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**Premature Indonesia Support Group in Health
Communication: Efforts to Prevent Retinopathy of
Prematurity in Indonesia**

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Abstract

This study aimed to discuss the role of the Premature Indonesia support group in health communication as an effort to prevent retinopathy of prematurity (ROP) in Indonesia. ROP is an eye developmental disorder due to premature birth, which results in a child's permanent blindness. The awareness about the risk of ROP is still very low so health communication efforts are currently necessary. This study was conducted using a qualitative research approach with in-depth interviews as the primary data. The secondary data were collected through literature study, observation, and researcher's experience. The results showed that Premature Indonesia's health communication efforts were carried out through several stages namely analyzing main problems, selecting credible and experienced educators, using social media as the main communication medium, and formulating and delivering explicit health information messages. Through these health communication efforts, the Premature Indonesia support group could increase health awareness and the risk of ROP in premature babies along with its prevention efforts.

Keywords: health communication, retinopathy of prematurity, prematurity, child blindness.

INTRODUCTION

This study discusses the role of the Premature Indonesia support group in health communication efforts to prevent retinopathy of prematurity (ROP) in Indonesia. ROP is typically an eye developmental disorder due to premature birth. It triggers retinal detachment that leads to permanent blindness. All infants born prematurely are at risk for ROP, however, the highest risk is those born less than 32 gestation weeks or birth weight of fewer than 1500 grams (Tah et al., 2014). Currently, Premature Indonesia is the only organization that actively raises public awareness regarding premature birth and ROP, which can be prevented by eye screening. Premature Indonesia is a support group established in 2015 by dr. Agung Zentyo Wibowo. This support group was created as a forum for communicating many premature babies'

health issues in terms of providing information, education, and support, as well as assistance to parents with premature babies. Among all, the education aspect is about edifying the health risks of premature babies and calls for undertaking a premature baby's complete organ screening, especially an eye screening to prevent permanent blindness due to ROP.

This group is existing in the midst of the scarcity of information regarding premature babies' health issues, especially the prevention of ROP. This issue has not been the main focus of increasing health awareness in Indonesia, so to the best of the researcher's knowledge, there have been few studies undergoing this topic. In fact, Indonesia becomes a country with a high potential to experience an ROP epidemic due to the high rate of premature births. From 2010 - 2014, Indonesia was ranked 5th in the world as the country with the most preterm births, up to 10.4% of cases (Blencowe et al., 2012; Chawanpaiboon et al., 2019).

ROP is a major cause of blindness in children especially in many developing countries, such as Indonesia, India, and Africa (Dewi et al., 2016; World Health Organization and the International Agency for the Prevention of Blindness Joint Initiative, 2012). This is mainly due to the lack of health workers and public knowledge about the risk of ROP in premature babies. Most of them brought home from the Neonatal Intensive Care Unit (NICU) without an eye screening. In addition, the lack of hospital facilities and knowledge of ROP management also exacerbates the condition. In fact, visual impairment and permanent blindness in premature babies might affect the quality of life (Rasmi, 2021). The high incidence of ROP is caused by the increasing number of premature babies who are able to survive, but the awareness of the ROP risk is very low (Siswanto et al., 2021). To increase the awareness of preventing premature birth and the risk of ROP, health communication efforts are required (Blencowe et al., 2012; Mariyana, 2018).

Health communication focuses on increasing the public's ability and awareness of health issues so that they can adopt healthy lifestyles (Notoatmodjo, 2010). Health communication includes the delivery of messages containing information and promotions about disease prevention, and health policy formulation, as well as increasing individual awareness of health problems, risks, and solutions through strategic communication. This also means covering socialization, education, mentoring, advocacy, the use of mass media, and the internet as a health communication strategy. Public health problems do not only stem from individual negligence, but also from ignorance and misinformation about many related diseases.

