

Family Awareness of Congenital Rubella Syndrome in Palembang, Indonesia

1st Amrina Rosyada
Public Health Faculty
Universitas Sriwijaya
Indralaya, Indonesia
amrinarosyada@unsri.ac.id

2nd Dini Arista Putri
Public Health Faculty
Universitas Sriwijaya
Indralaya, Indonesia
dini.aristaputri@unsri.ac.id

3rd Rini Mutahar
Public Health Faculty
Universitas Sriwijaya
Indralaya, Indonesia
rini_mutahar@yahoo.co.id

Abstract—Rubella infection is a dangerous infectious disease that mostly affects pregnant women. This infection causes children born with some disabilities called congenital rubella syndrome which is visual impairment, deafness, calcification of the brain, and heart trouble. Treatment for this syndrome is quite expensive. This study therefore aims to identify the level of awareness in the community about this disease. This research furthermore is a cross-sectional study with a sample of 100 families in Palembang and the selection is made using a random sampling method. The selected clusters were Srijaya, Demang Lebar Daun, Bukit Lama, Talang Kelapa, Siring Agung, Sukabangun, and Kebun Bunga. The result was analyzed using descriptive analysis and around 41% of mothers don't know this condition. They indicate that average mother in Palembang knows about rubella only in children and does not understand the fatal impact of rubella when exposed to pregnant women. Around 77% of families are aware of the condition. Health interventions and promotion awareness about rubella in pregnant women should be done as this will help in habilitation difficulties and cost, decreased human resource quality, and low acceptance in society.

Keywords: rubella, disability, pregnant women, awareness

I. INTRODUCTION

Rubella virus infection is air-borne and is mostly transmitted through sneezing or coughing hence pregnant women are at a higher risk of contracting the disease[1]. More than 50% of cases are asymptomatic. In clinically apparent cases, after an incubation period of 13 to 20 days, the characteristic includes fever, malaise, adenopathy, and characterized by small pink papules. The unborn children are at high risk and will experience a set of disabilities called Congenital Rubella Syndrome. Limitations appear in the form of visual impairment, deafness, calcification of the brain, and heart disruption[2]–[4]. The risk of congenital infection and defects is highest during the first 12 weeks of gestation and decreases after the 12th week of gestation; defects are rare after infection in the 20th week (or later) of gestation[2], [3], [5].

Rubella virus transmitted through breathing that is through droplets released by a person infected with rubella, after being exposed to droplets, this virus will undergo

replication in nasopharynx and in the lymph node area. Viremia occurs between the 5th day until the 7th day after exposure to rubella virus. Rubella infection causes fetal damage due to the cleavage process is inhibited[6].

Treatment of this syndrome requires a very large cost because disability cannot be repaired, it can only be minimized[2], [3]. In addition, congenital rubella syndrome also requires a patient's lifetime of habilitation. This condition has potential to cause stress to parents, so the support system in the community and family must be good to prevent this[7], [8]. In 2015, there were 5 villages in the province of South Sumatra that experienced the extraordinary occurrence of rubella [9].

MR vaccination is given to protect children from rubella infection which if the child is transmitted to pregnant women will be very dangerous. The most effective prevention of rubella is by vaccination, especially for women who plan to become pregnant. About 90 percent of people who receive this vaccine will avoid rubella [10]. Palembang is one of the regencies or cities with the lowest MR immunization achievement compared to other regencies or cities in Indonesia[11]. The awareness of the condition in women is quite low, and there are low socialization and knowledge of the importance of MR (Measles-Rubella) immunization. Therefore, this study aims to measure the level of awareness of CRS in the community.

II. METHOD

This research was focused on Palembang. The mix-method quantitative technique was used to carry out the research that involved 100 respondents in the city. For qualitative design in-depth interviews were used with 5 informant. Subject for this study are mother or prospective mother. The study was conducted for four months between July 2019 to October 2019. Quantitative results were presented in descriptive form while qualitative results were analyzed using content analysis.

The variables measured in this study are demographic variables such as age, education, and mother's occupation, knowledge variables and awareness of CRS. Low awareness category if the mother is known to have low knowledge, plans to get pregnant again but has never been vaccinated with rubella before.

Data collected use multistage random sampling method, in the first stage the cluster is selected and the second stage selects respondents. Cluster in this study is district that Palembang consist of 17 districts. Application used to select sub-districts is

c-survey with selected clusters namely Alang-alang Lebar, Ilir Barat 1, and Sukarami. Minimum sample in this study was 100 people calculated using the proportion estimation formula and the results have considered deff value.

This study use a questionnaire that has been tested for validity and reliability. The questionnaire consisted of 3 parts. The first part is questions about social demographic, the second part is about knowledge of rubella and CRS and the third part is about the awareness of CRS in mothers.

