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The process of acceptance and resilience of a mother with deaf child: Life history

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ABSTRACT

Every mother hopes to give birth to a perfect, normal, and healthy child, hope arises from the moment the child is still in the womb. Things turned around when the mother heard the diagnosis of her child with special needs. Various psychological problems experienced by mothers before finally reaching the stage of self-acceptance to be able to accept the state of themselves as mothers of children with special needs is a difficult process. Every mother has her own process and way to reach this stage. The purpose of this study was to see the picture, process, and factors of self-acceptance of mothers with children with special needs. This type of research uses qualitative with Life History. Data collection techniques use observation of family activities and interactions, in-depth interviews and document studies. Data collection was conducted from November 2022 to January 2023. The data obtained are analysed using thematic analysis techniques inductively. Based on the results of the study, the process towards maternal acceptance of deaf children begins with grief, anxiety. Self-acceptance is evidenced by the mother's adaptation process to master the situation, seek information, be sincere, think positively, and endeavour treatment. The process of self-acceptance is influenced by good family reciprocity, warm family support, good religious knowledge, and a supportive environment

Keywords: *Life history; mother with deaf child; resilience; self-acceptance*

INTRODUCTION

Child with disability is still a nightmare for most parents. In many parts of the world, disability and children with disability are a sensitive issue because of the stigma attached. Moreover, social stigma against families who have members with special needs is considered like a curse, unlucky carrier, and social burden. According to Kayama & Haight (2014), individuals with socially defined "undesirable otherness" experience varying levels of stigma.

Their differences with "normal" people can affect not only other people's attitudes and behaviors toward them (social stigma) but also their own self-concept (internalized stigma). This stigma results in the tendency of families to hide their children at home and makes parents stop seeking further care for their children (Fox et al., 2017). Preparing for the birth of a child with a diagnosis of a child with a disability is a challenge for parents. In this condition, parents have a choice between maintaining the pregnancy or aborting. If the first option is chosen, parents need to prepare themselves, empathy and acceptance.

Some parents can also show expressions of grief in the form of feelings of sadness, anger, emotions of blaming themselves and others around them, a mother will vent to herself or those around her (Ramadayanti, 2022). In this condition, mother is a figure who is prone to disability problems in children. This is because the mother plays a direct role in the birth of children.

Discussing about hearing impairment, Isaacson (2010) defines hearing loss (including deafness) as a sensory disability in which sounds cannot be perceived, conducted, and/or interpreted normally by the person. Deafness is a physical condition felt by someone who does not have the ability to observe sounds in any form, generally a deaf person also suffers from speech impairment or inability to dialogue (Makausi et al., 2022).

In some cases, hearing loss can cause learning disabilities that are more serious than vision loss (blind children). Deaf children are usually more difficult to master and use symbolic language. For decades, mental health issues in deaf and hearing-impaired children and adolescents have been of concern to many researchers.

Aanondsen et al. (2023) define mental health problems as the presence of symptoms of mental health disorders (e.g. bad mood, attention problems, etc.) and mental health disorders based on diagnostic classification, i.e. the combination and severity of symptoms combined with clinically significant loss of function.

Raising a deaf child can have a significant impact on the well-being of parents, their relationship with the deaf child, and their ability to parent effectively. Sealy et al. (2023) have researched the parenting styles of deaf children exploring the relationship between diagnosis resolution, parenting style and spirit, and child vulnerability.

The results of Sealy et al. study shows in sibling care, parents feel a higher child vulnerability in deaf children compared to hearing siblings. Despite this, no sibling differences were found regarding parenting styles. But the findings of Sealy et al. also points out that the experience of having a deaf child can negatively impact parental morale and perceptions regarding a child's vulnerability, especially when parents still have no decision on the diagnosis, highlighting the need for further support.

A process of acceptance to a child who is not in accordance with expectations, the first thing that parents usually feel is distrust. Furthermore, parents will be overwhelmed with insecurity and shame. Moreover, it is shame on the family about the state of their child to admit that it happened in their family. This situation becomes worse, if the family experiences social pressure from an environment that does not understand the situation of children with special needs.

Parents of children with special needs experience higher levels of stress, more depression, and anxiety than parents of ordinary children growing up. Parents of children with disabilities develop coping strategies to cope with the stresses associated with raising a child with special needs (Chin et al., 2023).

