

# The Communication Pattern of Community based Organization in Preventing and Caring of People Living with HIV/AIDS in Bali

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**Abstract---** Bali is a region in Indonesia that has significantly contributed to spreading HIV Virus to workers in various sectors. The workers' origins are from many areas in Indonesia, but East Java has the most significant contribution. Its data records from two Community Based Organization (CBO), namely Yayasan Kesehatan Bali (YAKEBA) and Yayasan Kerti Praja (YKP) in Bali. This research focuses on describing the model communication of YAKEBA and YKP as the CBOs in handling HIV/AIDS in Bali. It aims to reveal the method of YAKEBA and YKP in identified and described HIV/AIDS cases; as well as to reveal the model communication of YAKEBA and YKP in preventing and caring of PLWHA. The result shows that YAKEBA and YKP are taken preventive and curatives measures systematically in handling HIV/AIDS in Bali. The actions conduct with two methods, which are a mobile visitation and snowball toward the hidden population or key population (communities). The CBOs in Bali are employed model interpersonal communication with face-to-face methods toward People Living with HIV (PLWH). Moreover, to the LGBT communities, the CBOs utilize social media. As for the public, they apply group communication to promote and educate people on HIV/AIDS.

**Keywords---** Communication Pattern, Community-Based Organization, HIV/AIDS, Model Communication; PLWH.

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## I. INTRODUCTION

Bali is the first province in Indonesia that has found HIV/AIDS cases in 1987 [1]. Now, Bali is the fourth highest province with HIV/AIDS cases. The details are East Java (16,911), Papua (13,398), DKI Jakarta (8,648), Bali (6,803), Central Java (6,444), West Java (5,251), North Sumatra (3,897), South Sulawesi (2,812), West Kalimantan (2,567) and NTT (1954). p;[According to ORBIT Foundation in East Java, who is concerned in coaching People Living with HIV/AIDS (PLWH), stated that, in general, PLWH in East Java who got infected with HIV/AIDS while they were working in Bali. This statement is in-line with the report from the YAKEBA; it is said that most of PLWH who is currently working in Bali, relatively origins from Surabaya and its surrounding areas in East Java. This phenomenon illustrates that Bali is considered as one of the places of HIV/AIDS transmission, especially for PLWH in the Surabaya area.

Bali has been stated as the fourth biggest HIV/AIDS case. However, the facts that are found from the test conducted to key populations, most of the people who are infected are generally origins from the East Java Province. It means Bali is the HIV/AIDS spreading area for the key population who will ultimately infect the closest people,

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especially those who have sexual contact with them. The key population or hidden population is a term that refers to a group of vulnerable people who have a higher chance of infecting HIV/AIDS. Many factors made Bali well-known as a place for spreading HIV/AIDS. One of them is the reputation of Bali as a prime tourist destination in Indonesia, both for domestic and foreign tourists. This reputation has encouraged the emergence of entertainment areas like discos, nightclubs, karaoke, and spas. These places are often colored by "concealed sexual transactions."

Moreover, to anticipate a large number of tourists, many hotels and villas are built. Consequently, these buildings require a lot of construction workers, which are mostly recruited from Surabaya, Jember and Malang, places in East Java as the nearest region. These workers who are primarily male usually have to stay for months or even years. They need entertainment, which leads them to visit female sex workers localizations. Whereas women who work there also come mainly from the East Java region. This phenomenon raises the assumption that the number of cases of HIV-AIDS in East Java is the impact of East Javanese people's behavior while they were staying in Bali. Having observed this situation, Bali could be the third-largest number of HIV-AIDS cases in Indonesia.

