

ORIGINAL RESEARCH

# Parents' Experiences of Caring for Children with Congenital Rubella Syndrome (CRS) in Remote and Rural Areas of Indonesia



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## Abstract

**Background:** Parents of children with Congenital Rubella Syndrome (CRS) in rural areas face limited access to medical care and specialised services, financial difficulties, social isolation, and stigma. Research on their experiences is limited.

**Purpose:** This study explores parents' experiences of caring for their children with CRS in rural areas of Indonesia.

**Methods:** The research used a descriptive phenomenological approach, purposive sampling to collect parents of children with CRS from the shelter, and snowball sampling for other participants. Inclusion criteria included parents who cared for CRS children over than two years old, could express their experiences, and spoke Indonesian. Twenty-five parents participated in an in-depth semi-structured interview. The data were analysed using the Colaizzi method.

**Results:** This research found that parents caring for sick children in rural areas experienced life-altering situations that affected their mental health. In addition, caring for sick children also caused emotional disturbances and tension in family life. Other challenges included getting proper treatment for their child, especially in remote rural areas, and difficulty to reach health services. Therefore, proper mental health treatment and support were essential for parents who cared for sick children in rural areas.

**Conclusion:** This study describes complexities of parents' experiences of caring for children with CRS, such as difficulty to accept the child's condition and feeling burdened by their child's case. Further studies are needed to understand cultural influences and expand the study area.

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## 1. Introduction

Congenital rubella syndrome (CRS) is an infant disease caused by infection with the rubella virus in the mother during pregnancy (Lanzieri et al., 2020). Globally, based on the World Health Organization's report in 2020, the number of CRS cases was 603; in Southeast Asia, it was 248. In Indonesia, it was 110 cases, which made Indonesia the country with the most significant number of CRS cases in Southeast Asia (World Health Organization, 2021). The existing CRS case data shows that this problem can significantly pressure children and families regarding symptom management, emotional burden, and treatment costs.

Early recognition of CRS cases is significant for patients. However, identifying cases of CRS is difficult because clinical symptoms such as sensory disturbances, endocrinopathy, and thyroid often appear later (Wondimeneh et al., 2018). In addition, the characteristics of CRS, such as cataracts, congenital heart disease, hearing loss, and developmental delays, can lead to worsening chronic disease (Nahar et al., 2020).

Parents' burden while caring for a child with a CRS hurts their emotional, social, financial, physical, and spiritual functioning. A study in the Philippines explains that the average health cost for children with CRS in the 16-14 months age is US\$ 7.45; most of the costs come from treating heart complications, with the highest average being US\$ 2.12 to US\$ 15.5 (Tan & Leon, 2023). Reports from Ethiopia show that parents who care for children with congenital abnormalities due to CRS experience high emotional stress (Taye, 2021). Studies in America show that parents who care for children with CRS who experience high caregiver stress have a poorer overall quality of life (Armstrong, 2015). Studies of parents' experiences of caring for CRS children show that they

experience emotional stress, need family support, lack knowledge, and try various ways to help their children (Leon et al., 2018).

The problems faced by parents when caring for children with CRS in the Indonesian context are increasingly complex, considering that currently, Indonesia still has remote areas (left behind =left behind, leading/farthest=remote, and outermost=frontier/outermost) consisting of 9 provinces (out of 34 regions) defined by government regulations (Ministry of National Development Planning of Indonesia, 2020). These underdeveloped areas need more resources for health workers; only a portion of the population has received national health insurance services (Wenang et al., 2021). Therefore, it is difficult for parents to bring their children to health facilities and get proper treatment. In addition, due to limited facilities, this study shows the disparity of health facilities in Indonesia, where adults living in urban areas tend to use hospital outpatient facilities 1,246 times higher than adults living in remote areas. Furthermore, the possibility of simultaneously using outpatient and inpatient facilities for adults living in urban areas is 1.134 times higher than in rural areas (Wulandari et al., 2022).

CRS has various clinical patterns and treatment modalities, and early recognition of cases of CRS is significant for patients. In rural areas, the problem of CRS is complex because of the need for more detection tools, human resources to provide long-term care, and surveillance funds so that early detection of cases is not optimal (Brown et al., 2020). Parents' various complex problems in raising children with CRS require a comprehensive study to provide appropriate psychological assistance so parents can take good care of their children. Little information is available from previous studies about the experiences of parents caring for children with CRS, especially in remote areas that require access to health resources. Therefore, this study explores parents' experiences of caring for their children with CRS in underdeveloped regions of Indonesia.

