Great Mother for Special Needs Children: A Qualitative Study of The Role of A Single Mother

Frida Tia Rahma¹, Tulus Winarsunu¹ and Ibnu Sutoko¹*

¹Faculty of Psychology, University of Muhammadiyah Malang, Indonesia
*ibnusutoko20@gmail.com

Abstract

The presence of children with special needs is a challenge faced by parents of children with special needs. Sometimes some families experience things that are not ideal, such as losing their husband’s role and thus becoming a single mother. Challenges in parenting are often faced by single mothers with children with special needs. The aim of this research is to explore the experiences of single mothers who have children with disabilities in less than ideal family living conditions. The research method is qualitative with a phenomenological approach. The sample was selected using a purposive sampling technique with four participants and data collection using interviews and observation. Data analysis uses descriptive phenomenological method with presentation in the form of themes. The research results show several themes that combine the phenomena experienced by single mothers, namely the loss of the role of husband, challenges in raising children, financial independence, negative environmental experiences, figure support, religious coping. The conclusion of the research is that the life journey of a single mother with special needs requires a difficult and long process starting from acceptance to positive adjustments in parenting patterns as well as interesting religious coping strategies and can be a model for other single mothers and increase self-esteem.

Key words: child with special needs, family, mother role, religious coping, single mother

Introduction

Generally, the presence of children in a family is considered a gift which is a hope as a successor to the family. All parents have plans and hopes for their children, often parents will even imagine the child's development and future. In the future, parents expect their children to achieve success, even though they have limitations in their adaptive functioning (Cless, 2018). Parents who have a future vision for their children can make it a strength as an effort to achieve success in parenting (Chen, 2019).

Children in this world are born with different conditions in each family, whether children are born with normal conditions or with special needs. In 2021, the National Center of Health Statistics, based on a survey conducted on children, found that 8.56% of children in the world were born with disabilities, both physical and mental. The existence of limited physical and mental conditions often becomes an obstacle to the growth and development of children with disabilities (Ginis, 2021).
Disabled children experience dysfunction which is likely to occur in the prenatal period, namely during the womb, or perinatally during the birth process and shortly after the birth process, or postnatally after birth until before the developmental age is complete (Hasanah & Retnowati, 2017). The assumption is that if there are 42.8 million school age children aged 5 - 14 years in Indonesia, then it is estimated that there are around 4.2 million children with special needs in Indonesia (Desiningrum, 2016). This large population is a concern for the government and society and is a burden for parents who have children with special needs (Hasanah & Retnowati, 2017).

Having a child with a disability is an experience that the family does not expect (Yamaoka et al., 2016). The presence of a child with a disability may have an impact on the lives, emotions and behavior of family members. Rejection is usually the first reaction seen in families, when they find out that their child is born with a disability, although this rejection is not always permanent (Da Paz, 2018). Several previous studies stated that mothers who have children with special needs experience difficulties in accepting their children, show rejection behavior towards their children's disabilities, and feel hopeless because of their children's disabilities (Papadopoulos, 2021; Zembat & Yıldız, 2010). The process of accepting a child's condition is not an easy process and is often a process that takes time.

Not only related to acceptance, parents face various conditions that make it difficult to raise children with disabilities. Caring for children with special needs can be lifelong care and this can affect the quality of life of the parents (O'Connell, O'Halloran, & Doody, 2013). One of them, having children with special needs is more vulnerable to stress (Dardas & Ahmad, 2014) compared to parents who do not have children with special needs (Hsiao, 2017). Factors that contribute to increased stress in parents of children with disabilities include lack of intellectual function, physical limitations, low self-care skills, and limited social skills of children with disabilities (Lessenberry & Rehfeldt, 2004). These limitations not only make it difficult for children during their growth and development but also make it difficult for the people who care for them (Hasanah & Retnowati, 2017).

Moreover, if you have the role of a single parent, in this case a single mother who alone cares for a child with special needs is more vulnerable to experiencing distress in childcare (Nurhamidah & Retnowati, 2018). The presence of high stressors such as daily difficulties, social isolation, and economic pressure, results in single mothers experiencing a higher risk of emotional distress and disruption in parenting (Taylor & Conger, 2017). Mothers play an important role in raising children, regarding the presence or absence of disabilities in children (Yamaoka et. al, 2016). Raising children as a single parent is a complex and dynamic matter, which can significantly affect well-being (Williamson, 2018).

Facing various conditions of distress without the presence of a husband causes single mothers to feel responsible for various areas of life which include the health and well-being of themselves and their family members (Hashim, Azmawati, & Endut, 2015). Plus, the condition of disabled children is likely to require lifelong care and be dependent on the mother as a single parent. Mothers are the center of care, education and supervision of children with disabilities (Kandel & Merick, 2007).

