

## An ethnographic study of communication with HIV-infected children at Rumah Cemara

Yustikasari<sup>1</sup>, Atwar Bajari<sup>2</sup>, Ponpon Idjradinata<sup>3</sup>, Eni Maryani<sup>4</sup>

<sup>1,2,3,4</sup>Universitas Padjadjaran, Bandung, Indonesia

### ABSTRACT

This study examines the ethnography studies of communication with HIV-infected children at Rumah Cemara Bandung by reviewing the elements of communication components. This research uses a qualitative approach with an ethnographic type of communication study. The research subjects were children infected with HIV in Bandung who was selected using the purposive method. Data were obtained through in-depth interviews, participatory observation, document analysis, and literature study. The results revealed that the genre in the communication component of children infected with HIV at Rumah Cemara was seen in the delivery of problems, namely the presence of viral infections in children. The setting that occurs in the communication component is carried out at the child's home/residence and Rumah Cemara as a community location and Klinik Teratai, Hasan Sadikin Hospital, Bandung. Children use Indonesian and Sundanese as their daily languages. All HIV-infected children are infected with the virus because it is transmitted from their parents, namely the mother, and the mother is infected with HIV from her husband. Conversations that are usually carried out by informants when meeting at Klinik Teratai, Rumah Cemara, and at home are usually related to conditions of health development, children's adherence to taking anti-retroviral drugs, and mental and social development of children with messages of mutual encouragement and support as well as instilling a sense of optimism. Psychologically among People With HIV/AIDS (ODHA). The non-verbal language that children do in the form of silence; smiles; a nod of the head; shaking of the head, and laughing out loud.

**Keywords:** Ethnography study of communication; communication component; children; HIV-infected; Rumah Cemara

## Kajian etnografi komunikasi anak yang terinfeksi virus HIV di Rumah Cemara

### ABSTRAK

*Penelitian ini bertujuan untuk mengkaji etnografi komunikasi pada anak yang terinfeksi virus HIV di Rumah Cemara Bandung dengan mengkaji unsur komponen komunikasi. Pendekatan penelitian yang digunakan adalah kualitatif, dengan jenis studi etnografi komunikasi. Subjek penelitiannya adalah anak yang terinfeksi virus HIV di Kota Bandung yang dipilih dengan menggunakan metode purposif. Pengumpulan data yang didapatkan dengan cara melakukan wawancara mendalam, observasi partisipatif, dan analisis dokumen dan studi pustaka. Hasil penelitian mengungkapkan; bahwa genre dalam komponen komunikasi pada anak yang terinfeksi virus HIV di Rumah Cemara terlihat pada penyampaian masalah yakni adanya infeksi virus yang dialami pada anak. Setting yang terjadi pada komponen komunikasi dilakukan di rumah/tempat tinggal anak dan di Rumah Cemara sebagai lokasi komunitas serta di Klinik Teratai RS Hasan Sadikin Bandung. Bahasa yang dipergunakan sehari-hari oleh anak adalah Bahasa Indonesia dan Bahasa Sunda. Anak yang terinfeksi HIV seluruhnya terinfeksi oleh virus karena ditularkan dari orang tua yaitu ibu; dan ibu terinfeksi HIV dari suaminya. Percakapan yang biasa dilakukan oleh para informan saat bertemu di Klinik Teratai, Rumah Cemara dan rumah biasanya berkaitan dengan kondisi perkembangan kesehatan, kepatuhan anak dalam mengkonsumsi obat anti retroviral dan perkembangan mental dan sosial dari anak dengan isi pesan saling memberikan semangat dan dukungan juga menanamkan rasa optimis pada anak secara psikologis diantara ODHA (Orang Dengan HIV/AIDS) tersebut. Bahasa secara nonverbal yang dilakukan oleh anak berupa terdiam, senyuman, anggukan kepala, gelengan kepala dan tertawa lebar.*

**Kata-kata kunci:** Etnografi komunikasi; komponen komunikasi; anak; infeksi virus HIV; Rumah Cemara

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**Correspondence:** Dr Yustikasari, M.I.Kom. Universitas Padjadjaran Jl. Raya Bandung-Sumedang KM 21, Jawa Barat, 45363, Email: [yustikasari@unpad.ac.id](mailto:yustikasari@unpad.ac.id)

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## INTRODUCTION

Acquired Immuno Deficiency Syndrome (AIDS) is a chronic disease that affects more than 20 million people. HIV/AIDS has become a global problem, particularly in Indonesia, where the first case of HIV/AIDS was discovered in 1987, and the number of people infected with the virus continues to rise year after year. According to the World Health Organization, there will be approximately 1.5 million cases of HIV infection by 2020, with Africa having the most cases (Herbawani & Erwandi, 2019).

Jakarta Province and East Java Province, in terms of the number of people infected with HIV. West Java Province, one of Indonesia's largest provinces, comes in third place, behind DKI. West Java Province is one of the most populous provinces in Indonesia. Adults are not the only ones affected by the spread of this virus; currently, children are also susceptible to infection with this virus. In this particular instance, the number of cases of HIV infection that occur in West Java Province can be considered relatively high. West Java Provincial Health Office has cumulatively recorded 51,553 instances of HIV-AIDS, accounting for approximately 80% of the estimated 64,635 cases until 2021, according to the most recent data available. The findings were higher than expected based on the input indicator of the National Action Plan (RAN) 2020-2024 for 2021, with a total of 69 percent of the whole recorded. Frequent HIV/AIDS cases are reported in West Java's regencies and city areas.