## **2. Methods**

### *2.1 Research design*

This study used a descriptive phenomenological method that systematically describes the structure of a phenomenon reflected in the participants' life experiences by using language that reflects the transformation of the participants' natural expressions (Bartholomew et al., 2021).

### *2.2 Setting and participants*

The study was conducted in January-June 2022. Determination of participants in this study was done using the purposive sampling technique. The researcher collected parents with CRS children from the shelter where the patients lived during their child's referral care in Jakarta. In addition, the researchers used a snowball sampling technique to recruit one participant to another based on the inclusion and exclusion criteria of the study to track participants through associations of parents with children suffering from CRS.

The participants of this study were parents with CRS children from the provinces of East Java, South Kalimantan, East Kalimantan, East Nusa Tenggara, Papua, Southeast Sulawesi, and West Sumatra. Participants included in this study were parents who (1) cared for a child with CRS for more than two years, (2) could reveal their life experiences, and (3) could speak Indonesian. This study used a sample of 25 participants aged 30-40 years who were recruited in different numbers from seven regions according to the availability of participants and the fulfillment of inclusion criteria to increase the variety of participants' demographic backgrounds, broaden research subjects from the various areas, and allow the birth of diverse experiences.

### *2.3 Measurement and data collection*

The interview process in this study was conducted face-to-face and via video conference through the Zoom application conducted by three researchers. The researcher visited the participants for face-to-face interviews and contacted the interviewees via the Zoom application before the interview to ensure that the participants met the inclusion criteria. The researcher also conducted a preliminary assessment, explained the research, and provided an interview time contract. Interviews were conducted with 25 participants. Data saturation was reached in the 23rd participant when the participants' answers during the interview remained consistent.

The researcher used questions from the interview guide to help focus on the interview. The method used in this research was in-depth interviews with semi-structured interview techniques where the questions were not asked in a specific order but were asked based on the conversation

that appeared, and each statement was explored in detail to get the meaning according to the research objectives. Two researchers conducted the interview process for 45-60 minutes separately for each participant. The participants submitted a recording permit to record voices during face-to-face interviews in Jakarta in February 2022. Video recording was recorded during interviews via the Zoom application in March-May 2022. The researcher used open-ended questions and tried to understand the phenomenon from the participants' perspectives without giving opinions, criticisms, and evaluations during the interview. Some of the questions in the interview included (a) How do you feel about trying to care for a child with CRS?, (b) What obstacles are experienced when caring for a child with CRS?, (c) What treatment efforts have been made so far?, (d) What support is received from the closest people, the government, and the surrounding community?, (e) What are the expectations regarding the childcare process in the future?.

#### *2.4 Data analysis*

The pre-recorded data was transcribed verbatim. Next, the researcher listened to the recordings to improve the accuracy and reliability of the data. Data were analysed using the Colaizzi method (Sanders, 2014). In the first stage of the analysis, seven researchers (PKST, HMAD, EF, YMKL, MYB, MYG, AMG) reread the transcribed data, focusing on the context of the data and participants' responses and selecting significant statements. Then, similar words were grouped into the same category, followed by theme extraction by similar grouping categories based on factual statements. Five researchers collected and analysed data simultaneously (PKST, HMAD, EF, YMKL, MYB). In this study, the interviews were conducted until saturation was reached so no new content emerged in the discussions, and the same concepts and themes appeared in the data analysis.