III. RESULTS

Palembang is the capital of South Sumatera province that has population of 1,602,171 residents. In 2018, MR immunization coverage for children aged 9 months to 15 years in the province of South Sumatera is 47% and has not reached the target. Palembang achieved only 30%. MR immunization is strongly related to rubella transmission which is very dangerous for the fetus in pregnant women.

The results of the distribution of 100 questionnaires on the demographic characteristics of the respondents in the community are as follows:

Table 1. Characteristics of Respondent Demographic

Variables	Total (n)	Percent
Address		
Alang-alang Lebar	35	35
Ilir Barat I	36	36
Sukarami	29	29
Mother's age		
12-16 years old	1	1
17-25 years old	14	14
26-35 years old	51	51
36-45 years old	28	28
46-55 years old	6	6
Mother's job		
Does not work	73	73
Entrepreneur	13	13
Government employees / Soldiers / Police	4	4
Private	6	6
Farmers / Laborers / odd jobs	4	4
Mother's education		
Not go to school	1	1
Elementary school	13	13
Middle School	21	21
High school	48	48
D1 / D2 / D3 / S1	17	17
Total	100	100.0

Source: Primary Data, 2019

Based on the table above, the majority of respondents were aged 26-35 years, accounting for 51%. 73 % were not working, and 48% were graduate from high school.

In this study, respondents' knowledge related to rubella and congenital rubella syndrome was measured. Based on the results of the analysis in table 2, it is known that 68% of mothers know about rubella, but as many as 40% of mothers answer the wrong impact of rubella on children. Although as many as 22% of mothers know about rubella symptoms, but

almost all mothers know the rubella prevention method through MR immunization (93%).

Table 2. Knowledge about Rubella

Question	Percent
Do you know about Rubella?	
Yes	68
No	32
Effect Rubella in children?	
Dead	1
Fever and Rash	14
Disability in Children	51
Do Not Know	28
What are the typical signs of rubella infection?	
Flu	3
Cough	3
Convulsion	14
Rash	22
Do Not Know	58
What ways of rubella transmission do you know?	
Sneezing	20
Eating	15
Virus	15
Sugar	0
Salt	0
Do Not Know	50
Can rubella infection be prevented?	
Yes	96
No	1
Do Not Know	3
What is the most effective way to prevent rubella infection?	
Take Medicine	7
Nutritious Food	10
MR Immunization	75
Hand Washing	2
Do Not Know	6
Do you know about MR immunization?	
Yes	93
No	7
Do you know the benefits of MR immunization in children?	
Yes	81
No	19
Have you ever seen a rubella public service advertisement on television?	
Yes	95
No	5
Have you researched about Rubella?	
Yes	14
No	86
Total	100.0

Source: Primary Data, 2019

On questions related to the characteristics of rubella there are 22% of mothers know that is a rash. 95% of mothers have seen rubella advertisements on television. This shows that television media can reach the attention of mothers. Messages

related to rubella immunization are well known, but messages related to congenital rubella syndrome have not been conveyed properly.

Other's knowledge of congenital rubella syndrome shows quite a large number compared to mother's knowledge of rubella which is only 12%. 87% of mothers do not know the cause of congenital rubella syndrome. As many as 56% of mothers know the impact of rubella infection in pregnant women in the form of disability in children or miscarriages but do not know the specifics of their disability. 46% of mothers know about rubella prevention through TORCH examination and 26% prevention through MR immunization. However, there are still many mothers who do not do related to financial and fears faced.

Table 3. Knowledge About Congenital Rubella Syndrome

Question	Percent
Do you know about Congenital Rubella Syndrome?	
Yes	12
No	88
What causes Congenital Rubella Syndrome?	
Virus	11
Disorders of spirit	2
Do not know	87
Effect Rubella in Pregnant Woman?	
Maternal Death	1
Fever and Rash	1
Disability in infants/miscarriages	56
Do Not Know	42
At what stage of pregnancy is rubella fatal to the pregnant mother?	
9 months	5
More than 6 months	21
Less than 3 months	26
Do Not Know	48
What are the effects of rubella in children whose mothers were infected with rubella while pregnant?	
Brain	17
Cataract	20
Heart	8
Cannot Walk	13
Deaf	10
Paralyzed	12
Down Syndrome	4
Do Not Know	48
How does one check if pregnancy is safe from rubella infection?	
Check TORCH	46
MR Immunization	26
Take Vitamin Regularly	6
Eat Nutritious	14
Do Not Know Not Good	8
Do you know about TORCH infection?	
Yes	14
No	86
Total	100.0

Source: Primary Data, 2019

Scores were taken based on the questionnaire so that the level of mother's knowledge of rubella in Palembang was obtained as follows.

