

## Parenting Style and Family Resilience with Children Congenital Rubella Syndrome

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**Abstract:** This study aims to determine parenting patterns, family resilience with Congenital Rubella Syndrome, and the factors that influence family resilience. The method used is naturalistic with a case study approach. Research data was obtained by interview, observation, and documentation techniques. The data triangulation technique tested the validity of the data. The results of this study are: parents apply democratic parenting, parents can accept the child's condition, and the supporting factors are family and friends. Parents also seek information about their children's needs through seminars and others.

**Keywords:** Parenting Style; Resilience; Family; Special Needs Children; Congenital Rubella Syndrome.

### INTRODUCTION

Every parent wants their baby to grow up healthy. However, in reality, some special people are born or grow up with special needs. From September 2014 – March 2018, the Ministry of Health was surveyed in collaboration with 28 hospitals. There were 1,085 babies born with congenital abnormalities (Kemenkes RI, 2018).

Of course, it is not easy to be a family with children with special needs, especially parents. Not all parents who have children with special needs can immediately accept their children's condition as soon as they are born. It takes time and resilience. According to Herrman, et al., resilience is a positive adaptation or a person's ability when something is not following the wishes, it can be in the form of physical, mental health, parenting, violence, war, natural disasters, poverty, and traumatic events (Herrman et al., 2011). Resilience is an essential thing that a person must have in order to be able to survive the intense pressures of life.

Based on research conducted by Faradina, 1 out of 3 subjects who have children with special needs has not been able to accept their child's condition. This is due to a lack of understanding and limited time. The inability of mothers or fathers to accept their special children causes dissatisfaction and less than optimal as parents and impacts children's development (Faradina, 2017).

Research conducted by Pancawati supports this. Someone who has not been able to accept the child's condition tends to feel sad, run out of energy, and have a hard time running it. When the condition cannot be overcome, emotional support, attention, and stimulation given to children are less than optimal. Self-acceptance in question does not mean having to accept the child's condition at that time immediately.

Nevertheless, self-acceptance is a form of someone being able to recognize these conditions and have the desire and make efforts to develop themselves for the better. (Pancawati, 2013).

In this study, children had Congenital Rubella Syndrome, which was caused by the Rubella virus. Measles is a contagious disease. A person who is sick with measles can easily transmit the disease when he sneezes or coughs. Generally, the symptoms of measles are redness of the skin, high fever, and runny nose, cough, or conjunctivitis. Complications of measles with diarrhea, meningitis, and pneumonia can be fatal, such as death. A person who is infected with measles can infect 90% of people who interact closely. If Rubella infects someone pregnant in the first trimester, the teratogenic effects can cause Congenital Rubella Syndrome and fetal death. (Kemenkes RI, 2017).

Regardless of the child's condition, parents still should provide a living, provide healthy food and drinks, protect children from infectious diseases, treat children when they are sick, teach children not to endanger themselves and others, get children to exercise and ride horses and instill character. persistent, officer and ascetic ('Ulwan, 2017). Meeting the needs, assistance, and getting the same treatment as other children includes special protection for people with disabilities, as stated in Article 70 (Undang-Undang Republik Indonesia No 35 Tahun 2014, 2014) toxic chemical products formed as secondary metabolites by a few fungal species that readily colonise crops and contaminate them with toxins in the field or after harvest. Ochratoxins and Aflatoxins are mycotoxins of major significance and hence there has been significant research on broad range of analytical and detection techniques that could be useful and practical. Due to the variety of structures of these toxins, it is impossible to use one standard technique for analysis and/or

detection. Practical requirements for high-sensitivity analysis and the need for a specialist laboratory setting create challenges for routine analysis. Several existing analytical techniques, which offer flexible and broad-based methods of analysis and in some cases detection, have been discussed in this manuscript. There are a number of methods used, of which many are lab-based, but to our knowledge there seems to be no single technique that stands out above the rest, although analytical liquid chromatography, commonly linked with mass spectroscopy is likely to be popular. This review manuscript discusses (a.

Not only parents but siblings also have a role in developing the lives of children with special needs. Because siblings of children with special needs also take care of and care for their siblings. There needs to be an effort made by parents to build good relationships, and there is no sibling rivalry, one of which is by applying appropriate parenting patterns. Rofi'ah explained that permissive parenting is related to sibling rivalry (Rofi'ah, 2013). This opinion is in line with research conducted by Hanum and Hidayat, which states that there is a significant influence between sibling rivalry and parenting applied by parents (Hanum & Hidayat, 2015).

Based on these problems, there are three focuses in this research. They were first parenting in families with children with Congenital Rubella Syndrome. Second, family resilience with Congenital Rubella Syndrome. Third, factors that affect family resilience. Fourth, parents' efforts to foster resilience. Novelty in this study is the resilience of families with children with special needs and focuses on children with Congenital Rubella Syndrome.