#### *2.5 Trustworthiness*

The data validity in this study is maintained based on Cypress's (2017) following steps; (1) Dependability, seven researchers conducted the research by discussing the appropriate method related to the study approach, data analysis, and data interpretation. Three researchers with previous qualitative study experience focused on developing appropriate methods. Three researchers extracted significant ideas from participants about their specific experiences when interpreting the data. In contrast, four researchers were explicitly tasked with reviewing the transcribed material to validate themes and appropriate descriptions. If the identified theme is different, it is agreed not to use it. (2) Credibility was fulfilled using prolonged involvement of researchers and persistent observations to study the context of existing phenomena and minimise distortions that might infiltrate the data. To achieve this, the two researchers spent six months with the participants to build trust and rapport with them, participants, throughout the data collection process. The same questions were asked in different forms to allow for repeated identification during interviews and analysis. Peer debriefing was conducted through meetings and discussions among the seven researchers to find deficiencies in research activities. In addition, a source triangulation process was carried out from previous studies to ensure the correctness of the data. (3) Confirmability is carried out by member checking with participants to ensure the data is complete, representative, and written without the researcher's bias. In addition, authors with different academic and clinical backgrounds and interests read and discussed each other's interpretation of the data each week, which helps identify implicit concepts. (4) Transferability to measure whether or to what extent study results can be applied in other contexts, circumstances, and settings. It was done by expanding study locations, increasing the diversity of participant demographic status, and using a purposive sampling technique. Moreover, the recorded data was carefully transcribed by five researchers. During the analysis phase, all aspects of the analysis were documented. Analysis refers to the categorisation and organisation of information in such a way as to understand the data and to write a true and accurate final report.

#### *2.6 Ethical consideration*

Ethical clearance and research permission were obtained from Universitas Citra Bangsa with a reference number of 5/UCB.FIK/01.01/2022. Each recruited participant had received an explanation of the purpose and benefits of the research and signed a research consent letter.

### 3. Results

#### 3.1 Demographic data of participants

Table 1 shows that the majority of participants were aged 20-30 (76%), females (64%), senior high school graduates (52%), homemakers (64%), and Muslim (68%). Participants mostly came from East Java, with a presentation of 32%. The majority of illness duration is 2-10 years (64%), and the diagnosis of most children's diseases is congenital heart defects (52%).

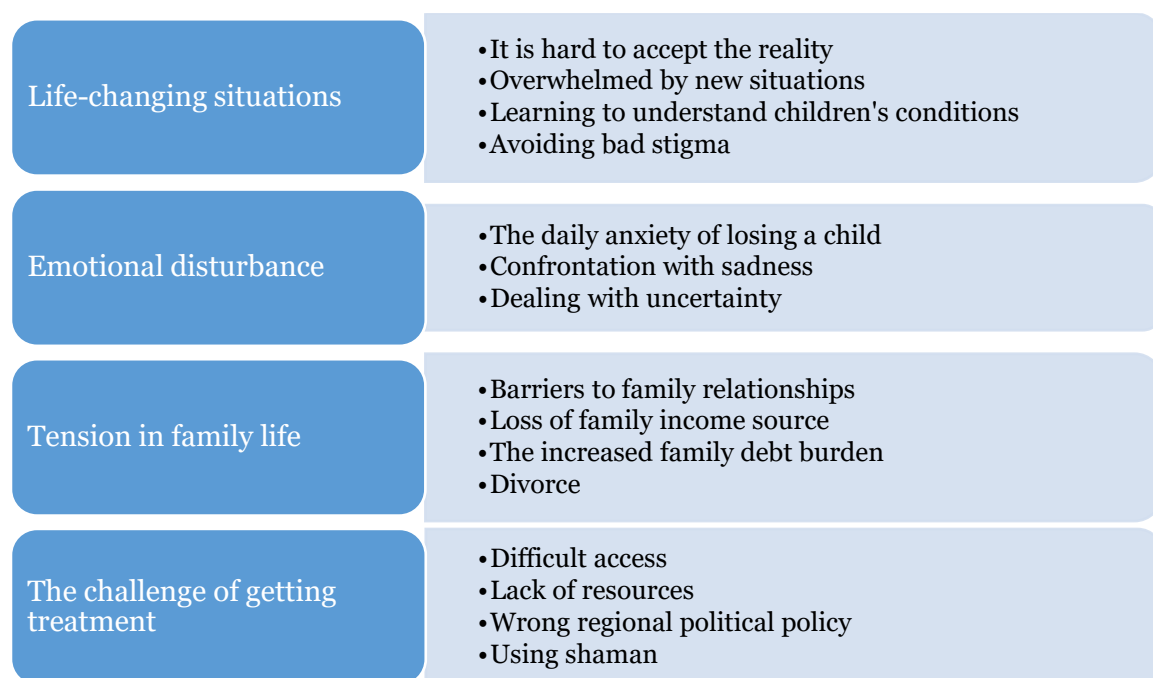
**Table 1.** Characteristics of participants