Health communication has an influence on the success of public health (Rahmadiana, 2012). In this case, the role of the support group is very important. Support groups are a trusted source for people seeking health information. They allow two-way interaction and are considered able to provide relevant health information and mental support. Two-way communication in a support group allows for interpersonal communication. It is a direct communication between the communicator and the communicant. This way of communication is considered the most effective way to change attitudes, opinions, and human behavior. Interpersonal communication is dialogic with direct feedback between participants (Rosmalina, 2018). Interpersonal communication does not only occur direct interaction between 2 people but also occurs within a small group or a large group, such as in a support group (Panitra & Tamburian, H.H., 2019).

Therefore, the role of support groups is very important in the success of health communication. However, along with the internet's development, health support groups also have sprung up online through various kinds of social media (Parsons, 2019).

In this regard, the researcher discusses health communication efforts, especially on the ROP prevention carried out by Premature Indonesia, as the only active support group that focuses on this field in social media. ROP is a disease that is rarely known. Research and activities related to this topic are also rarely carried out, especially in Indonesia. Thus, research on efforts to prevent ROP in Indonesia is important to do. This become an interesting research topic.

METHODOLOGY

This study used a qualitative research approach. The data were collected by using in-depth interviews with three informants:

Table 1: List of Informants

Informants	Role
dr. Agung Zentyo Wibowo, B.Sc. Med (dr. Agung)	Founder of Premature Indonesia
Primaningrum (Mima)	Educator of Premature Indonesia
dr. Rozalina Loebis, Sp.M (K) (dr. Roza)	Pediatric ophthalmologist who treated premature babies with ROP risk

Each interview was conducted online on August 5, 2021 (for Mima), September 1, 2021 (for dr. Agung), and September 14, 2021 (for dr. Roza). Each interview for each informant was conducted for 90-120 minutes. The results of the in-depth interviews were converted into transcripts and were referred to as the primary data of this study. The interview transcripts were reduced, interpreted and analysed by the researcher. We use the concepts and theories related to health communication and its strategy, to conduct the interviews and to analyse the results. In addition to the primary data, this study also used secondary data consisting of literature studies, observations, and researchers' experiences, as well as other supporting data obtained from various studies or observations, especially from Premature Indonesia's social media.

DISCUSSION

The main objectives of health communication are to provide information to the public about health care and facilities, to motivate and empower the community to adopt healthy behavior, and to assist health workers in analyzing problems, evaluating, and carrying out management (Cassata, 1980; Somers, 1976). To attain this goal, in developing health communication strategy, it is necessary to understand the important elements of communication. The communication element consists of a communicator as a messenger, a communicant as a message recipient, key messages, and communication media. These elements are expected to have an effect in accordance with the purpose of health communication (Rakhmaniar, 2021) as a comprehensive and sustainable effort to achieve long-term goals (Notoatmodjo, 2010). For this reason, the role of support groups is needed in

health communication efforts. Support groups can facilitate information, communication, interaction, and support when individuals experience health problems.

Parsons (2019) stated that joining a support group can increase individual empowerment in improving their health condition because the information presented is considered more reliable. Thus, support groups provide two-way communication which has elements of therapeutic communication. It is the process of exchanging messages, thoughts, and feelings, to achieve health communication goals. Therapeutic communication allows to reduce excessive anxiety and fear among people who are experiencing health problem. It can increase awareness, acceptance, and empowerment (Shan & Sari, 2019). Nowadays, support groups are popping up online because they are more accessible.

ROP Problems in Indonesia and the Urgency of Health Communication

Health communication was carried out because of the discovery of health problems found in the community. Thus, a problem analysis needed to be carried out to understand the condition of public health and the urgency of health communication (Notoatmodjo, 2010). All of these steps were taken to identify gaps and determine strategies (Kemenkes RI, 2019). Based on data collected by researchers through interviews and Premature Indonesia's social media, there were at least three basic problems that did not carry out ROP screening in premature infants, thus triggering an increase in the incidence of ROP (Ayu, 2019). The first problem was the lack of information from health workers. This was caused by the inadequacy of Standard Operating Procedures (SOP) in the management of premature babies. The SOP did not require an ROP screening or the examination was only mandatory for babies who were at high risk (e.g., those born under 32 weeks and weight below 1500 grams). In fact, ROP could be experienced by all premature babies. Based on the narrative of a parent of a child who survived ROP through his blog, when his child was born prematurely, there were no health workers who conveyed information about the risk of ROP and the obligation to have regular eye screening. So, it was too late to do it and the screening was just carried out after parents actively searched for information on the internet when they realized that their child's eyes did not respond to any stimulation. At this stage, preventive measures were impossible and permanent blindness occurred (Aditya, 2016). This was supported by interview data as follows:

"The big problem is that if there is no advice from pediatricians or other health workers. The key is within the parents. If there is no referral, parents do not want to go and BPJS cannot afford it either. Screenings are sometimes carried out because parents are insistent on the pediatrician, or indeed meet with a pediatrician who is already aware. Now, what really matters is if the child's doctor doesn't give a referral from the pediatrician, there will be no information, and the parents will not know and have any information. Once asked to take a screening process, this will be a long and wide debate" (Mima, interview, August 5, 2021)

The second problem was the limited equipment and ophthalmologist who were competent to perform ROP screening. Unfortunately, many of those

were only available in big cities like Jakarta, Bandung, Yogyakarta, and Surabaya. Many parents ignored the importance of eye screening because of distance, time, and cost constraints. The third problem was the low level of awareness and response of parents to perform eye screening on their premature babies. In fact, ROP could be prevented and treated if detected early. However, due to ignorance, parents tended to ignore the importance of screening. The description of the problem was also emphasized by dr. Agung in the interview as follows:

“Actually, in my opinion, there are five, the first one was not recommended by the doctor, the parents didn't know, the third didn't have any tools, the fourth didn't have a doctor check it out, the fifth didn't cost anything. If it is concluded, the problem will revolve around only those five” (dr. Agung, interview, September 1, 2021).

In addition, this problem occurred in India. The high incidence of ROP in India was caused by several things that were similar to those described previously. Because of these problems, health communication efforts really needed to be completed (Katoch & Dogra, 2018). According to Cutrona's (1986) cited by Miller-Ott & Durham (2011), support groups in health communication acted as social supports that might overcome problems, one of which was as a source of information and credible facts about the disease, as a social network, and as a source of emotional support. Research by Miller-Ott & Durham (2011) showed that people tended to carry out health checks if they received advice and support from their social networks, especially when credible information about the disease was still difficult to find. This implied that support groups such as Premature Indonesia had an important role in providing information so that health communication on ROP prevention could be carried out more effectively.

Former Premature Parents as Main Communicators in Premature Indonesia

Communicators performed an important position in the communication process as a messenger. According to Rakhmat (2018), the factors that influenced the strength of communicators encompassed credibility, attraction, and power. Credibility was influenced by two factors, namely expertise and trustworthiness. The attraction was influenced by physical attractiveness, similar fate, and experience. In coping with power, a communicator could influence others because he had power. Communicators were expected to be able to speak according to their competence, position themselves and understand the interlocutor, and have a good attitude and motivation. They, moreover, must be careful in conveying information, especially if the information concerned the public interests (Paramasari & Nugroho, 2021).

In accordance with the health communication on ROP prevention, the selection of communicators or educators became a significant aspect, such as the following interview:

“We are members of a support group. So, I determine that educators should be parents of premature babies so they can

share what parents of premature babies feel. There was once a pediatrician who wanted to join as an educator, but he was not a parent of premature babies so he was afraid that his perspective would be different from that of parents. If you look at it, our educators are mostly non-medical parents, who are experienced and willing to share. So, they can position themselves as parents of premature babies.” (dr. Agung, interview, September 1, 2021)