Previously, the transmission pattern in HIV-AIDS cases in Bandung had been from injecting drug users, but this pattern has now shifted to heterosexual relationships. In conjunction with this, there has been a significant increase in HIV-AIDS cases among homemakers in the following years. Although users of circumcision drugs are responsible for the majority of HIV-AIDS virus transmission, they are also responsible for the majority of HIV-AIDS virus transmission. According to Dr. Rita Verita Sri H, MM, MH, the Director of Disease Control and Environmental Health of the Health Service (Dinkes) in Bandung, the situation is as follows: "There were 2,541 cases of HIV-AIDS in Bandung from 1991 to September 2020, a cumulative total of 2,541 people. There were 1,204 HIV cases among

them, and the remaining 1,337 AIDS cases were among them" (H, 2013).

The virus that attacks human immunity no longer only affects people over the age of 18, but it is now also affecting children. In Indonesia, the prevalence of HIV among children is increasing. Children and women are particularly vulnerable to the spread of HIV. Their predicament is concerning due to a lack of adequate treatment and the presence of negative stereotypes associated with them, both of which are true. These children are frequently infected with diseases that are not always the result of their mistakes. It is not uncommon for children to inherit the condition from their parents. Unfortunately, this type of transmission can occur between mothers who are unaware that they are HIV-positive. This is to the data from the Ministry of Health of the Republic of Indonesia in 2020, which indicates that most HIV / AIDS virus transmission cases currently occur through the mother rather than through blood transfusion. Consequently, the transmission process that should have been prevented occurs due to a lack of medical intervention that is deemed adequate.

There is a link between a lack of knowledge and public insight about HIV/AIDS and the negative stigma attached to HIV. This is supported by other research (People living with HIV AIDS/ODHA). Because of this lack of knowledge and insight that HIV/AIDS has finally resulted in misconceptions about what it is, which has led to the development of a negative stigma against HIV and ODHA. The myths and beliefs (religion) embraced by the community are the next factor contributing to negative stigma. Since the number of HIV cases continues to rise year after year, numerous efforts are being made to prevent the HIV/AIDS virus from spreading by various societal elements today. Patient retention is critical in HIV treatment, and increasing patient retention is a top priority.

HIV/AIDS prevention efforts have been carried out for a long time in various ways that have continued to be improved, ranging from the number of people who have been infected to the quality of the programs and the coverage of the target area. All required to bring this epidemic under control is a behavior change. One of the keys to the expected behavior change in society is effective communication,

which can be accomplished through various means. Communication allows for the careful implementation of HIV / AIDS prevention and treatment programs ODHA. It is also planned to conduct several communication activities such as counseling, socialization, and social mobilization by communicating strategic behavior changes and organizing them in a directed manner. It is expected that this will be able to answer various problems related to HIV/AIDS virus prevention efforts to keep the number of people affected by the virus from increasing.

Communication can also be accomplished through social media. According to the report, social media can help bridge communication between people who live in different geographical and social environments, thereby aiding in preventing the spread of the HIV/AIDS virus. Prevention can reduce the number of people living with HIV/AIDS by 25-45%, and the number of ODHA can be reduced to less than 2% (Ministry of Health of the Republic of Indonesia, 2012). The prevention of HIV infection in children and the mitigation and reduction of the impact of HIV must be done in a direct, massive, and continuous manner. Due to a lack of investment and resources, including inadequate testing, limited administration of anti-retroviral drugs, and a lack of prevention and awareness programs in the community, children will continue to suffer from the epidemic.

It has been stated by doctors from the Department of Psychiatry at the Royal Singapore Medical Centre and University Hospital, Dr. Kristiana Siste, SpKJ, that children with HIV are frequently subjected to negative stereotypes from the community and are even ignored by their own families. In fact, according to the fundamental law, children have the right to healthy survival, growth, and development and the right to be protected from violence and discrimination, among other things.

Rumah Cemara is a particular community for drug addicts, and ODHA was established on January 1, 2003, as part of the effort to combat the problem of HIV/AIDS virus transmission. Rumah Cemara has been providing assistance services to children infected with HIV since 2007. It is a well-known fact that HIV and drug users continue to face negative stigma and discriminatory treatment from their peers

and the general public even after they have stopped using. Due to such treatment, these individuals are rendered unable to work or interact freely in the community. Based on this consideration, Rumah Cemara and its four colleagues eventually established Rumah Cemara as a place for them to gather, confide in one another with people who had experienced the same thing, share experiences, strengthen one another, and provide support to one another among its members.