The latest data reported by Spiritia Foundation Jakarta [2], shows that the highest percentage of HIV risk factor is heterosexual relationship (53%), while 35% are from the MSM (Male Sex Male), 11% are from other types of relationships, and 1% are from the use of unsterilized needles in IDUs. Meanwhile, the highest percentage of AIDS risk factors are also heterosexual relationships (71.9%), whereas MSM at 21.3%, prenatal at 3.6%, and unsterilized needle syringe in IDUs at 2.5%. The percentage of men is twice as bigger as it of women. The above data become valuable references for the parties in HIV/AIDS prevention, including for *Yayasan Kesehatan Bali* (YAKEBA) and *Yayasan Kerja Praja* (YKP) in Bali. These parties will be called Community Based Organizations (CBO) for further references to this article.

The data indicate social problems that need to be addressed or responded through mass media. However, even though mass media can reach large populations, there is no guarantee that the intended message can be fully understood by the audience. Therefore, the interpersonal communication approach is needed to change the attitude and behavior of the targeted audience. In this context, the targeted audience is People Living with HIV/AIDS (PLWHA).

Many studies and pieces of literature exist related to communication in terms of HIV/AIDS prevention. However, none of them mentioned the involvement of Community Based Organization. For instance, Trijupitasari & Riauan [3] discussed the communication pattern of The Aids Commission Pekanbaru in socializing the danger of HIV and AIDS to the gay community and sex workers. Another study that was conducted by Fitriyah [4] has illustrated the communication strategy of The Aids Commission Banten in handling the HIV/AIDS epidemic. Therefore, this study tries to explore the activities of CBOs in Bali that support the prevention and caring of HIV/AIDS.

## II. LITERATURE REVIEW

Health communication can be defined as a method of informing, influencing, and motivating the individual, community, and public decisions that enhance health [5], [6]. It also has powerful effects on attitudes, knowledge, social norms, risk perceptions, and behavioral decisions. How it can affect and when the virus is transmitted, where

and when testing or care is sought, how care is delivered, and how well adherence to antiretroviral therapy (ART) is maintained [7]. It plays a fundamental role in preventing the spread of HIV as for many other aspects of health issues. When it failed, it can lead to stigma and discrimination towards the virus or the people with the virus.

In Bangil City, East Java, Indonesia, Ahwan [8] stated that due to lack of knowledge about HIV/AIDS Islam community, Nahdlatul Ulama (NU) do stigma and discrimination towards PLWH. Their perception of HIV/AIDS as a filthy disease, the myths surrounding their society and misperception in religion, strengthen negative behavior towards PLWH. Maharani [9] found that PLWHA receives discrimination during their treatments and services in the hospital, even after they died, the medical workers are portrayed negative attitudes.

PLWH tends to receive stigma and discrimination because HIV is associated with bad behavior such as prostitution or promiscuity [10]. A study by Shaluhayah, et al. [11] in Grobogan District, Central Java, Indonesia, most of its participants got infected while they were working in the big cities and were engaged in risky sexual behavior. The family who supposed to play as a support system shows stigma that causes self-pity within PLWH. Its response can hold back up the program of decreasing stigma, providing comprehend information to the families and the public may decrease the stigma [11].

PLWH, who gets helped from NGOs, tends to have more confidence than PLWH who is not. Self-disclosure is conducted as a sign of personal health and satisfaction. Sanjaya [12] revealed that PLWH who do self-disclosure with their family, friends, and community, relatively have a strong motivation to have a better quality of life. Raising awareness of the key population to promote behavior change and gain knowledge of the public on HIV/AIDS may promote reducing the spreading of HIV/AIDS. The research on the communication perspective that is implemented in this study can bring wider and comprehend information that can be useful to reduce the problem of HIV/AIDS more comprehensible.

### **III. RESEARCH METHOD**

This research applied a case study as a research methodology. The case study investigates a contemporary phenomenon in depth and within its real-life context, especially when the boundaries between phenomenon and context are not evident [13]. Mulyana [14] stated that a case study is a comprehensive explanation and description of various aspects as an individual, groups, communities, programs, or social situation.