In brief, Premature Indonesia chose educators who were also parents of premature babies who were more experienced and educated. This selection was based on the attraction factor, namely the similarity of fate and experience so that educators shared a sense of empathy for parents of new premature babies who were looking for information about their baby’s health, especially ROP. Among them, there were educators who were parents of children or adolescents with ROP case survival experience with permanent blindness. Currently, the educators were around 20 people. This number always changed depending on the willingness of each educator because the activities in Premature Indonesia were voluntary. To accommodate audiences from various regions and circles, educators also came from various cities in Indonesia. According to Mulyana (2008), this was important because educators’ diverse backgrounds would encourage people to communicate effectively. This discussion was in accordance with the following informant’s statement:

“The number of educators is growing and changing because some people leave due to the fact that they are no longer active or choose other organizations’ activities. In total, there are 20 people in Indonesia from Pekanbaru, Jakarta, Bandung, Semarang, and Central Java. Moreover, there are some from Jogja, Bojonegoro, and Sukabumi. Yes, it's not evenly distributed but it is sufficiently diverse. Oh, one more thing, there are some from Pontianak” (dr. Agung, interview, September 1, 2021).

Rahmawati (2018) argued that audience acceptance of information was highly dependent on trust. If the trust was high, then the audience was willing to accept and share the information, otherwise, if the trust level was low, the audience would refuse or not respond. Thus, Premature Indonesia as a support group whose educators consisted of experienced parents of premature babies was a very influential communicator.

The selection of communicators was determined in such a way since the target audience or primary communicants were also parents of premature babies, either new or not knowing the health information of premature babies at all. Communicants were heterogeneous and consisted of various educational, economic, social, and cultural backgrounds (Rakhmaniar, 2021). Parents of premature babies were the primary target audience of the health communication program about the dangers of ROP conducted by Premature Indonesia. If parents already understood the dangers of ROP and its prevention, then parents would be able to decide for themselves to act. This was clarified through interviews as follows:

“Because we are a support group. Our priority is the parents as the easiest way. Hopefully, the parents who become members can understand and can avoid the risk of ROP. If the parents understand, they can do autonomously” (dr. Agung, interview, September 1, 2021).

Furthermore, the secondary target was health workers because the number of ROP cases was also influenced by the ignorance of health workers about the risk of ROP in premature babies. This was also stated by the informant as follows :

“We also target the health workers, such as midwives and nurses. They can be the spearhead too because the range of midwives is sometimes wider than pediatricians. They are in remote areas or villages. So, there are quite a lot of midwives who join here as the target of our information” (Mima, Interview, August 5, 2021)

In the Premature Indonesia support group, the leader’s opinions were mostly trusted by the above target audience. According to research conducted by Saw et al. (2021), leaders’ opinions were trusted because they were able to provide assistance, advice, and credible information that influenced individual attitudes and decisions regarding their health condition. Currently, many official health organizations relied more on leaders’ opinions in support groups to provide health education to the public. Moreover, there were some shreds of evidence that official health organizations lacked direct contact with the community, making it difficult to provide health education (Lynn-Sze & Kamaruddin, 2021). Currently, leaders on health social media were able to interact and communicate with the target audience through various videos, live broadcasts, photos, and infographics. Social media was currently able to facilitate the ease of sharing information and experiences (Saw et al., 2021). Based on the article by Lynn-Sze & Kamaruddin (2021), leaders’ opinions could influence audiences with three strategies, namely building closeness, providing social support, and providing consultation. This was also what Premature Indonesia did as a support group. Premature Indonesia used social media to spread information and communicate with target audiences in achieving health communication on ROP prevention.

Premature Indonesia uses Social Media on ROP Prevention

Along with the development of technology, social media has been the main source of health information and communication for many health practitioners (Kinanti et al., 2020). The delivery of health messages is undertaken in an interactive and sustainable manner to the target audience (Miyane & Mansur, 2021). Several previous studies have stated that social media, such as Facebook and Instagram, were effective to be used as health communication media (Malik et al., 2021; Rahmawati, 2018; Wulantari & Rahmayanti, 2019).

Therefore, many support groups are formed on social media, including those for child’s health communication. According to Haslam et al. (2017), the increasing use of social media makes parents seek online support groups, in the midst of the confusion of the parenting process. The existence of social

media motivates them to look for information about a child's health so that parenting is carried out easier. This phenomenon is indeed very common among today's parents (Sari & Basit, 2020). Moreover, it is easier for those who have children with special conditions including premature birth, which has both short-term and long-term consequences (Clinic, 2021; Mariyana, 2018; Nugroho, 2018), e.g., ROP.