Rumah Cemara is a network of people with the most significant number of people infected with HIV and drug users in West Java Province. The vision of the establishment of this Rumah Cemara is to be a positive place for improving the quality of life of ODHA and for former drug addicts, both physically, socially, especially psychologically and spiritually, from their members. The existence of Rumah Cemara has finally become a growing community and has become a social organization engaged in mentoring ODHA and former drug users. This community turns out to assist its members, then the Founder of Rumah Cemara and his colleagues also empowers its members, including HIV-infected children. In December 2009, as many as 200 drug users were provided with addiction treatment services by the Rumah Cemara. Rumah Cemara's membership amounted to 4,317 drug users. Members of 1,276 drug users include ODHA, including 61 peer support groups, including 3 Rumah Cemara offices in Bandung, Sukabumi, and Cianjur.

Rumah Cemara's assistance includes assisting HIV-infected children at Klinik Teratai, located at the Hasan Sadikin Hospital in Bandung, among other things. Located at Hasan Sadikin Hospital Bandung, the Klinik Teratai serves as a hub for HIV prevention activities. Hasan Sadikin Hospital, through its Klinik Teratai, has been actively involved in the prevention and treatment of HIV cases for many years. Along with providing therapy, Klinik Teratai has implemented several prevention strategies to ensure that HIV does not spread further throughout the community. Socialization, counseling, treatment, and research are just a few of the activities that have taken place in this clinic over time.

The comprehensive service carried out by the team at Klinik Teratai is by conducting a program called *medical review* every Tuesday

and Thursday; this program is carried out to evaluate the health progress of each patient in the clinic so that the progress and success of the treatment that is being carried out can be monitored to the maximum by the medical team. This team also routinely conducts medical compliance checks and conducts compliance counseling in treatment. This is done by establishing good relationships with patients' spouses/families/relatives and with various parties such as Regional Hospitals, Non-Governmental Organizations (NGOs), and various other organizations.

Since 2012, Rumah Cemara has run a Love for Life program, which assists HIV-infected children. Following the interview with the Public Relations Officer of Rumah Cemara, the results revealed that "Love for Life is a mentoring and support program for HIV-infected children on all levels: physically, psychologically, and socially." The program helps the physically, psychologically, and socially disadvantaged (Kis, 2013). In addition to providing assistance and support to HIV-infected children, Rumah Cemara also reminds them to conduct routine health checks, take ARV (Anti Retroviral) drugs every month, and every 3 (three) months of nutrition such as milk and breast milk companion food as a result of collaboration with the Commission on AIDS Prevention (KPA) in Bandung, among other things. Rumah Cemara conducts a psychological support program through stimulation classes for children's development and provides funding assistance to schools, particularly for HIV-infected children, who are disproportionately represented among economically disadvantaged families.

As part of its collaboration with the Faculty of Psychology at Universitas Padjadjaran Bandung, Rumah Cemara has also been conducting fingerprint tests on HIV-infected children since 2012 to determine their abilities and potential for learning. In collaboration with Bandung Tourism College (STPB) and NHI, Rumah Cemara has organized storytelling activities, fun games, and cooking activities for parents of HIV-infected children. Parents will learn how to cook or process food more diversely with these activities, ensuring that their children receive adequate nutrition. Rumah Cemara provides whole motivation and support to HIV-infected children who participate in social activities because they require the support

of their closest friends and family members to succeed.

It was a significant decision made at the United Nations General Assembly Special Session on HIV/AIDS (UNGASS) in 2001, which stated "the need to provide extended services, provide care and support for ODHA, and protect the human rights of ODHA by preventing, reducing, and eliminating stigma and discrimination against them." Efforts to care for, treat and support ODHA are carried out through clinical approaches, such as providing community and home-based care, and as a form of support for forming relationships among HIV-positive people.

The efforts made by Rumah Cemara in assisting with the treatment of HIV-infected children demonstrate the existence of a communication component between HIV-infected children involving parents/families, chaperones in the Rumah Cemara, medics at the Klinik Teratai, peers, and the environment in which the child is located (i.e., the neighborhood). Components of this communication activity occur continuously, allowing researchers to gain insight into the communication process between HIV-infected children when they interact with various parties and individuals. An element of the Ethnographic study of communication is composed of factors contributing to the communication process. These include the genre or type of communication used, topics of discussion, objectives/functions of the communication process, settings/places where the communication takes place, participants, message forms and contents, sequences of actions governed by rules of interaction, and norms of interpretation. There are some unique characteristics to the communication component of the communication activities of HIV-infected children. Based on the issues raised above, this study aims to determine how the communication component of HIV-infected children in the community of Rumah Cemara Bandung is affected by communication activities.

## RESEARCH METHOD

This type of study in research is the ethnographic study of communication. Thomas R. Lindlof, in his book *Qualitative*

Communication Research Methods, states, "Ethnography of Communication (EOC) conceptualizes communication as a continuous flow of information, rather than as segmented exchanges message." An Ethnography of communication, the concept of communication refers to a continuous flow of information rather than just the exchange of messages between its constituents. An ethnographic study of communication has its roots in language and social interaction and the rules of qualitative communication research. The traditions inform his psychology, sociology, linguistics, and anthropology." The ethnography of communication is concerned with cultural codes and rituals. The ethnographic research method is one of the research methods that fall under the constructivism paradigm, which advocates that knowledge must be discovered by researchers (Lindlof & Taylor, 2011).