## METHOD

The data were analyzed in three ways, namely reduction, data presentation, and conclusion drawing. The subject of this research is a family consisting of a father, a mother, and two children. The first child had CRS.

The research method used is qualitative with a case study approach. The qualitative method is also known as the naturalistic method, which according to Machali this method is carried out by researching in natural conditions and the researcher being the critical instrument (Machali, 2018, p. 19).

The criteria in this study were: (1) Children with Congenital Rubella Syndrome. (2) Has a parent. (3) Having a sibling. Techniques of data retrieval are done with the interview, documentation and observation. Interviews were conducted with the mother of Ab. Observation and documentation based on the observations of researchers on family Ab. Data validity is tested with the data triangulation technique.

## FINDINGS AND DISCUSSIONS

### Findings

Based on the results of interviews with research subjects, after a blood test, it was found that the mother was infected with the Rubella virus when she was pregnant with Ab, the first child. Symptoms experienced at that time were fever, fatigue, and skin rash. Ab's mother initially did not know if she had ever been exposed to Rubella. It was only known when Ab was 5 months 22 days old. Suspicion began when giving birth, Ab did not cry shortly after birth. The doctor suggested doing an echocardiography test because he heard a loud noise in Ab's heart. The test was performed when Ab was 1 month 17 days old, and the results showed abnormalities in Patent Ductus Arteriosus (PDA) and Atrial Septal Defect (ASD). Furthermore, the BERA (Brainstem Evoked Response Audiometry) test was carried out, which stated that Ab could only hear sounds at a frequency of 105dB, a condition where the hearing loss is categorized as severe or Profound Hearing Loss.

Parents took the initiative to attend a seminar related to child development. The seminar provided a Developmental Pre-Screening Questionnaire (KSPP). After an evaluation, the results showed that it was very likely that Ab experienced obstacles in his growth and development. Based on the results of the assessment, the parents decided to perform a brain ultrasound on Ab. As a result, there are white patches on the brain. Then after a blood test, it was discovered that Ab had a condition called Congenital Rubella Syndrome.

Steps taken by parents to relieve CRS are by doing physiotherapy and taking drugs. Parents also decide to use a back slab elbow that supports weight, straighten hands, and help children learn to sit and crawl longer. Parents perform follow-up hearing tests, namely Oto Acoustic Emission, Tympanometry, and Auditory Steady-State Response (Melia, 2014). Based on the test results, it is known that Ab has very severe hearing loss, so he needs a hearing aid.

The parenting style applied by the family is democratic. Children are given the freedom to do what they want but within the limits that have been set. Based on the observations, the mother did not give physical punishment to the child. The mother firmly asked what the child did, especially when Ad violated the boundaries. Parents ask what the child is doing right or wrong, express feelings, and determine boundaries and solutions. Children are invited to discuss what they are doing to realize that they are not correct.

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Parents also involve Ad in taking care of Ab according to his ability, such as throwing diapers, turning on the TV, taking care of his brother, and playing together. Parents also explained to Ad regarding Ab's condition. The mother explained that according to the child's understanding, from the beginning, it was limited to explaining if her brother could not walk, so he still had to practice and use a wheelchair. As she got older, Mother told Ad that she was exposed to the Rubella virus when she was pregnant, a virus that entered through the placenta, causing her sister to get Rubella too.

Parents have introduced sexual and reproductive education to their children so that children already know the process of pregnancy. Mother explained to Ad that Mother was sick with Rubella during the first trimester, during the formation of vital organs, so my sister had Congenital Rubella Syndrome. Parents also explain about the brain, so that Ad understands his brother's condition.

The parents' explanation regarding the older brother's condition also made the younger brother accept the situation. Ad never shows jealousy when parents take care of and give more understanding to Ab, so there is no sibling rivalry between Ab and Ad. Parents have a special time to play with each of their children, so there is a good bond between all family members. When asked if Ad loves Ab? Ad replied, dear. Ad does not show any jealousy towards his special Brother. Ad also says love to Ab. However, when her sister tantrums quite intensely (banging her head, screaming) Ad feels uncomfortable because he is disturbed. Ad's reaction was to sigh and ask "Brother why?" and said "Already tha, Sis." Not yelling or hurting Ab.

In addition to husbands, friends, parents, and other family members also provide support both morally and materially. The family also helps with Ab's medical expenses so that parents do not feel like struggling alone. The mother explained that the costs needed for Ab tests and treatment were not small. The financial support provided by the family eased the family's needs.