Based on the description above, there are many challenges and distress experienced by single mothers who have disabled children. There are parents who can accept and care for them positively, but there are parents who need time or cannot even accept it positively. Previous research has mostly focused on parents who use coping dysfunctionaly, while parents who successfully use coping to overcome crises have not been studied adequately (Kandel & Merrick, 2007). The aim of this research is to explore the experiences of single mothers who have children with disabilities in less than ideal family living conditions.

Method

Participants

The selection of subjects in this research used purposive sampling with specific participants. Participants in this qualitative phenomenological research used 4 participants, all of whom were single mothers. Inclusion criteria are being a single mother under 40 years of age, having children with disabilities who are children or teenagers, being a single mother under four years of age. The exclusion criteria were single mothers who experienced mental problems, had certain medical conditions, the subject refused to participate.

Research Instruments

The data collection method used in this research was interviews. The instrument used for data collection was through guideline interviews which were prepared based on research phenomena and theories attached to the role of single mothers.
Data Analysis Techniques

The data analysis technique used in this research is interpretative phenomenological analysis (IPA) with a thematic model. IPA is used to identify findings from interviews in the form of patterns and themes which are arranged into a framework for research results.

Results and Discussion

Based on the results of interviews with four research subjects, the formulation of research themes was found. The themes found are related to the experience of the single mother’s life process in the family. These themes are arranged as follows:

Results

Acceptance process

Having children in perfect physical and mental condition is the hope of most parents. However, in certain circumstances, children are born with disabilities. When children show different developmental conditions, parents feel confused about their child’s condition. The three subjects in this study did not previously know about children with disabilities, until they received examinations by doctors or psychologists. For parents, knowing that their child’s imperfect condition is difficult and causes negative emotions. Subject YY mentioned how he felt when he learned about his son’s diagnosis of Autism syndrome:

“At first it was really hard, just because we, never mind, given a child like this, just accept it. At first it was really hard. Yes, it’s very difficult to accept children like this. Adapting to neighbors and friends is really difficult.”

This reality that must be faced requires acceptance from parents as the child’s primary caregiver. The four subjects said that the condition of the child was a destiny from God. Subject LN stated:

“If we feel that way at first, we don’t accept it. How come we are given a child’s trials like this but after a while we learn what the lesson is? Maybe we are tested, God is tested, so that we can be patient, we can improve ourselves, like that. Introspection, it’s much better that way”

Severe or mild disabilities in children are difficult for parents to accept. When first learning about a child’s disability, parents have difficulty accepting the child’s condition. The admission process usually requires a long process. One way to accept a child’s condition is to consider that a child who is entrusted to his parents is a destiny given by God.

Losing the role of husband

The three subjects in this study were single mothers due to divorce. After their husbands left, these single mothers experienced feelings of worry about raising their children without their husbands’ support. Subject IN said:

“If you think about it first, okay? How do I take care of my child, is that possible? If I used to think about it, oh, how do I get him to go to the doctor, okay? I’m afraid of having a seizure on the road. If we think about it now, thank God we just carry on, bismillah. Surrender to Allah, everything is surrendered to Allah. Done it a.e. Yes, now thank God I can”

In the subject of LN who is a single mother due to divorce, LN feels guilty because her child grew up without receiving love from his father. LN stated:

“Sometimes we feel like we are so guilty, why do we have to separate, we feel sorry for the child. It’s like he doesn’t get love from his father.”

Even though her child received love from LN’s parents and siblings, LN considered that the love given to them would be different if it was given by her child’s biological father. The four subjects were aware of the husband’s role as a partner in parenting, breadwinner, and figure that the children needed. However, the existence of conditions that mean the husband is no longer present in the family requires the single mother to take over her husband’s duties while simultaneously carrying out her duties as a mother.

Challenges of Parenting Disabled Children

Children with special needs usually have limitations in independence and self-care. Apart from that, the IN subject has other concerns regarding the health condition of the child who suffers from epilepsy, so IN feels worried when he is away from his child:
"... he can't go to the bathroom, he can't go to the kitchen. You can defecate yourself but it's not clean, if you shower it takes a long time. So you have to control it. You can eat it, it just takes a long time, sometimes I'm not careful, even if I don't want to eat it, just spit it out and don’t swallow it until it hurts. ... But yeah, it’s hard to eat, grandma wants it or not, grandma doesn't, but it's eaten with terogne sauce. Now, Wes Angel, I don't know what the effects of the drug are. Taking medicine makes it difficult to eat, right? I’m feeling so numb. Then, come on, what, strength comes from food."

The four subjects explained that difficulties in raising children were related to the child’s limited self-care abilities, such as personal hygiene, eating arrangements, and the child's abilities being limited and not like those of children his age. This is a stressor for single mothers who are the main caregivers of children where children become very dependent on the mother figure.