To have a comprehensive cognition on how the communication pattern of CBO in preventing and caring PLWH in Bali, two Community Based Organizations (CBO) which are Yayasan Kesehatan Bali (YAKEBA) and Yayasan Kerti Praja (YKP). The data is gathered through depth interviews with the leaders/managers organization to have wide, comprehensive information of their programs, as well as their outreach to perceive the real-condition on the field.

Interview sought information related to their knowledge, perception, and understanding about HIV/AIDS in Bali, the current challenges of the PLWH faced within their communities. It also sought their program on the prevention and care for HIV/AIDS, and their method to executes in terms of communication. The interviews were last approximately about 2-3 hours at the office of the CBO and it also audio-recorded and transcribed.

## **IV. RESULT AND DISCUSSION**

### ***a. Identifying HIV-AIDS cases in Bali***

The Community-Based Organizations (CBO) aware that the Hidden Population/Key Population has an important role in spreading HIV/AIDS. The key population consists of Female Sex Workers (FSW), Male Sex Male (Gay), Transgender, Injecting Drug Users (IDUs), and FSW's Consumers. Therefore, CBO's field officers who have a role as peer consolors do the outreach to identify cases of HIV-AIDS directly inside the key population. The process of outreach is determined by the targeted population and areas.

YAKEBA proactively visited the key population; in this case, commercial sex workers and construction workers. The visit has to be conducted with legal permission for the outreach to be ably conducting socialization on HIV/AIDS and promote HIV tests while YKP has a different area in approaching and visiting key populations. They directly go to the localization area and entertainment areas, such as karaoke places, night clubs, and Spas. Its visitation sometimes is accompanied by the officials from the Social Services. Similar to what is conducted by YAKEBA, the outreach from YKP does socialization by presenting comprehensive information on HIV/AIDS. Information consists of how the virus can be transferred, who can be infected by this virus, how to stay safe from the virus, and such, and it will be followed by HIV testing.

However, for the Lesbian, Gay, Bisexual, and Transgender (LGBT) communities, the CBO's outreach conduct socialization through social media. The key population is found by the outreach who formerly part of LGBT communities. They contacted their friends or colleagues who are still in a "role as LGBT" position. The outreach goes to specifics groups that are done by the snowball method. This proactive method by visiting the hidden population is known as "mobile visitation."

They have several methods to cover problems in handling HIV/AIDS. Alongside mobile visitation, the community in Bali has requested to CBO to give socialization to their society (Banjar-Banjar) by presenting information and education about the misuse of drugs, as well as HIV/AIDS. This method is a part of CBO's method in preventing the spreading of HIV/AIDS, but this method is not followed by doing the HIV test.

The mobile visitation method has more useful in reducing the spread of HI/AIDS since it will be followed by an HIV test. The CBO's eventually can obtain the data on each key population. Moreover, it can be known the number of positive infected by HIV or not. By knowing this amount of number, the preventive program of spreading HIV/AIDS can be done.

After the key population did the test and received the result, the CBO can identify the key population who are positive or negative of HIV/AIDS. On that account, the outreach can take the next step by referring to the client's wants and needs. For clients who are HIV test results are negative, the outreach gives information on how they should take care of their health. Avoiding risky behavior by staying safe, for example, for sex workers are encourage for using condoms, so they will not get infected with the virus and to prevent the spread of HIV/AIDS. In the following months, the CBO will contact the negative client of HIV/AIDS and do a re-test. This method continues happening to the key population as long as they still on high-risk behavior.

Meanwhile, people who are tested positive HIV, the CBO will provide an assisting and consulting routine. The CBO will give information on where they can access Anti-Retroviral (ARV), as until now it is the only medicine that can delay the growth of the HIV in the body, in the result PLWH can have a better quality of life.