Facts prove that patience, sincerity and good acceptance, as well as the cooperation of parents who support each other provide good and meaningful results for the development of children's hearing, but many parents treat children with special needs inappropriately. For example, through physical violence, sexual abuse, even hourly behavior towards parents or to the point of killing them.

Parental self-acceptance of deaf children requires a long process. Factors that influence the attitude of parents make them to be ready for everything that the child has, in order to accept the status and existence of the child is very important for the development of children with disabilities. an expression of gratitude for the blessings given by God.

Roberts' (2000) presentation at the symposium with the theme *Hearing Problem* explained rubella infection in mothers in the first trimester of pregnancy in 85% of cases resulting in severe/very severe bilateral hearing loss combined with classic heart defects, cataracts, retinopathy, bone lesions, low birth weight and learning difficulties. Infection in the second and third trimesters of pregnancy is associated with a reduced risk of hearing loss. Subclinical infections in the mother can cause hearing loss of its own.

This article presents the results of research that aims to determine the process of acceptance of mothers to children with special needs. Wulan (40 years old, not her real name) was the main participant in the study. Related to ethics, the name in this article is an anonymous name. At the age of 35, Wulan was expecting a baby boy. At the age of 11 weeks, Wulan was infected with the Rubella virus. The obstetrician educated Wulan about the risk of disability in her unborn child so that she had a choice between preserving the pregnancy or doing abortion.

METHODS

This study used a qualitative approach and life history method. Life history is one of the qualitative approaches to knowing an individual's life experience from the perspective of how that individual interprets and understands the world around them. Wulan, who has a child named King, as the main source of research data. King is Wulan's third children. The data collection technique used observation of King's activities at school and family interactions, in-depth interviews with Wulan, King's family, teachers, and study of King's medical record documents. Data collection was conducted from November 2022 to January 2023. The data obtained were analyzed using thematic analysis techniques inductively.

RESULTS AND DISCUSSION

I had a great childhood

Like other children, little Wulan spent her childhood playing with friends. Moreover, little Wulan had many cousins who were same age as her at that time. Little Wulan grew up in a warm and well-off family. Their families occasionally took time to go out with extended family. Even in one year, Wulan's family always returned home from Lampung to Java. For her, the ritual became a memorable moment.

"My Mama's family is a big family, so many cousins are the same age. Every weekend we often gathered at grandma's house. And played together. There were also neighbor friends near home," (Wulan).

Wulan saw that her parents had positive figures. They maintain harmony, closeness, and always strengthen family ties. A positive family impression is also obtained from a large family that is supportive and compassionate. Wulan always express a happiness and proud to have her parents and family. Similar hopes were pinned by the children to Wulan.

"It is like Pak Dhe (Mama's older brother) and his spouse. They are a romantic couple, always together, and shows twinkles in love. Besides them, there are also Mama's sister, uncle and auntie. They are a romantic couple, a gentle couple, full of affection," (Wulan).

My son is special kid

Having a child who is born healthy is the dream of all parents. However, not with Wulan. At 11 weeks' pregnancy, she was infected with the Rubella virus. She maintained a risky pregnancy until she gave birth by sectio caesarea at 37 weeks. Wulan's child named King received special attention because since 14 weeks of pregnancy, the baby was positively infected with the Rubella virus. The obstetricians who handled Wulan said that the baby may be healthy or the baby may suffer from Congenita Rubella Syndrome. This pregnancy case was the first time they had encountered a phenomenon in Wulan's family.

I once thought about (understanding children with special needs). I've watched TV, Kick Andy show (a reality show on television) or that tells the story of children with special needs, but I just saw the positive, how parents can be strong, their self-system is strong. If the mother is strong, the child is also strong, " (Wulan).

Wulan's baby was born with various records. Various treatments and efforts have been made by Wulan and his family. They seek treatment in various hospitals such as Bunda Asy-syifa Mother and Child Hospital Lampung, Gulardi Centre Maternal Fetal Clinic, Bunda Mother and Child Hospital Jakarta, RSUP dr. Sardjito, RSKIA Adinda Yogyakarta, RS Mata YAP Yogyakarta, RSA UGM Yogyakarta, Hermina Yogyakarta, RS JIH Yogyakarta, RSCM Kencana Jakarta, RS Pantai Indah Kapuk, Jakarta, Nobel Audiology Centre, dan Klinik Tumbuh Kembang Anak Pelangi Hati.