Social stigma
Apart from the problem of raising children without a husband, there are other challenges faced by single mothers. The negative experience received by EL and LN was related to the child’s disability condition, LN stated:

“When we were in Kindergarten, the teacher used to be rude about hitting us, actually we didn’t accept it, right, ... finally we found out, we got angry at school, .... As long as it’s said like that, it’s okay, we just accept it. In my heart, it hurts people to say things like that, but yeah, just accept it when people are like that.”

Apart from being related to the condition of disability in children, there is still a negative stigma from the social environment regarding widows faced by IN and EL subjects. IN stated:

“That’s a bad feeling for sure, it’s called a young widow. But yeah, Wes doesn’t take care of it, Wes is indifferent... Yes, I don’t know how people feel when they think it’s bad, I don’t know.” In fact, the EL subject resulted in the subject feeling sad and annoyed with the social environment. Meanwhile, IN subjects don’t think too much about other people’s judgments.

Financial Independence
The four subjects in this study, before their husbands left, were used to earning a living. IN says:

“... work habits, when my husband left me, I was shocked or not. You can work, you can eat snacks, you can accompany people to work. I’m not ashamed anymore”

Thus, the four subjects who are the backbone of the family, do not experience significant financial difficulties in terms of their living expenses. Therefore, subjects IN, EL, and LN chose to fulfill their living needs by working in non-formal jobs, namely jobs that have flexible working hours and can mainly be done at home. Meanwhile, YY’s job is as a teacher at an autism school where her child also attends. So the subject can divide his time between working and caring for children. On the other hand, the subject’s family provides financial assistance which is mainly aimed at their children.

Source of strength
The figures who support the four subjects in living a life that is not easy are their closest families. YY tells the story:

“People who help, parents and siblings, friends. The child’s support is what gives strength, child”.

The main supporting figures of the subject are the subject’s parents. Subject YY, LN and EL live close to their parents, while subject IN lives far from their biological parents, but communicates quite intensely via telephone or video call. On the other hand, subjects IN and EL have a close relationship with their husband's family. The support provided by the family often takes the form of emotional support intended to strengthen single mothers in facing daily difficulties. The family’s role in supporting the subjects is not limited to emotional support, but also provides financial support. Even though single mothers are used to earning a living even before their husbands leave. Sometimes the economic situation we face is not always easy. So, their family and those closest to them help single-mothers with financial matters. Apart from that, subjects who have children other than disabled children, namely subjects YY, IN, and EL, stated that children are a motivation in living their lives.

Discussion
Having a child with a disability is something unexpected for parents (Yamaoka et al., 2016). Research Papadopoulos (2021) found that the condition of children with special needs has the potential to cause emotional burdens, family burdens and social burdens for parents. This different condition of the child is a condition that really hits the parents
and may even cause feelings of sadness to arise. Denial is the reaction that usually first appears when someone experiences grief (Santrock, 2011) although denial is often a temporary defense (Zembat & Yildiz, 2010; Santrock, 2011). Not only denial, knowing the condition of a child who was born with a disability causes negative emotions to emerge such as feelings of guilt, frustration, anger, despair (Chandramuki et al., 2012; Mohan & Kulkarni, 2018). This psychological impact does not only affect parents, the presence of a child with a disability is likely to have an undesirable impact on the lives, emotions, thoughts and behavior of all family members (Zembat & Zildiz, 2010).

This difficult situation requires parents, including family members, to form an acceptance of their child's disability. The research results of Chandramuki et al. (2012) shows that the process of accepting a child’s disability is not an easy thing. Acceptance of a child's condition is important for coping (Mohan & Kulkarni, 2018) so that parents can care for their child despite their disability. When parents, especially mothers, accept their child’s disability and create a positive and warm relationship with their child, the child will have a positive impact on all areas of their development (Zembat & Yildiz, 2010).

The absence of a husband figure in caring for children with disabilities puts pressure on single mothers. The underlying reason for the stressors experienced by single mothers is that they take over the duties and roles of fathers, while simultaneously carrying out their duties and functions as mothers. Single mothers are the main figures who are responsible for all aspects including the health and well-being of themselves and their children (Hashim et al., 2015). It can be said that the single mother is the backbone and tries to compensate for the absence of her husband in child care and other functions (Kotwal & Prabhakar, 2009). On the other hand, single mothers are vulnerable to experiencing loneliness, without a husband with whom to share the burden and caregiving responsibilities (Cairney et al., 2003; Kotwal & Prabhakar, 2009), there is difficulty dividing time between work and caring for children (Nurhamidah & Retnowati, 2018).