Premature Indonesia used Facebook, Instagram, and Whatsapp as the main communication media. Face-to-face activities such as seminars and workshops were conducted before the COVID-19 pandemic. However, after the COVID-19 pandemic, health communication on ROP prevention was carried out through social media.

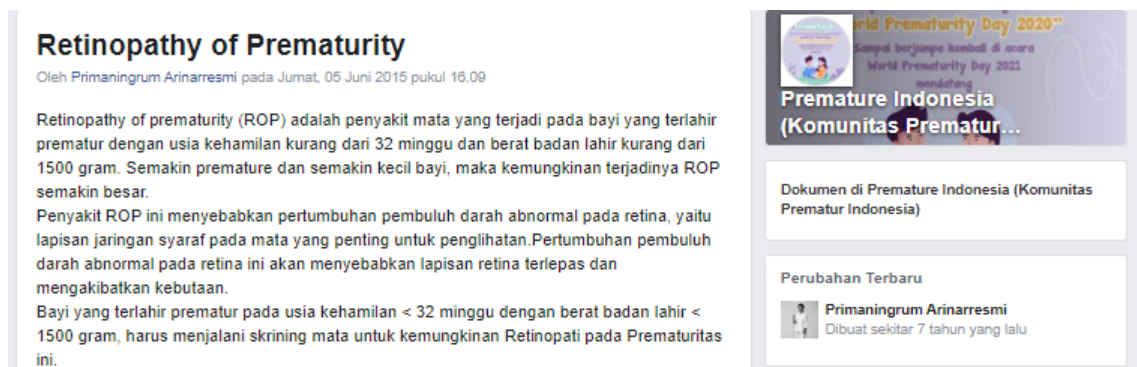


Figure 1: Educational content about ROP on Premature Indonesia's Facebook page

Source: <https://www.facebook.com/notes/premature-indonesia-komunitas-prematur-indonesia/retinopathy-of-prematurity/1858921764333329/>

This picture above is one of educational content about ROP on Facebook page. It consists general information and definition about ROP. The use of social media such Facebook and Instagram, made it easier for Premature Indonesia to reach audiences throughout Indonesia. This was conveyed by the informant as follows:

“In the past, we once held an event such as a healthy walk from Taman Suropati Menteng to the HI Roundabout while raising awareness about prematurity. Furthermore, we also often held education in the form of direct seminars at public hospitals or mother and child hospitals. At that time, we were actually already using Facebook, Instagram, and Whatsapp groups. Then, there was a COVID-19 pandemic, all activities continued but were maximized through the social media that we already had. The seminar also turned into a webinar. We usually uploaded the webinar on IGTV or Youtube. But for Youtube, it's still on my channel. Apparently, social media actually made it easier for us to deliver education to a large audience” (dr. Agung, interview, September 1, 2021).

Based on this statement, in conveying ROP prevention messages, Premature Indonesia employed the social media most widely used by the Indonesian people, namely Facebook, Instagram, and Whatsapp. Based on the 2019 Research and Development Center for Aptika-IKP Kemkominfo

survey, Whatsapp was the most accessed and actively used application by users (96.54%), followed by Facebook (91.62%) and Instagram (44.87%). Information about health was one of the most accessed information by social media users (Rizkinaswara, 2019). Then, according to data compiled by We are Social (Kemp, 2020) as of January 2020, the most accessed social media in Indonesia included Youtube (88%), Whatsapp (84%), Facebook (82%), and Instagram (79%).