HIV-infected children live in the Rumah Cemara in Bandung, and this study uses ethnography of communication to describe their experiences. The qualitative approach is taken in Ethnography of Communication. The ethnographic method of communication applies ethnographic methods in the group communication patterns discussed in this section. Researchers employ this method when investigating the modes of communication employed by members of a cultural community (Lindlof & Taylor, 2011). Group communication and organization research can be carried out using this method, as can approaches to groups and organizations that are culturally diverse.

The research method uses The Speaking Model from Dell Hymes. This model reveals the components contained in a communication activity so that it looks like a typical rule that can be identified in communication activities. Dell Hymes introduced this model in 1962 that cultural communication can be done differently. Still, all communication form requires the same code that the communicator knows and uses as a context instrument code of sub-message patterns subject and events generated by spreading messages (Littlejohn & Foss, 2011). This model is an acronym for several different communication components, which can be explained as follows:

S: The setting and context associated with the context in which the communication took place. Setting refers to when and where a

conversation takes place, the time of place, and the psychological state of the conversation.

P: Participants; refer to the parties involved in the debate, the speaker and listeners or sender and receiver.

E: Cover; Refers to the intent and purpose of the discourse and the role of each participant in a conversation situation.

A: order of subject; this refers to the form of statements or words used and the content of speech or arguments between what is said to be the topic and what is said to be the subtopic.

K: Key refers to the tone with which a message is delivered.

I: Tools; This refers to how it is communicated.

N: Norma; refers to standards or rules that are similar to those that the author also refers to form an interpretation of the speaking of the opponent

G: Genre; refers to the style of delivery used in poetry, stories, and other forms of expression.

Participatory observation and interviews with HIV-infected children who receive assistance from Rumah Cemara and their parents and volunteers from Rumah Cemara who provide assistance to these children are used as Data collection techniques. For approximately three months, observations were conducted at the location where the children were receiving treatment, namely at the Klinik Teratai Hasan Sadikin Hospital Bandung, in their homes, and at Rumah Cemara. Interviews are conducted in an informal setting to learn about their experiences, feelings, and circumstances. Interviews were conducted with as many as two volunteers, as many as seven parents, and as many as seven HIV-infected children.

Analyses are conducted using qualitative data. Detailed descriptions, direct quotations, and case documentation are included in the quantitative portion of the report. It is not attempted to match a symptom with a predetermined standard category, as indicated by the question in the questionnaire. Instead, the information is collected in an open-ended narrative format (Agusta, 2003). Purposive sampling is used to select informants for interviews. When choosing the subjects for the study, the researchers established some criteria. This study aims to examine the communication of HIV-infected children in Rumah Cemara Bandung, specifically their

communication activities, communication components, communication competencies, and communication patterns, among other things.

Moreover, in qualitative research, more data collection on participatory observation, in-depth interviews, and documentation” (Sugiyono, 2012). The process of data analysis is divided into three activity flows. Three lines of activity that coincide are data collection, data reduction, data presentation, and conclusion/verification withdrawal (Miles, Huberman, and Saldana, 2016).

## RESULTS AND DISCUSSIONS

The setting is one of the elements that comprise the communication component when conducting an ethnography study of communication. Following the identification of communicative events, communication patterns can be discovered due to the relationships between communication components through the ethnography study of communication. As a result, the communication component is indirectly responsible for the researcher’s ethnographic communication while on the ground.

It refers to the types of communication events that HIV-infected children may encounter, including forms of delivery such as HIV disease issues and treatment issues and conversations about the child’s daily experiences and condition, among other things. The following are the topics that were brought up by the informants, as revealed below:

“Neighbors around the house were unaware of DEV’s illness and his late father. Usually, if I accompany DEV and he wants to go to Bandung for treatment, on the trip from Indramayu, I always try to entertain DEV with stories or songs to keep him entertained; it is also a long trip, mom. Thus, he is unconcerned that” Clearly, Mrs. Y while smiling at the author” (Y, 2014).

Furthermore, the author inquired the informant about their daily experiences related to their health condition; the following are the results of interviews conducted with informants who were aware of their health condition: Because it prefers to be taken by the mother to Klinik Teratai, R.A.F. is rarely ill. “RAF is

rarely sick. The most pain is headache, cough, colds.” (RAF, 2014).

He described his first visit to the Klinik Teratai, prompted by his mother’s invitation. He admitted that he was unaware that he had been infected with HIV at the time of the interview. In his own words, he did not inquire why his mother invited him to the Klinik Teratai every month, even though he admitted that he was sometimes reluctant to accept his mother’s invitation. He claimed that he was always examined for health and required to take anti-retroviral therapy drugs. His mother had previously stated that it was done to maintain RAF’s health. In a soft voice, he told the author that when he was in the sixth grade of elementary school, his mother explained the actual state of his health, which he had been experiencing since birth.