Characteristics	n (%)
Age (Year)	
20-30	19 (76)
30-40	6 (24)
Gender	
Female	16 (64)
Male	9 (36)
Education	
Elementary school	5 (20)
Junior High School	5 (20)
High School	12 (48)
College	3 (12)
Profession	
Homemakers	16 (64)
Farmer	2 (8)
Civil Servant	2 (8)
Driver	2 (8)
Domestic Workers	3 (12)
Religion	
Islam	17 (68)
Protestant	5 (20)
Catholic	3 (12)
Origin of Participants	
East Java	8 (32)
South Kalimantan	2 (8)
East Kalimantan	2 (8)
East Nusa Tenggara	3 (12)
Papua	1 (4)
Southeast Sulawesi	4 (16)
West Sumatera	5 (20)
Child's Disease Duration (years)	
2-10	16 (64)
11-20	9 (36)
Diagnosing children's diseases	
Congenital Heart Abnormalities	13 (52)
Eye Anomaly	4 (16)
Sensorineural Hearing Loss	4 (16)
Bone Defects	4 (16)

This study produced four themes which can be seen in Figure 1.

#### 3.2 Theme 1: Life-changing situations

Parents finally accept their child's congenital disabilities caused by CRS. This situation changed their lives due to their difficulty caring for them and the social stigma. There are four sub-themes in this theme: it is hard to accept the reality, overwhelmed by new situations, learning to understand children's conditions, avoiding bad stigma.



**Figure 1.** Summary of themes and subthemes

### 3.2.1 It is hard to accept reality

Parents have high hopes for their child before birth but have difficulty accepting it at birth with CRS. Participants expressed the following statements: *I rejected my child's condition and considered it normal, like other children, for six months (P4); My husband and I thought our son was normal for some time (P7).*

### 3.2.2 Overwhelmed by new situations

The birth of a child with CRS is new for some parents who feel overwhelmed by their child's complex problems. Participants expressed the following statements: *The first child is normal, and I feel overwhelmed caring for the second child with CRS (P13); My son's diagnosis is very complex so I am confused about how to treat it (P16).*

### 3.2.3 Learning to understand children's conditions

Parents often do not understand their child's condition when they are under pressure due to change but learn quickly to help overcome their child's problems. Two participants stated: *Learning about childhood illnesses and how to deal with them is important and must be done quickly (P21); Children get sick easily, I learned to measure body temperature and give warm compresses when they have a fever (P15).*

### 3.2.4 Avoiding bad stigma

Conditions experienced by children, such as mental disorders, make children get a bad stigma from the community; parents' efforts to protect their children limit themselves from social activities for fear of getting wrong statements from the community. Participant expressed the following statements: *I avoid activities where there are many people; I am not active in neighbourhood meetings because of society's statements that call my child a stupid monkey (P7); I have never featured my child on social media or brought him to church for worship; I have heard someone say my child has no future (P11).*

## 3.3 Theme 2: Emotional disturbance

Various emotional problems are expressed by parents when dealing with child's condition. It makes parents stuck with a variety of emotional issues. This theme has three subthemes: daily anxiety of losing a child, confrontation with sadness, and dealing with uncertainty.

### 3.3.1 The daily anxiety of losing a child

When a child is seriously ill, parents worry about the possibility of the child dying. Life-threatening illness raises the harsh reality parents face about possibly losing a child. Two participants stated: *When my child suffers from a severe decline in physical condition, I realise that, at any time, due to the development of the disease, or a crisis, it may result in me losing my child* (P1); *We are part of a parent group with a child with CRS, when a fellow parent reported that their child had died, I was worried that this would happen to my child* (P17).

### 3.3.2 Confrontation with sadness

Despite the imminent threat of losing a child, parents must always deal with the loss and sadness associated with their child's physical weakness. They must constantly adapt their own lives to fulfill their nurturing role. Participants expressed the following statements: *It can be tough when your child is sick and can't attend school, eat alone, or communicate. It can be difficult even if you try to escape the situation* (P20); *Due to breathing difficulties and hospitalisation, he could not celebrate his birthday with his friends. Sometimes I feel sad, but I hope he can heal from the burden he's been under* (P23).