Dissemination of information on ROP prevention through Premature Indonesia's social media was in line with the habits of today's parents. Today, social media was used by new parents to find information on children's health because it was easier to access and reach. Social media also facilitated interaction with other new parents to share experiences (Afrilia, 2017). Today's parents tended to look for online communities that could not only provide information but could also provide social and emotional support (Haslam et al., 2017). This was in line with Premature Indonesia's goal, which was to become a support group between parents of premature babies to share information and experiences with others. Premature Indonesia's social media were not only used to convey information, but were also used as interactive media for discussions between educators and audiences. Health communication on ROP prevention through social media was considered effective because quite a lot of parents brought their children to check ROP after reading information on Premature Indonesia's social media. This was expressed by dr. Roza as a pediatric ophthalmologist:

"It's actually quite difficult to judge whether education in Premature Indonesia is successful or not because it requires thorough quantitative research, if you want to know. But if I can subjectively say that so far, those who have come for the screening are because they know from Premature Indonesia's social media" (dr. Roza, Interview, September 14, 2021).

In compiling content regarding ROP on social media, Premature Indonesia always consulted with practitioners, namely pediatric ophthalmologists who handled ROP so the content compiled was accurate and credible. This was in accordance with the statement of the informant below:

"In compiling content regarding ROP on social media, Premature Indonesia always consults with practitioners namely pediatric ophthalmologists who handle ROP. So, the content is accurate and credible. (Mima, interview, August 5, 2021)

Significant Message of Health Communication on ROP Prevention

In communicating ROP prevention through social media, Premature Indonesia educators adhered to several core messages consistently. Basically, the core message must pay attention to the following: (1) understand: the audience was able to understand the problems and information about the health conditions they were confronting, and (2) memorize: the audience was able to remember the advice given. Messages would be easier to remember if there were no medical terms that were difficult to recognize and comprehend. If the message was easy to understand and remember, then health communication would be more effective and the communicant ably responded

to the advice given (Rahmadiana, 2012). In the early stages, Premature Indonesia focused on the message of preventing premature birth, as stated by the informant as follows:

“The main message is to prevent premature birth. So, you do not need to check ROP if it’s not premature. So, we want to create awareness that there are premature babies with their conditions. We always include the topic of preventing premature birth and the risk of ROP in seminars, webinars, and social media” (dr. Agung, interview, September 1, 2021)

This key message became a part of ROP prevention. What the communicant must first understand was that ROP occurred because of premature birth. The next key issue was about what ROP was and its dangers. This aimed to provide education and understanding to the communicant that there was a risk of visual impairment called ROP that could be experienced by premature babies. Then, it continued with an appeal to carry out an ROP screening, including a referral to a doctor who could carry out the screening. This was done as a suggestion or solution to prevent the occurrence of ROP. This message appears in content such follow at Figure 2.

This content on Figure 2 explain the importance of ROP screening for premature babies. So, it could be concluded that the significant message consisted of three aspects namely preventing premature birth, ROP education, and an appeal for ROP screening. Messages in health communication aimed to encourage parents to be independent, aware, and fully active in child health care (Patel et al., 2014).



Figure 2: Educational content about ROP on the Premature Indonesia Instagram page

Source: <https://www.instagram.com/premature.indonesia>

CONCLUSION

Health communication can be a solution to solving problems related to health and can change the public’s healthy lifestyles or behaviors. Its efforts to prevent ROP with the assistance of the Premature Indonesia support group are carried out through several stages starting from analyzing the main problems, selecting credible and experienced educators, using social media as the main communication medium, and formulating and delivering clear health information messages. Through this stage, the main expected effect is to increase awareness about the conditions and health risks of premature

babies. Consequently, the public might realize the importance of preventing premature birth.

In addition, there is an increase in awareness about the risk of ROP in every baby born prematurely so the public can understand the importance of ROP screening. The use of social media such as Facebook, Instagram, and Whatsapp is considered significant to succeed the awareness. However, comprehensive health communication efforts involving all parties such as hospitals, neonatologists, ophthalmologists, nurses, parents of premature babies, social communities, and the government still need to be carried out optimally to overcome all problems and prevent the occurrence of ROP in Indonesia. In conclusion, this research is expected to increase awareness and become an important reference for parties involved in health communication, prematurity, and ROP prevention.

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