“Yes, my mother explained why I have to go to Klinik Teratai once a month. Whenever I go to the clinic, it is usually the same mother who greets me. I used to know when I was infected with HIV, but my mother ordered that I not tell anyone else if I was sick; she also stated that my mother should be excited rather than depressed because I still had to go to school and play with my other friends... If you are going to take medicine, do not forget to take it on time, as the doctor instructed. I also get HIV-related information from the internet every day, now and then.” (RAF, 2014)

Meanwhile, the informant, ARV, who has also been informed of his health condition, added:

“My mother had told me I had HIV, and I was shocked. Even though I am not an expert, I know some things. My mother’s advice was simple: if you are invited to the clinic, you should go, and you should take the medicines, even if you get tired of it sometimes.” (ARV, 2014)

ARV is one of the HIV-infected children whose health development has been hampered by pneumonia and other diseases. ARV is a shy child and somewhat introverted, in addition to those who have a hearing impairment. When he communicates with the author, they use nonverbal communication such as facial expressions, hand gestures, and body postures, which should be used more frequently. Generally

speaking, parents who have HIV-infected children do not provide any special treatment to their children. They continue to give their children the freedom to get along, move around, and interact with their surroundings as they would typically do.

On average, HIV-infected children can continue to participate in their usual activities; however, compared to old enough patients, their endurance is minimal and cannot be helped. In addition to allowing their children the freedom to move around in the environment, the informant's family always makes an effort to speak with their children. Topics discussed include activities children participate in, relationships with friends, current events on television, and other casual conversations.

Setting refers to the physical location of interactions at Klinik Teratai, Rumah Cemara, and the informant's home. Here are the results of interviews about the form of messages, including non-verbal channels, and the nature of the code used, such as which language is used, which variety, and the content of the message, which includes what is communicated: "Now DEV is not embarrassed or afraid to be examined by a doctor," (DEV, 2014)

Another case with NAY, who was not too shy when talking with the author and even his mother, Mrs. W, told that while inside the Klinik Teratai, NAY was quite familiar with the medical personnel who handled it during her time at Klinik Teratai. Similarly, when NAY is included in the activities held by Rumah Cemara." Nay is easily approached even by people he just met. Isn't it, mom? The first time I met NAY, NAY was immediately familiar. Because basically, NAY is not shy and happy to be invited to chat" (W, 2014)

Similarly, some informants approached by writers, such as RAM, ALG, CAL, and FAR, are not difficult to come. They are easy to talk to and found in Klinik Teratai and Rumah Cemara. They appeared to have no reservations about being in that location and mingling with the other party. Even children want to be loud and run around while at the Klinik Teratai and Rumah Cemara.

The existence of support group facilities and regular meetings that bring the child with peers become a means for HIV-infected children and parents to share and provide support to one another, which is very beneficial to the children's

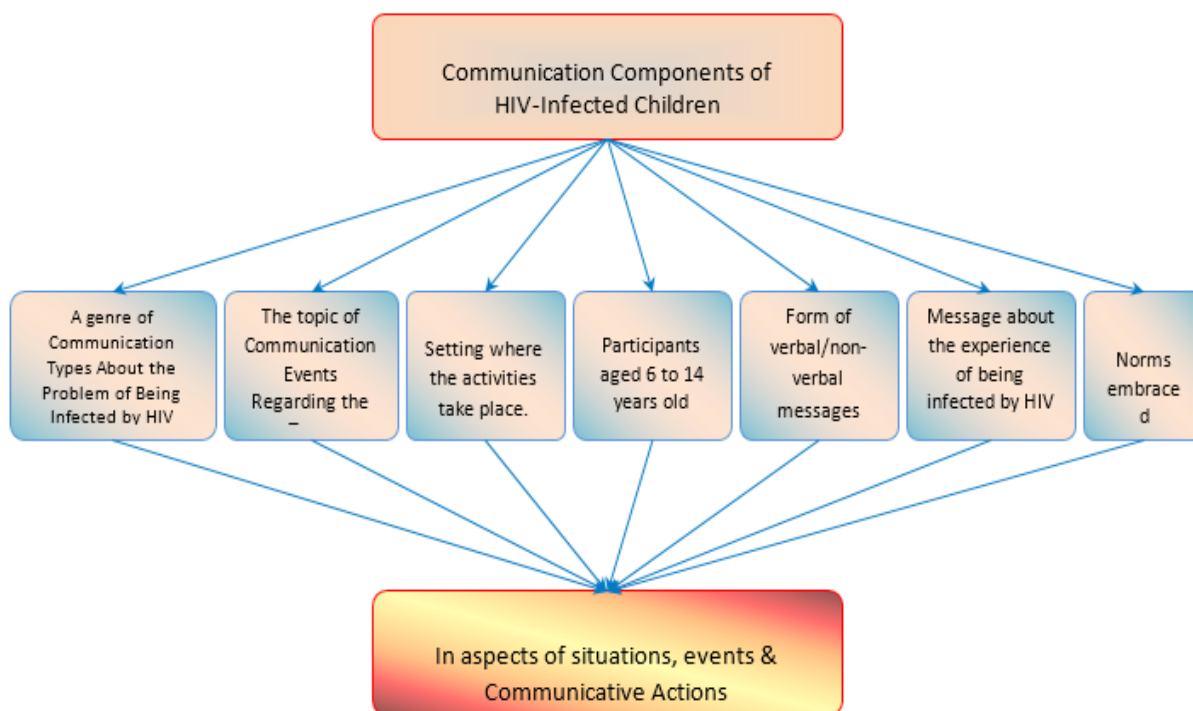
growth and development process. Parents who participate in activities are always enthusiastic and hope to be able to attend similar events in the future, given the many things they must know about the many psychological conflicts and challenges that must be faced about the stigma obtained from the environment concerning their health conditions.