Moreover, there are physical and psychological limitations in children who need special care. These limitations are caused by children having insufficient abilities in intellectual function, physical limitations, low self-care skills, and limited social skills (Lessenberry & Rehfeldt, 2004) which makes children dependent on the mother figure. In order to adapt well in conditions of parenting without a husband, single mothers must be able to use the resources they have, such as internal resources (resilience, acceptance and positive adaptation) and external resources (social support and socioeconomic conditions) (Hasanah & Retnowati, 2017).

The stress of being a single mother who has a disabled child does not only come from within the family, but sometimes the social environment provides an unpleasant response. There is still a negative stigma regarding widowhood, which is one of the stressors faced by single mothers. Research by Carney et al. (2003) states that social stressors may have the greatest impact on the relationship between single parent status and depression. Apart from that, single mothers also experience unpleasant responses from the environment regarding children’s disabilities. The presence of different physical appearance and behavior, plus a lack of understanding of the social environment regarding children's disorders, can cause parents to face hostile attitudes from the social environment (Cauda-Laufer, 2017).

The difficulties and stressors in caring for a disabled child as a sole caregiver without a husband make the subject need support from the people around them. Although support from a partner is important, meaningful support can come from other sources (Taylor & Conger, 2017). Family members and friends are more likely to offer support to single mothers, given the unavailability of support from partners (Carney, et al., 2003). Cauda-Laufer (2017) stated that there is no doubt that social support from the family is very beneficial for single mothers who have children with disabilities. It is believed that supportive social relationships are closely related to positive psychological well-being in parents of children with disabilities (Chandramuki, et al., 2012). The subject’s family and friends can provide informal support in the form of information, advice or other forms such as childcare assistance. In certain circumstances, relatives and friends are the people who help single mothers financially and also help them organize their daily lives (Endut, et al., 2015). Support from family can reduce parenting stress and feelings of isolation in single mothers (Cauda-Laufer, 2017), help build self-confidence, increase self-esteem, (Chandramuki, et al., 2012) increase psychological adjustment and self-efficacy in parenting (Taylor & Conger, 2017).

It is known that the single mothers in this study interpreted their lives based on religion. Several studies have shown that many people return to religion as a source of their efforts to understand and deal with difficult stressors in their lives (Pargament et al., 2011). Other research also states that religion is an important resource in raising children for single mothers (Pett, 2012). Thus, single mothers view their lives from a religious perspective in dealing with various stressors, ranging from internal stressors, difficulties in raising children, to negative responses from the environment. The single mothers in this study mainly used religious coping strategies to deal with these stressors. Religious coping refers to the use of religious beliefs or practices to overcome stressful life situations (Afakakir & Mahdiyar, 2016; Pargament et al., 2011). There are two types of religious coping strategies, namely positive religious coping strategies and negative religious coping strategies.

Carpenter et al. (2011) stated that positive religious coping strategies include positively reappraising religious values in response to stressors, seeking spiritual connections, and seeking spiritual support from other people. In this case, the single mother subject considers that the child, along with his or her disability, is a destiny entrusted by God, so their task is to live it and surrender it to God. Apart from that, the subject also believes that the subject will
receive God’s reward if they raise the child well. This positive way of assessing stressful life situations allows a person to relieve anxiety and change feelings of hopelessness and hurt (Aflakseir & Mahdiyar, 2016). Thus, positive religious coping is significantly associated with increasing positive adjustment and reducing negative adjustment (Carpenter et al., 2011) and is associated with health and well-being, especially in individuals who face critical problems in their lives (Pargament, et al., 2011). Religious belief becomes its own strength to survive in facing trials that have been entrusted by God (Hasanah, Retnowati, 2017).

**Conclusion**

Based on the research results, it can be concluded that life for single mothers with disabled children is a difficult life process and requires time to be lived positively. The process undertaken is not easy because there are many factors that strengthen and weaken, starting from internal factors such as doubt, fear and rejection and external factors such as environmental views, economic conditions, the missing role of the husband and other findings and overall impact increase self-esteem. It is hoped that these findings will provide an overview of parents in general and single mothers with children with special needs in family life.

**Implication**

It is hoped that these findings will provide an overview of parents in general and single mothers with children with special needs in family life. From these results, single mothers with special needs can start making alternatives based on similar experiences in this research. It is hoped that future research can explore the experiences of single mothers with various background problems of children with disabilities. Apart from that, you can also explore single fathers to get another picture based on gender in caring for children with disabilities independently.

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**Authors’ Contributions**

FTR contributed to preparing research plans, conducting research, analyzing data and writing papers. TW contributed to methods, data analysis, and writing of the paper. IS contributed to designing the research, providing the method, analyzing the data and writing the paper. The entire manuscript has been double-checked by all authors.

**Competing Interest**

This research has no conflict of interest.

**References**