As it has explained above, the biggest key population in Bali is origin from the cities or districts in East Java province, especially from Surabaya or/and surrounding areas. The people who are positive infected HIV and decided to not stay in Bali, and prefer to return to their home areas, the CBO provides recommendations and referrals to continue the treatment at Community Health Clinic (Puskesmas), or local hospitals, or local CBOs. It shows that there is a cooperation between CBOs in Bali with CBOs and Hospitals in Surabaya. The process of identifying and managing HIV/AIDS in Bali can be illustrated in the figure of model communication entitled The Communication Patterns of Community Based Organization in Preventing and Caring of People Living with HIV/AIDS in Bali.

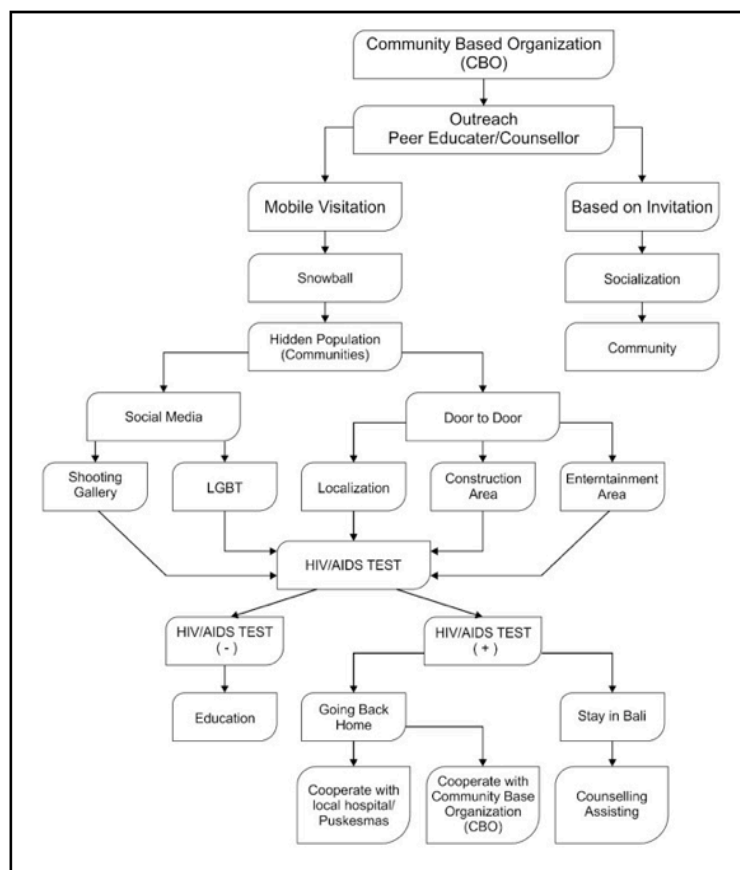


Figure 1: Communication Pattern of Community Based Organization in Preventing and Caring of People Living with HIV/AIDS in Bali

Source: Research Data

**b. CBO's Communication Pattern in Handling with HIV-AIDS in Bali**

In identifying HIV/AIDS, the outreach of the CBO applies interpersonal communication as an approach. By using this approach, people can share their ideas, information, experiences, and even their feelings or personal. It is an effective method for the CBO in gathering data and information from the key population. As mentioned above that the key population is not easy to be approached; many of the outreach are a former or still a part of the

community. Most of the key population want to be invisible; they do not want their HIV status to be known by others. Therefore, the outreach comes from their world, for instance the outreach for the sex worker is a former/still sex worker, the outreach for the IDUs community is a former drugs user, as well as the outreach for the Gay community, usually the member of the community who has concern on HIV/AIDS.

Having a similar social and cultural background of an individual can have an effective communication [15, p. 117]. Therefore, by choosing the outreach who has a similar background with the client in the aspect of frame of reference and field of experience, can make an effective and harmonies communication because of the client's trust. It is a key aspect for the message recipient to receives the information comprehensively and well-accepted, to be able to change their behavior towards good behavior [16, p. 129]. The most important factor affecting interpersonal communication is the trust factor. Interpersonal trust is one of the major themes which has a substantial role in managing human capital effectively [17]. It started since the first stage of interpersonal relations (stage of introduction), to the affirmation stage, trust determines the effectiveness of communication. Rakhmat [16, p. 131] stated that trust is grown by accepting, empathy, and honesty. Accepting is the ability to relate with others without judgment and without seeking to control. Trust is emerged by seeing and treating other people as human beings who have equal rights with no differentiation. In the context of this study, it has become the understanding for the outreach that when they do interpersonal communication with their clients, they cannot force the clients to change their behavior based on the outreach opinion, but because of they willing to change voluntarily.