"We understand, ma'am, that many people are unaware of the disease we suffer from. As a result, no one in my neighborhood was aware that I and DEV were infected with HIV until now. They know Dev has pneumonia, so he must be treated in Bandung once a month," she said, her face gloomy. (Y, 2014)

Until now, ODHA continues to experience stigma associated with their condition. When it comes to explaining to children about other people's attitudes when they are aware of their actual health condition, it can be difficult. Families are concerned about the possibility of discriminatory treatment, particularly in the case of children and adolescents. These individuals are aware that children are victims, that children deserve to live everyday life, and that children deserve a bright future, just like other children. Based on the description of the study's findings above, it is possible to construct the following model of the communication components of HIV-infected children, figure 1.

According to the interview findings, the author learned that the informants are typically used to communicating in Indonesian, with some also speaking Sundanese in their everyday lives, according to the informants. Additionally, when they communicate with medical personnel at Klinik Teratai and interact with volunteers from Rumah Cemara, they use the same language. When it comes to communicating with HIV-infected children, there are no differences. Everything continues to run smoothly, including the health of children whose conditions are not affected by the virus.

The same procedures for other healthy children are followed, except for ARV informants who have limited communication due to hearing loss. However, ARV can still be invited to communicate similarly to other healthy children. Although, when speaking with ARV, the author employs a great deal of nonverbal communication, which is sometimes



Source: Research Results, 2016

Figure 1 Model of Communication Components of HIV-Infected Children

aided by explanations from ARV’s mother, who is always with her. She is shy and sometimes difficult to express herself, so her mother will be able to explain the author at times. Despite its reserved demeanor, ARV is one of the informants who has been following the activities organized by Rumah Cemara with a high level of dedication.

Mrs. AS, ARV’s mother, stated that by including ARV in meetings and inviting her daughter to interact with the environment outside the nuclear family, she has more or less awakened her daughter’s confidence and independence. According to Mrs. AS, when she first invited her daughter, ARV was awkward, shy, and tended to withdraw. This was because ARV only moved around the house daily due to her decision not to continue her formal education due to her limited hearing. However, ARV adjusted after participating in several ARV activities, meeting with friends who had similar health issues, and receiving acceptance and support from volunteers and medics at Klinik Lotus. ARV and her mother continue to take part in Rumah Cemara-sponsored activities.

Eaves and Leathers (2021) mention the reasons why *nonverbal* messages are so important: (1) Nonverbal factors determine meaning in interpersonal communication; when chatting or communicating face-to-face, many convey ideas and thoughts through nonverbal messages; (2) Feelings and emotions are more carefully conveyed through nonverbal messages than verbal messages; (3) Nonverbal messages convey meanings and intentions that are relatively free of deception, distortion, and confusion; (4) Have a metacommunication function that is required to achieve high quality. The metacommunication function entails providing additional information that clarifies the intent and meaning of the message; (5) Nonverbal messages are more efficient than verbal messages.”

Informants use Indonesian or Sundanese when interacting with nuclear family members, such as parents, siblings, and other families. It is all based on how families raise their children and teach their children to speak. Informants should be able to use the language they are most comfortable with within their



everyday interactions. Even when informants meet regularly with Klinik Teratai staff and volunteers from the Rumah Cemara NGO, the exchange is smooth and without a hitch. The language used is Indonesian or occasionally Sundanese. This helps reduce stiffness after the informant meets regularly with volunteers from the Rumah Cemara.

Interacting and communicating effectively with informants who are still young necessitates a unique set of skills, such as conveying the message clearly so that it can be understood correctly and the intended action can be taken. In this case, each family has a different approach to parenting their children, so the communication skills are not identical. A person's attempts to make sense of their life events are never in vain. You might get a detailed picture, but you might also get something hazy and contradicts what you were expecting. Anyone can benefit from a more flexible and valuable interpretation of events by deciphering another person's communication.

Communication with children or families can lead to the development of positive relationships if it is done with special consideration. As a party who will interact with children, such as medical personnel, the information obtained will come from parents who have much more communication time and can claim to have a high level of familiarity with the children. The information obtained from parents is reliable and can be used to make reasonable assumptions about the children.

Older children can take an active role in communication because children are generally responsive to nonverbal cues such as sudden or threatening movements that make them feel threatened. The best thing that can be done is to speak in a calm, friendly, and confident tone of voice. Having a big smile and making specific hand movements when entering a room will hinder the formation of relationships; therefore, the attitude that must be demonstrated is one of grace and calm, allowing the children to take the lead in interpersonal relationships. It should also be noted that children do not like to be looked at, even though we must make eye contact when communicating. Especially in situations involving interaction with healthcare professionals, young children frequently believe they are powerless to help themselves (Flickinger et al., 2013).

When an explanation or instruction is required, the medical personnel communicating with the children should use plain and simple language, be truthful, and avoid misleading the children by claiming that the painful procedure is not painful, as this will only enrage them. To alleviate fear and anxiety in children, health professionals should always inform them immediately of what will occur. Drawing and playing with your children are effective ways to communicate with them. This enables the children to communicate both non-verbally (e.g., through drawing) and verbally (by explaining the image). Professionals and medical personnel can use the image to initiate communication.