Mother's way to get resilience is by telling stories with family and friends. The mother also studied mental health, parenting, attended seminars, and continued her studies. Parents have me time and quality time. Mother does quality time with Father, Father with Child, and Son with Mother. During the quality time, the activities carried out are telling stories, playing, reading books, and others.

## Discussions

Rubella is a virus of genus Rubivirus family Togaviridae. This type of RNA virus with the cause of German Measles / Rubella can result in congenital infection. Man is the host of the Rubella virus, and it spreads through oral droplets, whereas in the fetus can be through Transplacental. As many as 90% of infants infected with Rubella mother during pregnancy were born with Congenital Rubella Syndrome. Children with Congenital Rubella Syndrome can be impaired in the eyes, ears, lung, central nervous system, etc. On the eye organ is glaucoma, blurring the cornea, cataracts, and retinopathy. In the ear can cause deafness. Disorders of the heart such as PDA, VSD, and Pulmonary Stenosis. While on the central nervous system can lead to calcification of the brain, mental retardation, encephalitis, and microcephaly. Moreover, it can cause bone changes, purpura, thrombocytopenia, and anemia (Soegijanto, 2016).

Treatment in CRS is supportive and non-specific, so it is given according to the affected organ. Babies with hearing loss can be given speech therapy, use of hearing aids, cochlear implantation, or send children to school for children with special needs (Fitriany & Husna, 2018).

Diana Baumrind suggests 4 types of parenting, namely authoritarian, democratic/authoritative, ignoring/neglecting, and obedient/permissive (Santrock, 2007). First, the authoritarian pattern. Children are required to follow parental orders, if they do not comply, the child will be punished, but if the child can achieve something, he will not get appreciation. This parenting pattern makes children not give children the opportunity to decide something (Ayun, 2017).

Second, democratic parenting or also known as authoritative. Contrary to authoritarian parenting, in a democratic parenting style, children have the freedom to express their opinions and do whatever they want but still have to comply with shared boundaries and rules. The role of parents is to be a guide who provides direction and input. The open attitude of parents makes children learn to be independent and creative individuals (Adprijadi & Sudarto, 2020).

Third, parenting ignores / neglect. Control and supervision from parents are low, child development is not of interest to parents, not much interaction with children, and lack of warmth in the family (Ayu et al., 2017). Fourth, permissive parenting. In this parenting pattern, parents are involved in the upbringing of children, but the children are free to behave and make decisions. If there is a difference of opinion, the parents succumb to the child. Although parents give freedom, they do not neglect their children (Nuryatmawati & Fauziah, 2020).



Resilience is a dynamic development involving various factors, such as individual, social and environmental factors, that show resilience to rise from difficult situations and emotional or significant obstacles (Wiwin Hendriani, 2017).

There are 4 resilience factors. **First**, Personal, includes optimism, self-esteem, positive interpretation, self-efficacy, openness, and abilities. **Second**, genetic factors. **Third**, the systemic environment, both at the micro and macro levels. Macro-level environment such as support from family and friends. While at the macro level are culture, spirituality and religion, society, community, and others. **Fourth**, a combination of personal, genetic, and environmental factors. The combination of these factors creates resilience in a person (Herrman et al., 2011).

Religious coping is problem-solving done by using worship practices that connect oneself with God so that a person can adapt to difficult situations. Positive seeking support is the source of strength and support from those closest (Rahmanawati & Wibowo, 2017). Support from other family members, especially the father's family, provides a role for families with children with special needs. In addition, the community of parents with children with special needs also contributes, not only from the aspect of information but also provides support, hope, and optimism (Lee & Park, 2016).

There were times when Ab's parents often fought because of the current conditions, felt shaken and sensitive, but parents realized that it was time to wake up. Parental resilience is done by seeking information related to Congenital Rubella Syndrome, sharing with trusted people, and continuing to pray for their children's good. This shows religious coping and positive seeking support. Although initially, the parents felt sad because the child's development was not like his friends in therapy, now parents are grateful for every achievement that the child can achieve.

## CONCLUSIONS

Parenting applied by the family is democratic. Parents give children the freedom to do something but still have to comply with the limits that have been set. The climate in the family is warm. Parents educate and explain to Ad regarding Ab's condition. So that Ad can understand and love his brother.

Families can accept special Ab conditions. Parents realize that every child has different developments so that all achievements achieved by Ab are appreciated. Parents also provide stimulation and therapy so that Ab can develop for the better.

Family and friends play a critical role for parents to be resilient. Support is given in the form of moral and material. Thanks to this support, Ab's parents do not feel like they are struggling alone. In addition, Ab's

parents also have a way to get resilience, namely by learning about mental health and deepening knowledge about CRS. Families also have quality and me time. So that the closeness between family members is well established, and everyone has time for themselves.

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