"There are no special children in the family, King is the first case our family has encountered. But I used to have a friend named Yaya, her speech is not clear yet... Yes, I was worried (pregnant with medical records), it is a pregnancy, but if the child has special needs, we must accept. I call it as is a fate, " (Wulan)

Table 1
Growth milestone of King

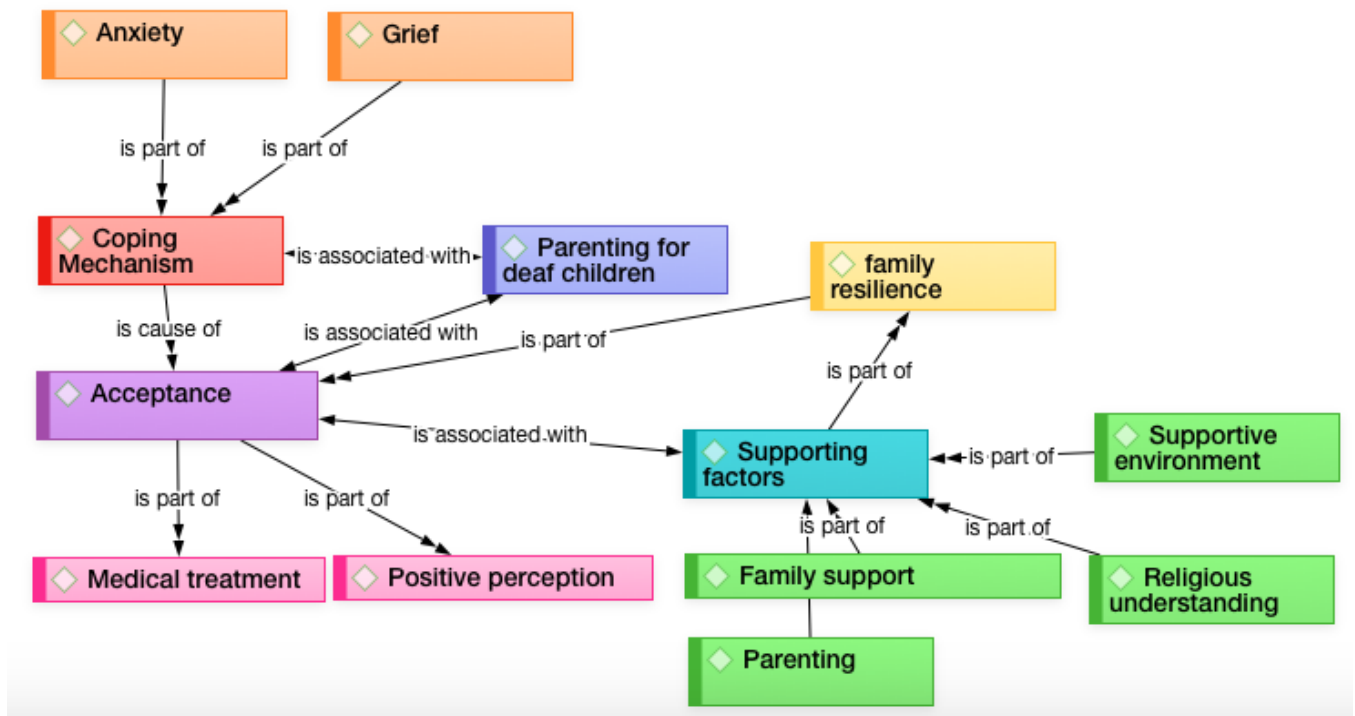
Year	Baby condition
2015	Pregnancy 11 weeks 2 days, mother IGG Rubella +, IGM Rubella +
2016	14 weeks pregnancy: Baby + infected with Rubella Virus. The chances of the baby being healthy, and the chances of the baby suffering from Congenita Rubella Syndrome
2016	37 weeks + 6 days pregnancy: Baby born with <i>sectio caesarea</i> surgery
2016	1 week of age: Seizures, stiffness, cold, respiratory arrest , requires ventilator to survive. Inflammation of the brain & lining of the brain
2016	Age 2 months: Indicated motor & cognitive delays, weak eye nerves
2017	Cochlear implant surgery
	Doctor <i>switches on</i> King's inner implant
	King's physical progress progressed rapidly until little King finally walked.