Children's communication is how a child communicates information to others hoping that the person inviting the children to communicate can meet his needs. Successful health care requires effective communication between health care professionals, children escorts, and the child. Communication with children is different based on the children's growing age. In addition to communicating with children, good communication between parents and medical personnel and escorts must be well maintained. Communication between medical personnel, escorts, and children clients is also inseparable from the factors that can affect communication (Kurniati, 2017) cognitive, and sosioemosional, which are often intertwined. Development of the period include infants, children of early, middle and late, teen, and adult beginning. Jean Piaget's theory of cognitive development of children which involves important processes: schemes, assimilation, accommodation, organization, ekuilibrasi. In theory, of cognitive development occurs in the sequence of the four stages, namely remote motor (from birth up to the age of 2 years).

The implications of communication in health care, particularly for HIV-infected children, are critical for Klinik Teratai's medical personnel and a companion from the NGO Rumah Cemara. Among the various assessments or examinations on children that can be conducted through communication, including the implications: (1) Prior to communicating with children, it is preferable to communicate with their parents to gather information about them. Then examined; (2) Communication with children begins with storytelling or other

techniques that encourage the children to be open; (3) Before entering the core conversation, give the children toys to help them relax; (4) Give the children the opportunity to choose the location and position of the examination; (5) Avoid reviews that may cause trauma to the children, and (6) Allow the children to hold the tools used to alleviate fear.

They covered the magnitude of the psychological component in HIV-infected children. Thus, it requires general knowledge, habits, culture, values, embraced norms, and taboos to avoid. HIV is a critical component of HIV prevention efforts because it affects people whose lives are directly impacted by the virus. They are the most accurate and comprehensive source of information on HIV. This understanding is critical for everyone, especially those whose jobs involve HIV. Many are incorrect in their perceptions of HIV's role. Occasionally, ODHA is invited to participate, but not as members of society. HIV is frequently used solely to arouse curiosity. ODHA is commonly used as an example—in negative connotations, ODHA is used as a symbolic substance (the sign of participation only). By endorsing ODHA or inviting it to a meeting, one can demonstrate political correctness. Sadly, ODHA is only used as a pity angler and a commodity.

How an ODHA lives is interesting, but there are still people who ignore HIV. They are in demand because there is a reason for them. It is not always easy for people who do not understand to just laugh at him. They still want to find out how his life is going. A person with HIV or AIDS can have many different things happen to their body, mind, and social life. HIV infection and AIDS status (Acquired Immunodeficiency Syndrome) can have many other effects on these things, too (Balatif, 2020).

In addition to having clinical symptoms, an ODHA also has a lot of psychological and social problems. So, even though ODHA cannot get better, that does not mean that ODHA is not worth living. Whatever happens, ODHA still needs to interact with other people to grow its social grid in society. As a result, it still takes a lot of knowledge from both the medical and psychological sides to ensure that HIV and other people do not get together severely. This is especially true for ODHA itself. HIV can come back into contact with people in the middle of their lives, so they need to keep their health in

check. People who are around them also need to pay attention. Getting attention from people in the community, police officers, and the rest of the environment can make HIV more likely to stay alive and heal. However, after being found to have HIV, anxiety will quickly take over. Conflicts between the interests of the community and ODHA happen all the time. This leads to the ODHA getting more rights. These events happen to save society, but the reason for them is based on misinformation and myths that are spread in society, like the myth that AIDS is very deadly, dangerous, cannot be cured, is contagious, and cannot be stopped.

Stigma is associated with power and dominance in society. So at its peak, the stigma will create social inequality. Stigma is a sign or a mark that designates the bearer as “spoiled” and, therefore, as valued less than average people (Goffman, 2016). In the norms and structure of a root-veined stigma society, this leads to group inequality, in which one group is superior to the other. Discrimination occurs when negative views encourage people or institutions to mistreat a person based on their prejudice toward a person's HIV status (Balatif, 2020). Anytime and anywhere, stigma and discrimination can occur among families, communities, schools, places of worship, workplaces, and areas of legal and health services. People can discriminate in personal and professional capacities, while institutions can discriminate through policies and activities.

Since the incidence of new HIV infection occurs before a person is diagnosed with HIV, stigma and discrimination do not play a role in limiting efforts to prevent the spread of HIV. Even if someone with HIV/AIDS is subjected to stigma and discrimination, they will be prepared if industry standards conduct the test. If he is later found to have HIV, it is agreed upon during pre-test counseling that the transmission of HIV will cease from him onward. HIV can be transmitted unknowingly by people unaware that they are infected. They do not have to worry about stigma or discrimination because they do not do anything wrong.

Some people are reluctant to get an HIV test because of the negative stigma in society, leading to discrimination against people with the disease. Disseminating inaccurate information about HIV/AIDS strengthens the community's stigma and discrimination. An excellent

example of this is the association between HIV transmission and “casual sex, snacks,” and other forms of sexual promiscuity like adultery and prostitution. These things have nothing to do with the transmission of HIV during sexual contact. People who understand the importance of providing people with the facts about HIV and AIDS and good treatment for those who have the disease must do their part to eliminate stigma and discrimination. Local regulations (PERDA) always link HIV prevention and prevention to morals and “faith and piety,” providing inaccurate information about HIV because of its moral context. False stigma and discrimination are common in communities where this association is present. Even though a person eventually becomes an ODHA, it is not because they lack ‘faith and piety,’ but because they are infected with the HIV because it is transmitted, such as the wife of the husband or the baby/child becomes infected from his mother since the womb. This is not their fault.