### 3.3.3 Dealing with uncertainty

Parents often face the unpredictable course of their child's illness and even the inevitable death. Unclear information about a child's development or physical changes can also lead to feelings of uncertainty and lack of control in parents. Two participants stated: *When dealing with children's conditions, everything that happens to us is uncertain. Sometimes he is healthy, but sometimes sick; everything happens so fast* (P8); *With my son's condition, sometimes I feel optimistic about his physical development, but I also sometimes doubt whether he can live well in the future like my other children* (P23).

## 3.4 Tension in family life

Caring for a child with CRS affects parents' time, relationships, work, and finances, leading to disruptions in family life and even divorce. This theme consists of four sub-themes: barriers to family relationships, loss of family income source, the increased family debt burden, divorce.

### 3.4.1 Barriers to family relationships

Parents devote much time caring for CRS children, giving them almost no time to interact with their families. When their attention is reduced to family, they are disliked and considered to have no respect for the extended family. Participants expressed the following statements: *My husband's family considers me a bad wife because, in every activity, my family is less actively involved; my time is spent taking care of children* (P19); *When my in-laws died, my husband and I cared for the children in the hospital and did not attend the funeral. My extended family forced my husband to divorce me because he was not filial to his parents* (P6).

### 3.4.2 Loss of family income source

Time spent caring for children makes parents have to leave or neglect their jobs, making them lose much income and get fired from work. Participants stated: *I cannot travel; my trip can only be one day. All my activities are scheduled around the house. If I go out, I must return as soon as possible. I lost much income* (P8); *I used to work in a company, but because I often got permission to care for my children, I was finally fired; now I stay at home; our family income is decreasing, and we only depend on my husband* (P13).

### 3.4.3 Increased family debt burden

One of the biggest challenges in caring for children with CRS who have complex diseases is the high cost of treatment, especially for the medical procedures that the National Health Insurance does not cover. Participants expressed the following: *My wife and I now have a fairly large loan at the bank due to heart surgery and cochlear implants; the costs are very high and are not covered by health insurance* (P19); *I was forced to sell our farmland to pay my child's medical bills and our living expenses during treatment in Jakarta* (P5).

#### 3.4.4 Divorce

CRS child-rearing pressures, such as lack of acceptance of the child's condition, relationship problems with family, loss of income, and increased debt burden, can cause high stress for families and lead to a quick divorce. Participants stated: *Since my child was born and diagnosed with a spinal disorder, my husband divorced me; he accused me of being a cursed woman for giving birth to a disabled child (P23); I just got divorced last month; my husband's family forced him to divorce me because he ignored them. After all, he was busy taking care of the children (P21).*

#### 3.5 Theme 4: The challenge of getting treatment

Children with CRS with complex health problems need adequate care; however, it is not easy in remote areas of Indonesia. Participants experience severe barriers to accessing services. Even if they reach them, the benefits are often not quality or effective. There are four sub-themes: difficult access, lack of resources, wrong regional political policy, using shaman.

##### 3.5.1 Difficult access

Parents of children with CRS face difficulties in accessing adequate health services. Factors influencing access include remote location, quality of healthcare facilities and providers, and physician practices. Some families must travel long distances to get the special care their children need. Participants stated: *We need help accessing the pediatrician because we must go to the district town, which takes 2-4 hours away, depending on weather conditions (P10); My son has a spinal cord disorder; on our island, there is no neurologist, so we took a boat to the provincial capital; the trip could take a full day (P5).*

##### 3.5.2 Lack of resources

Parents of CRS children must travel long distances to seek emergency medical care because local hospitals do not have the necessary resources. They also feel frustrated that medical staff do not understand the impact of chronic illness. Two participants expressed the following: *Our son was sent home from the hospital's emergency department despite his complex condition and officers focusing on only one symptom (P14); My child with a poor respiratory condition requires continuous evaluation, but no chest X-rays are available for a year because they are damaged and have not been repaired (P11).*

##### 3.5.3 Wrong regional political policy

The governance of health services depends on political policies, especially in remote areas, which affect financing and referral systems in health services. Poor parents with CRS children need local health insurance and appropriate referral channels when bringing their children to health care facilities. Participants stated: *Since the change of regent in our district, my health insurance card has yet to be recognised by the hospital; according to them, the new government no longer allocates a budget for it (P1); As a health insurance policy, we must follow the primary to secondary health services referral path. However, the government's secondary health services are far from where we live, so transportation costs are expensive (P7).*