Table 4. Respondent's Knowledge Level about Rubella

Variable	Frequency	Percentage
Low knowledge	41	41%
High knowledge	59	59%
Total	100	100%

Based on table 4 it is known that there are still 41% of mothers whose level of knowledge is still low. The topic that most mothers have not yet known is rubella relating to pregnant women. The average mother in the city of Palembang knows about rubella only in children and does not know the fatal impact of rubella when exposed to pregnant women.

Quantitative data was strengthened by 5 informants from qualitative research. The following are the statements of the informants:

"There is MR immunization from the school, but I didn't allow my child to be immunized with MR vaccine because a lot of news stated that after being immunized, there is a child who became paralyzed, and someone even died" (Informant 1).

"Healthy children after being immunized instead become sick" (Informant 2)

Some mothers are traumatized to immunize their children because their children are diagnosed with fake immunizations where the immunization vaccines received by children contain heavy metal

"When my child is called, the response is prolonged, he hears. I checked that his hearing was normal, but if he was told to do something, the answer was extended. That happened since immunization was given in one of the clinics. The pediatrician said, maybe my child was given a vaccine containing heavy metals. So I'm traumatized about vaccination. Moreover, this immunization is new, and its safety is unclear" (Informant 3).

The average mothers who bring their child to be immunized with MR vaccine are less aware of the benefits of this immunization. They only know that vaccination can prevent disease and do not see the connection to pregnant women.

"I was immunized with the MR vaccine yesterday. I don't know anything. Yesterday, I was told by the midwife to come again next month. So I just did the direction from the midwife" (Informant 4).

"Immunization is done so that my child doesn't become ill. But I don't know the benefits of the immunization carried out against pregnant women." (Informant 5).

Based on the knowledge, attitudes and behaviors of the mother, the level of awareness of the CRS in the family in Palembang city is calculated as follows. The level of awareness is calculated by looking at the level of mother's knowledge of rubella, whether the child has been immunized with MR vaccine';

Table 5. Respondent awareness Level for Congenital Rubella Syndrome

Awareness Level	Frequency	Percentage
High Awareness	77	77%
Low Awareness	23	23%
Total	100	100%

The Awareness against Rubella is quite good; 77 % of families have high acuity. However, it has been found that the diligence is related to Rubella that infects children but not at the stage of Awareness that affects pregnant women. Some of the emerging issues from the study include:

1. Pregnant mothers are not aware of Rubella's condition affecting their unborn children.
2. Most mothers do not immunize their children. This was attributed to the fear experienced by the public regarding fake vaccines, which are known to damage the child's brain and make children become down syndrome. Mothers who have children under the age of five prefer not to immunize their children due to the perception of fake vaccines.

IV. DISCUSSION

Interventions carried out by the government and the health department have to be directed at this aspect. From these two issues, it is known that awareness against rubella in pregnant women is still lacking and the safety guarantee of vaccines received by the public is still not well socialized[12].

The lack of awareness has an impact on the magnitude of Congenital Rubella Syndrome (CRS) cases in the future. CRS incurs high habilitation costs since it cannot be cured but can only be repaired. Rubella attacks vital organs and can be fatal if it strikes pregnant women. These organs include the eyes, ears, heart, and brain². The rubella infection in adults is manifested in the form of fever and a red rash. It has no severe effect on adults and might heal itself in a few days[2], [12].

Rubella is also something that cannot be underestimated because of the ease of transmission. Only by being exposed to the patient's sneeze or holding the places where the patient's sneeze is exposed, a person can get rubella when his immune system drops[2], [13]. Even though quantitative caution is quite high, (it does not cover aspects of pregnant women) this level of Awareness is still relatively low [12].

Since there is no specific treatment for CRS, hearing loss is overcome by using hearing aids, speech therapy, and cochlear implants. Visual impairment should be treated with surgery and aiding devices, congenital heart disease treated with surgery, mental retardation treated with physiotherapy, speech therapy, occupation. All treatment processes are quite expensive to a tune of 500 million. Besides, this treatment will not be effective if habilitation afterwards is not optimal[2], [6], [14].

Rubella conditions can be prevented through vaccination. An MMR vaccine (Mumps, Measles, Rubella) is used to protect against the Rubella virus[15], [16]. Mothers who have been infected, need to do a TORCH test or Ig M and Ig G

Rubella tests[5], [15], [17]. There's a need for a comprehensive effort among primary, secondary, and public services so that WHO's targets for rubella elimination in 2023 can be realized[18].

V. CONCLUSION

The awareness of Congenital Rubella Syndrome in Palembang is still low as mothers do not know the harmful effects of Rubella in pregnant women. The role of primary services needs to be encouraged to help reduce Congenital Rubella Syndrome cases.