The most crucial element in overcoming HIV is the existence of a form of promotion and protection of human rights. We all know that the rapid development of HIV has worsened, which paves the way for various forms of human rights violations afflicting. There are at least three interlinked paths where promoting and protecting human rights has an important relationship with HIV/AIDS. The points are the attack’s impact, response, and nature (vulnerability) (S.E.U. et al., 2018).

There is a stigma attached to HIV that affects people’s lives. To begin, let us consider the results (impact). In this case, the stigma imposed on HIV and its sufferers and the discrimination they face are related. According to many reports from ODHA, they have been subjected to discrimination and intimidation from their peers and coworkers because of their status. ODHA got prejudice, including the right to an education, a job, and good public service. Some ODHA were killed because they were serum-positive. Anxiety is a negative effect of the outbreak because it causes people to be afraid of infection and afraid that their human rights will be taken away (UNAIDS, 2016).

Secondly, it is vulnerable to attack. Human rights promotion and protection can be used to answer questions about the economic, social, and cultural conditions that lead to the infection of people with HIV. Women, gays,

and children were vulnerable to HIV infection in the past. Inevitably, the unfulfilled rights of sex workers, whistles and migrants, drug users and inmates, and those in prisons and jails are an issue for many. To fulfill their economic and cultural rights, women in this situation are often pressured into engaging in sexual activity they would rather avoid. Education and information are crucial for children who cannot access them. Such situations obstruct the implementation of HIV prevention and treatment initiatives.

Third, there is the response. This response aims to foster an environment conducive to implementing national HIV policies through the promotion and protection of human rights. Numerous critical factors influence the effectiveness of HIV/AIDS prevention and treatment programs, including freedom of expression, speech, negotiation, and the provision of information and education on related topics. According to the description, HIV prevention and treatment effectiveness are inextricably linked to the promotion and protection of human rights. As a result, when various organizations conduct human rights advocacy activities on a national and international level, ODHA’s human rights protection program takes precedence. Several legal sources serve as the foundation for the protection of human rights in the form of International Human Rights, including the International Covenant on Civil and Political Rights, the International Covenant on the Elimination of All Forms of Discrimination Against Women, the International Covenant on Economic, Social, and Cultural Rights, the International Covenant Against Torture, and the International Covenant on the Rights of the Child. Discrimination against HIV stems from all forms of abuse and violence directed at HIV.

It is possible to say that the communication component in HIV-infected children does not play a significant role in distinguishing one event. Other aspects of communication will be consistent in each communication event. Components of communication that do not play an important role include: (1) the message’s content, which is related to the language habits of HIV-infected children, which are no different from healthy children in general, with the difference being only the children’s health conditions because the language skills of anyone infected with HIV are the same as

those of healthy children in general when they are confronted face to face. (2) The order of activities on this communication component is also fixed because communication will involve the same sequence of actions at all events.

Understanding the components of communication in HIV is essential to understand. People living with HIV might experience abnormalities in language, phonology, sound, and swallowing (Downes & Foote, 2019). It is necessary to know if there are specific behaviors in which HIV/AIDS can affect pediatric and adult patients' speech, language, hearing, and swallowing. Various programs to prevent the spread of HIV can be done more optimally by targeting many goals and interacting more with populations that are not infected with the virus (Konda et al., 2017)9- and 18-months. GEE models assessed associations with HIV status communication at baseline using prevalence ratios (PRs). The negative stigma about HIV can be eliminated by providing information using various informal media and social networks that can change the stigma on behavior change. (Schwartz & Grimm, 2019).

## CONCLUSION

According to an ethnographic study of communication, the genre or type of communication event experienced by HIV-infected children refers to delivery forms such as HIV disease problems, treatment problems, and conversations about daily experiences about the children's condition. In this case, several informants have received information about their health conditions from their parents. This means that parents require their children's cooperation to be obedient, routine, and consistent in the treatment problems that must be lived. Compliance to be disciplined in taking anti-retroviral drugs, among other things. At the same time, the location of interactions with volunteers or medical personnel in Klinik Teratai, Rumah Cemara, and informants' homes is the setting, message forum, and message content. Informant conversations at Klinik Teratai, Rumah Cemara, and homes are usually about the children's health development. The contents of messages provide mutual encouragement and psychological support to people with HIV/AIDS. Children use nonverbal

communication in smiles, nods of the head, and loud laughter.

It is expected that research on an ethnographic study of communication in HIV-infected children will provide input and technical images that can be used for child protection, particularly in HIV-infected children. Furthermore, the research is expected to contribute ideas to the government, mass media, NGOs, and other parties involved in developing regulations, policies, and implementations related to protecting HIV-infected children from violence and discrimination. Another hope is to change people's perspectives and treatment of society in HIV-infected children, allowing them to live, develop, and participate in the community while still obtaining their rights by the dignity of humanity.

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