	King began an AVT (auditory verbal therapy) session often called hearing therapy.
	King began learning to listen for about 1 year of AVT therapy, stagnant progress.
2018	2 years of biological age but 1 year of hearing age
2022	Age 5 years 11 months indicated dyslexia disorder with ADD comorbid

King's parenting commitment is evidenced by choosing a school that can accommodate King's needs. At his school, the teacher noticed that the gap caused by his disability is not noticeable. He is able to show his confidence and comfort with peers at school.

As a mom, I hope my son can take responsibility for his life

Wulan shows her happiness to have children, King and his brothers. She claims that she has a husband who is loving, understanding, and always supportive. As a housewife in raising children, she seems to live it gratefully, proudly, and happily. Her expectations are the same as those of parents in general, namely having children who are happy, have good character, benefit others and do not harm others, and have Islamic character. Although her son is special, the son grows according to his age. Wulan has the view that a strong child is a child who is not easy with every failure faced. Children will continue to try, learn, endeavor, and sincerely accept fate. In the end, children are expected to be able to take responsibility for their lives before God.

Figure 1*The results of thematic analysis using Atlas.ti*

The acceptance process that Wulan went through is a different phenomenon from the theory of loss/grieving initiated by Kubler-Ross & Kessler (2014). According to Kubler-Ross & Kessler, the acceptance process goes through at least five stages, namely, the stages of denial, anger, bargaining, depression, and ending in acceptance. The process of accepting Wulan as a mother with a special need child did not take long. She did not experience a phase of rejection but feelings of sadness and worry predominated.

Wulan experienced a process of sadness and anxiety over the inability to care. But she shows more acceptance as a destiny that must be lived as well as possible. Religious understanding made Wulan look at this condition with a positive point of view. She shows the adaptation process such as studying children's health conditions from various books and meeting experts to get input in the childcare process.

From the research findings, Wulan's parenting success is also influenced by the close relationship between family members. In addition, a warm family background is a supporting factor in managing emotions during parenting. Her family was able to provide moral and material support, including medical treatment.

The importance of the role of family in the success of Wulan emotional management is in line with the results of research conducted by Widhiati et al. (2022). Research by Widhiati et al. shows that the family as the closest environment is an important part that can provide social support to children with special needs.

The importance of family social support for children with special needs is because it is the first environment that can be a natural source of support for children with special needs. Social support from the surrounding environment is also needed by children with special needs. They need confidence that they are capable of acceptance from the surrounding environment (Widhiati et al., 2022).

In addition to having a warm family and her parents' upbringing of her, religious understanding shaped the acceptance process faster. Her family environment shows strong family resilience. Family resilience is the success of family members in overcoming adversity that allows them to thrive with warmth, support, and cohesion (Black & Lobo, 2008).

Factors that influence family repression are shown by a positive outlook in responding to difficult situations and good communication. The communication pattern of the Wulan family is clear, can express emotions, and always solves problems together (collaborative problem solving).

The religion and spirituality shown by Wulan and her family also fostered family resiliency. A shared belief system of hope and victory makes families understand the crisis or change. When faced with problems, many families cultivate an optimistic attitude with spirituality, seeking purpose in faith (Black & Lobo, 2008).

Parents of children with disabilities know that society views persons with disabilities as less acceptable, and that persons with disabilities have difficulty in establishing satisfactory social relationships. Weinberg & Sterritt (1986) argue that to increase a child's chances of success, parents can encourage children to perform and behave at their best.

To the extent that their children can "graduate" as able-bodied, these parents believe that the likelihood of their children being accepted and succeeding will increase. Especially if the family has good literacy. Wang et al.'s (2023) research shows the literacy environment at home plays a complete intermediary role in the regression

relationship between parental education and reading interest of deaf children, and this effect has no significant differences between genders. Parental education has a positive and predictive effect on deaf children's reading interest, while creating a high-quality home literacy environment can enhance this effect.

CONCLUSIONS

The process of accepting mothers with deaf children begins with grief and worry over the inability of future caregiving. This is a natural response shown by humans when experiencing loss or feelings of grief. But this case study, which refers to a mother with a deaf child, the admission process happens very quickly.

The process of accepting mothers is influenced by a good family background, strong family resiliency, as well as religious understanding and spirituality that affect the process of accepting mothers. In addition, the mother has the moral and material support of a warm family. The acceptance process is then shown by positive guidance to the situation experienced and continuous treatment efforts.

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