##### 3.5.4 Using shaman

Scarcity of access to resources, lack of funds, and parents' distrust of health workers make parents use traditional birth attendants to care for their children. In addition, solid cultural factors make parents prefer shamanic practices to care for their children. A participant stated: *I do not have money to take care of my child, so I choose to use a traditional birth attendant to treat my child with traditional medicine, and so far, I am doing well (P1).* Furthermore, one participant expressed the following:

*In addition to using health services at the hospital, I took my child to a traditional healer for treatment; I was certain spirits and angry ancestral spirits had possessed my child. I need a shaman to eliminate spirits and make peace with ancestral spirits. (P23)*

#### 4. Discussion

This study explored parents' experiences of caring for children with CRS in underdeveloped areas in Indonesia. Four themes were revealed: (1) Life-changing situations, (2) Emotional disturbance, (3) Tension in family life, and (4) The challenge of getting treatment.

##### 4.1 *Life-changing situations*

Parenting a CRS child can change a parent's life. Some find accepting their child's condition complex because of the difference between expectations and reality. Parents need time to get their child's condition and focus on their health efforts because they are the primary source of joy, hope, meaning, and purpose in life (Yin et al., 2018). Caring for a child with CRS can be a new experience for parents. Studies show that parents view parenting with severe health problems as a new experience (Nayeri et al., 2021). This experience can have positive consequences if parents accept it well, but it will result in tremendous emotional pressure if parents refuse (Spinelli et al., 2020).

Parents try to learn simple actions to help their sick children. Parents who understand and learn about their child's illness will feel better and happier (Källquist & Salzman-Erikson, 2019). Parents reported social stigma in the neighbourhood. Support for overcoming stigma can be provided through positive adaptation, spirituality, and encouragement to love self (De los Santos, 2022).

##### 4.2 *Emotional disturbance*

Parents in this study felt emotional disturbances because they experienced anxiety about losing their child due to the child's declining physical condition. Previous studies have indicated that parents caring for sick or disabled children experience significant psychological and emotional impacts, such as post-traumatic stress and feelings of isolation (Wray et al., 2018). This feeling of anxiety needs to be considered because it will lead to the development of acute stress disorder (ASD) and post-traumatic disorder (PTSD) in parents and interfere with their efforts to care for their children (Nayeri et al., 2021).

Parents of children with complex health conditions may find themselves facing constant grief. However, they are still trying to fight for their son's recovery. This is in line with previous studies, which show that parents tend to give up on their child's illness but still try to make their child recover (Hubert & Aujoulat, 2018).

This study concluded that parents' uncertainty regarding the disease's condition and the child's future often arises. A previous study also showed that parents of children with chronic epilepsy feel diagnostic, asymptomatic, and future uncertainty for their child (Webster, 2019). Therefore, it is necessary to carry out discussions and improvements to overcome the fate of parents and children with such complex conditions. Counselling is used to reinforce hope. The higher the expectations of parents with chronic illnesses, the more confident and passionate they will be in caring for their children (Bell et al., 2019).

##### 4.3 *Tension in family life*

Pediatric chronic diseases have physical, psychological, social, economic, and behavioural effects on patients and their families that cause a decrease in function and quality of life (Toledano-Toledano & Domínguez-Guedea, 2019). Parents in this study reported that caring for a child with a chronic illness interfered with extended family relationships. Similarly, previous research has shown that caring for children with chronic diseases can damage personal relationships, reduce psychosocial functioning, and cause sleep disturbances (Lian et al., 2022). Loss of income sources is a common problem in caring for children with CRS because it takes up many parents' time (Hatzmann et al., 2014). Parents whose marriages are intact and have high socioeconomic status tend not to feel the adverse effects of loss of income, while single parents are more vulnerable (Brewer, 2018). In addition, the more complex the disease the child suffers from, the more significant the decrease in parental income is because time is devoted to their child (Roddy, 2022). Financial support is urgently needed for low-income families with CRS children, especially in Indonesia, with well-directed and well-controlled financial assistance. Health subsidy programs such as the Healthy Indonesia Card (KIS) can help with childcare. In contrast, social services such as the Family Hope Program (PKH), the Prosperous Rice Program (RASTRA), and village funds can help build community health centres and overcome shortages of medical personnel and equipment (Booth et al., 2019). Declining income and high maintenance costs have



left parents in debt, forcing them to sell their assets. Another study shows that caring for a child diagnosed with a chronic illness can hurt the socioeconomic situation of parents (Roser et al., 2019). Further efforts are needed to systematically implement an assessment of parents' financial difficulties with CRS children as part of care services.

