them feel valued and cared for, this can make them have a positive self-defense mechanism and be able to adapt to any situation and impact arising from having a child's mental retardation, even to prevent the occurrence of anxiety and depression [19].

This is in line with other studies showing that family support is a coping strategy of parents who have mentally retarded children in the form of moral support, attention, sharing and sympathy [8]. In addition to getting support from the family, parents also get support from people they trust, close friends and friends. This is what makes them feel that there are people who always pay attention, respect and love him [8].

The effectiveness of various programs to take care and increase the quality of life of children and adolescent who suffer from mental retardation depends on the role and supports of the entire family, because the successful of the program is not merely the responsibility of the educational institution. In addition, support and acceptance of each family member will provide the energy and confidence for the mentally-retarded children, that will aid them to be able to live independently [9],[21],[22].

### 3.5. Worry about the future

This current study found that the expectation to be reached by parents in term of nurturing or training in order the children be able to live independently [9],[10]. It expressed by some participants was being independent and make the parents be proud. In fact, teaching children to be independent is complicated; therefore parents' expectation is limited upon the independence of the child itself. Children with special need will adapt continuously through the lifetime to gain the better level of ability. Those are the intention of the parents to increase the ability of the children to achieve a better life either for children or the family, especially mastering the skills that the children have not had reached before.

Researchers assume that every parents expect their children grow and develop normally, as well as the expectation of parents whose children are mentally retarded, they always expect their children grow independently correspond to the developmental phase, but the hope is hampered by the limitations of the children itself, it depleting parents' hope for the children. Eventually, parents can only hope that the children that they raised can be independent and capable of themselves, in fact some of them still rely the aid from their parents.

As the child develops, many families must begin to face long-term uncertainties about the functioning of children today and the future and sometimes their questionable validity, even to lose hope [8],[17]. The biggest concern parents feel about having a child's mental retardation is how their children are able to live their lives after they die. Who will care for them with affection and patience, whether they can survive with all the limitations they have. Although they do not know what will happen, they are still trying hard to care for and train the ability of children to be independent in living his life.

### 3.6. Admitting god's will

Having children's with mental retardation is a great challenge for the parents since the ability of the children depends on the ability of parents providing the training. From the finding illustrates that patience was the key factor in coaching the independency for retarded children. Participants must repeat all the training program patiently, added with discipline. Teaching mentally-retarded children requires extra patience, and unconditional love. A mentally-retarded child is having adversity to obtain the stimuli given. This condition caused by a significant developmental disorder of the central nervous system [9],[10].

This reach found that the participants considered that having a retarded children is a test for the parents, because the participant considered that having children with mental retardation is a test and a trial. Participants accept the condition of their children as they perceived that children are a gift from God, they have accepted their children as they were.

The other studies show that having a mental retardation child is a trials of life, must remain grateful whatever he experienced so far, accepting the child's condition as it is, becoming more attentive, more understanding of the meaning of life and more patient in parenting [7],[14]. Spiritual aspect increased the confidence of what have been implemented in term of taking care the retarded children, growing optimism and fostering strong relationship among the family to build mutual assistance in aiding and accompanying the retarded children [14],[20].

Mothers who have children with limitations, feel their affinity with religion Increase trust and get closer to God, so as to accept this as a test from God that the child is a creation Parents are also convinced that life is a gift from God, so they are optimistic about healing for their child and after being tested with having a mental retardas child. Some parents also take the positive side of this situation and learn to be more grateful and accept everything that happens and live it sincerely. A strong religiosity aspect among parents

implicated behavior and the thinking pattern of the parents, thus all things which occurred beyond their capability and their control will be submitted to the Gods Almighty [8],[20],[23].

One source of strength used by parents who have children with mental retardation are the values and beliefs they have, so that they are able to think positively about every provision that God has destined. In previous research states that mothers who have children with mental retardation see all events is the fate and test of God. To be strong in this test, they are diligent to worship with prayer. With regular prayer and recitation they feel more calm, strong and happy [8].

#### 4. CONCLUSION

Parents attempt to accept the reality and consider that having children with mental retardation is a test as parents, and consider that children as mandate from God. Thus the parents are attempting to accept the reality sincerely. The themes that emerge describe the process of the adaptation of the parents towards changes. The adaptation behavior is including the acceptance of children's condition and having compassion to the children hearty.

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**BIOGRAPHIES OF AUTHORS**

Sri Endriyani is working as lecturer in Health Polytechnic of Palembang, Indonesia.  
She can be contacted through her email: [sriendriyani@yahoo.co.id](mailto:sriendriyani@yahoo.co.id)



Yunike is working as lecturer in Helath Polytechnic of Palembang, Indonesia.  
She can be contacted through her email: [Caby\\_deh@yahoo.com](mailto:Caby_deh@yahoo.com).