Furthermore, to cultivates, the self-confidence of others is the empathy factor is needed. Empathy is imaginative intellectual and emotional by putting yourself in other people's shoes. It means imagining ourselves in the events that happen to others. With empathy, we try to see as others see, feel as others feel [16, p. 132]. It is similar to what is conducted by the outreach; they empathize with their respective clients, namely Sex Worker, LGBT, and IDUs, especially with people living with HIV/AIDS (PLWH).

Moreover, another factor that generates trust is honesty. When we put trust in people, who have no false pretensions, honesty causes our behavior can be suspected. It encourages others to believe in us. When the outreach first contacts the client personally, the outreach has to be firmly, clearly, and honestly opened up, so the client can put trust, in the end, both parties become good partners and cooperate in dealing with the problem together. Another attitude that can lead to trust is a supportive factor; it is because supportive will reduce defensive reactions [16, p. 133].

Group communication also applies by the outreach to reach the key population, whether as an individual or in the community. In the context of group communication, the outreach has to play the role as a part of the group of the key populations, so they able to share their spirit of togetherness [16, p. 144]. The interaction in groups between the outreach and the client shared their common purpose, and mutual influence is the essence of a group.

To prevent the spreading of HIV/AIDS epidemic, proper and comprehensive communication is needed. In this case, communication plays a tool in presenting information on HIV/AIDS to the public as well as the PLWH. This socialization is an approaching method to raise awareness of PLWH. Therefore, persuasive communication will affect behavioral change, and it is useful when the message's format is tailored to match people's information

processing tendencies [18][19] — related to this research, the outreach of the CBO in Bali in handling HIV/AIDS epidemic they applying persuasive communication whether face-to-face communication or using social media.

## V. CONCLUSION

The results showed that the Community Based Organization (CBO) carried out preventive and curative actions in handling HIV/AIDS in Bali in a systematic and gradually method. In the first step, the outreach is actively visiting the home-based HIV/AIDS spreading places (hidden population) to socialize and test HIV. In the second step, the CBOs identify the clients who are negative or positive infected by HIV.

In the third step, the outreach educates the clients who are HIV negative, provides assisting and counseling for HIV/AIDS positive clients. In the fourth step, the CBO collaborates with a community health clinic, local community-based organizations and also local hospitals, for people living with HIV/AIDS (PLWH) when they are going back to their origins or their home areas.

Other preventive measures, of YAKEBA and YKP, also conducted Communication, Information and Education about HIV/AIDS to the general public. Therefore, the research found that Community-Based Organizations (CBO) in Bali applying interpersonal communication patterns either in face to face method or through social media, as well as group communication for facing the general public in handling HIV/AIDS epidemic. The similarity of Frame of References and Field of Experiences between outreach as a peer counselor with its clients (Sex Worker, LGBT, IDUs) has created effective communication between the two parties. Empathy, Honesty, Accepting, and Supportive are the factors that influence the success of interpersonal communication to grown the Client's trust in the outreach as a peer counselor. Persuasive Communication that is done by the outreach can reduce the spreading of HIV/AIDS that also known as *harm reduction*.

## VI. LIMITATIONS AND STUDY FORWARD

This research has not covered all of the critical areas in HIV/AIDS cases, such as Papua and Kepulauan Riau (Kepri), which are the two highest HIV/AIDS population in Indonesia. Therefore, the authors looking forward to having an opportunity to researching those areas where they have not been covered.

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