Parental tension with CRS children often leads to divorce. Separated parents have broad implications for increased depression, decreased economic status, and reduced family quality of life (Tosi & Albertini, 2019). In the Indonesian context, divorce has a worse impact, especially for women, where there is a harmful cultural construction for divorced women. They get a terrible stigma from society (Saraswati, 2019). Single mothers who take care of children with CRS will certainly become a serious problem when they have to be burdened by their children's condition and the bad stigma of divorce from society. Special assistance is needed for single mothers with children with CRS to suppress the adverse effects of severe psychological disorders.

#### *4.4 The challenge of getting treatment*

CRS childcare efforts in remote areas always need help accessing treatment, such as long distances that make it difficult for parents to take their children to health facilities. Financial constraints and expensive public transport also exacerbate this situation (Coombes et al., 2018). Barriers to access to health facilities in underdeveloped areas of Indonesia were also reported by another study, where the failure of TB treatment in Papua was related to the distance or cost of travel to health facilities (Ruru et al., 2018). Loss of treatment for mental disorders in East Java is also associated with the problem of accessibility to health facilities (Tristiana et al., 2018).

In addition to difficult access to services, parents also have difficulty caring for children with CRS due to a lack of health resources. Previous studies have shown that the low capacity of health workers, such as paediatricians, is an obstacle in treating children with chronic illnesses (Altman et al., 2018). In the Indonesian context, it has been reported that limited support from the health system, such as poor staff management and coordination and lack of medical equipment and supplies, are significant barriers to health care (Robbers et al., 2021). Also, security instability resulting from political and armed conflicts, such as in Papua, further impacts service delivery (Rizkianti et al., 2021).

Healthcare efforts are closely related to political policies, especially in health insurance decisions to support Universal Health Coverage (UHC) (Rizvi et al., 2020). The problem in this study is the certainty of health insurance and unclear referral mechanisms for parents. By previous reports, local governments still need help managing the health budget, including unevenly distributed health services and financing that could be more optimal, especially in regional health insurance for low-income and poor people (Kharisma, 2020). Serious efforts are needed from the government to manage the health insurance system to access health services for children with CRS can be more accessible.

When access to an adequate financing system is difficult, parents tend to turn to shamanic practices to care for their children, supported by strong cultural influences. Studies show that dissatisfaction with health services due to high costs, incompetent staff, and difficult access are factors causing Indonesians to choose shamanism as an alternative treatment (An et al., 2020). A people's culture supports shamanism in Indonesia, passed down through oral traditions and shared models of behaviour, which have historically been important for creating a collective faith-based social peace of mind. This is believed to strengthen the effect of non-medical efforts on the quality of human physical endurance (Sukmawan & Sahiruddin, 2021). Setting aside the results of the benefits received by children conveyed by parents and respect for local wisdom is necessary for this treatment to be seen as a complementary method that cannot replace services in health facilities.

## **5. Implications and limitations**

This study provides some implications. Since Rubella in children has complex implications for parents, including high psychological distress, nurses should consider psychological interventions to reduce the risk of depression in parents. The care team can coordinate to provide long-term care. The government must increase health insurance and social assistance financing to overcome parents' economic problems.

We recognise that this report has limitations regarding the number of participants and the geographical area of the study. In addition, the short research time, mostly through online

interviews without observation, could affect the depth of reports regarding the psychological conditions experienced, which might affect the physical condition of parents.

## 6. Conclusion

The results of this study show the complexity of parents' experiences in raising children with CRS. They face difficulties accepting their child's condition and feel overwhelmed by their child's case. In addition, social stigma, emotional distress, and problems accessing health services exacerbate the family's situation. Constraints such as lack of equipment and human resources and changes in political policies also affect access to health services. Further studies are needed to understand the influence of culture in each area and expand the study scope.

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## Author contribution

PKST, HMAD, EF, YMKL, MYB, MYG, AMG: study design.

PKST, HMAD: data collection.

PKST, HMAD, EF, YMKL, MYB, MYG: data analysis.

PKST, HMAD, EF, YMKL, AMG: drafting and revision of the manuscript.

## Conflict of interest

Contributing authors declare no conflicts of interest.

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