Awareness and Prevention efforts need to be done and promoted. There is a great need for surveillance of CRS and the public needs to create a support system that deals with patient habilitation efforts, therefore patients can be independent and live well in the community.

VII. ACKNOWLEDGMENT

We are really grateful to the Research Institution and Community Service of Sriwijaya University for Funding This Research.

REFERENCES

- [1] European Centre for Disease Prevention and Control, "Disease factsheet about congenital rubella syndrome (CRS)," 2019. [Online]. Available: <https://www.ecdc.europa.eu/en/congenital-rubella-syndrome/facts>. [Accessed: 30-Oct-2019].
- [2] J. Banarvala and D. Brown, "Rubella," *Lancet*, vol. 363, pp. 1127–1137, 2014.
- [3] WHO, "Rubella and Congenital Rubella Syndrome (CRS)," *who.int*, 2019. [Online]. Available: https://www.who.int/immunization/monitoring_surveillance/burden/vpd/surveillance_type/passive/rubella/en/%0A. [Accessed: 05-Mar-2019].
- [4] D. Mekonnen, "Clinically Confirmed Congenital Rubella Syndrome: The Role of Echocardiography," *Ethiop. J. Health Sci.*, vol. 27, no. 2, pp. 197–202, Mar. 2017.
- [5] A. Morice, "Congenital Rubella Syndrom : Progress and Future Challenges.," *Expert Rev. Vaccines*, vol. 8, no. 3, pp. 323–331, 2009.
- [6] J. Fitriany and Y. Husna, "Sindrom Rubella Kongenital," *J. Averrous*, vol. 4, no. 1, 2018.
- [7] E. Bouthry, O. Picone, G. Hamdi, L. Grangeot-Keros, J. M. Ayoubi, and C. Vauloup-Fellous, "Rubella and pregnancy: Diagnosis, management and outcomes," *Prenat. Diagn.*, vol. 34, no. 13, pp. 1246–1253, 2014.
- [8] ECDC, "Measles and rubella monitoring Main developments," no. October, pp. 1–12, 2017.
- [9] Dinas Kesehatan Provinsi Sumsel, "Profil Kesehatan Provinsi Sumsel Tahun 2015," Palembang, Sumatera Selatan, 2015.
- [10] Jawapos.com, "Dokter: Pencegahan Virus Rubella Paling Efektif Adalah Lewat Vaksinasi," *Jawapos.com*, 2018. [Online]. Available:

- <https://www.jawapos.com/features/humaniora/14/09/2018/dokter-pencegahan-virus-rubella-paling-efektif-adalah-lewat-vaksinasi/>. [Accessed: 07-Nov-2019].
- [11] Pemkot Palembang, “Capaian Imunisasi Rubella di Palembang Paling Rendah - *rmolsumsel.com*,” *RMOLSumsel.com*, 2018. [Online]. Available: <http://www.rmolsumsel.com/read/2018/10/22/102293/Capaian-Imunisasi-Rubella-di-Palembang-Paling-Rendah->. [Accessed: 07-Nov-2019].
 - [12] Kementerian Kesehatan RI, “Menkes: Pikirkan Risiko dan Dampaknya Bila Anak Tidak Diimunisasi MR,” *www.depkes.go.id*, 2018. [Online]. Available: <http://www.depkes.go.id/article/view/18080200003/menkes-pikirkan-risiko-dan-dampaknya-bila-anak-tidak-diimunisasi-mr.html>. [Accessed: 05-Mar-2019].
 - [13] T. Lanzieri, S. Redd, E. Abernathy, and J. Icenogle, “Chapter 15: Congenital Rubella Syndrome,” 2020.
 - [14] Kadek and S. Darmadi, “GEJALA RUBELA BAWAAN (KONGENITAL) BERDASARKAN PEMERIKSAAN SEROLOGIS DAN RNA VIRUS (Congenital Rubella Syndrome Based on Serologic and RNA Virus Examination).,” *Unair J.*, 2018.
 - [15] M. Papania, “Elimination of Endemic Measles, Rubella, and Congenital Rubella Syndrom form the western hemisphere: The US Experience,” *JAMA Pediatr.*, 2014.
 - [16] A. RM and M. RM, “Vaccination Against Rubella and Measles: Quantitative Investigation of Different Policies,” *J. Hygene*, vol. 90, pp. 259–325, 1983.
 - [17] P. Dewan and P. Gupta, “Burden of Congenital Rubella Syndrom in India: Systematic Review,” vol. 49, pp. 377–399, 2012.
 - [18] World Health Organization, “World Health Organization, WHO South-East Asia Region sets 2023 target to eliminate measles, rubella,” *SEARO*, 2019.