

Peer Support Group Health Literacy Case Study of HIVAIDS Patients in Karawang, Indonesia

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Abstract

The high mortality rate caused by HIV still leaves jobs for governments in developing countries, including in Indonesia; the government's efforts to reduce the death rate due to HIV certainly require support and community participation. Peer support groups were born as a form of community concern to complete and carry out health literacy to the community, both those affected by HIV and those who are not well literate about HIV. This study aims to see the communication activities carried out by members of peer support groups to patients infected with HIV and how peer support groups' efforts to carry out health literacy for HIV patients and the surrounding community. This research uses a case study approach that begins with what and how questions to form a scientific narrative of a case. This study's findings are that peer support groups carry out communication activities in the form of support when receiving test results from HIV-infected patients, creating mentoring groups to increase the self-potential of their members, literacy, and mentoring healthy lifestyles for group members. Peer support groups are also conducting various collaborations with the local government to conduct outreach and cooperation to prove that HIV-infected patients can live an everyday life.

Keywords: Health Literacy, Peer Support Groups, Group Communication, Health Communication

Introduction

Based on data from UNAIDS, there are 36.9 million people in the world living side by side with HIVAIDS sufferers in 2017. Of the total sufferers, 1.8 million are children under 15 years old; still, more people with HIVAIDS are women from this data. Namely 18.2 million and males 16.9 million. Indonesia is in third place with 5.2 million sufferers. Indonesia is a country that contributes to a figure of 620,000 out of a total of 5.2 million people in the Asia Pacific. Not everyone can accept HIVAIDS, considering that HIVAIDS is still a disease that is considered dirty because people with it are identical with immoral acts such as changing partners, drugs, and other sexual disorders even though anyone can get HIVAIDS, including children. The

problem of transmitting the HIV/AIDS virus is a health problem, and it requires a literacy process in the community to provide support and avoid negative stigma to those affected by the virus. Until now, people still think that people with HIV/AIDS cannot live normally and side by side in the community and tend to be shunned, even though people with HIV/AIDS need help to live everyday life, have a healthy lifestyle, and carry out therapy according to doctor's instructions.

In a study conducted by Brashers et al., It was reported that those who were not well literate about their illness would feel indistinct pain and depression. Therefore, we need superior support from the community in society to solve the problem. It would be excellent if everyone who has information deficiencies seeks non-medical support so that it will be easier to solve the problem and the costs will be less (1). Cases of stigma and discrimination and violations of rights are often concerning for people with HIV/AIDS, making people with HIV / AIDS close themselves to anyone, even their closest people. When people with HIV/AIDS are worried about discrimination, they are reluctant to get therapy. HIV stigma remains a significant problem of the AIDS epidemic in Africa (2), a support and health literacy are needed for people with HIV/AIDS (3) so that they can understand how to live a healthy life (4). When a person is declared to have HIV / AIDS, their immediate environment must prepare a condition so that people with HIV/AIDS can understand what they are suffering from and live like ordinary people and still follow the doctor's recommendations (5).

Peer support groups become a platform for those infected to support each other; discrimination and barriers to health access are resolved together. In the two decades since it was initiated in 1995, peer support groups have been active in Indonesia's regions. It cannot be denied that there are many problems and challenges to transforming peer support groups into meaningful organizations for people living with HIV/AIDS. Peer support groups exist as a form of support for people with HIV/AIDS so that they have the enthusiasm to live and believe that people with HIV/AIDS can live everyday life as long as they can change their lifestyle into a healthy lifestyle to health principles. A peer support group in Karawang Regency was present in 2017 as a form of the Bandung Female Foundation's concern for people with HIV/AIDS in Karawang Regency, a peer support group in collaboration with health workers Karawang Regency to provide psychological support and conduct surveillance for people with HIV / AIDS.

It is not easy for people living with HIV/AIDS to accept that they have HIV, given the negative stigma in society regarding people with HIV/AIDS. It takes simultaneous support, communication, and literacy to produce a change in the community's behavior and people living with HIV. Health communication must be present to change behavior in seeing and living life for people infected with HIV. The challenge of health communication is how to make people living with HIV want to live a healthy lifestyle and change behavior on an ongoing basis, and communication is a high contributor to resolving HIV (6). Health campaigns (7), use of social media (8), peer support groups, and public health literacy about HIV are expected to be among the big agendas to save the nation's next generation. This study aims to examine further how the communication activities of peer support groups in providing support to people living with HIV in Karawang Regency. This research will use a qualitative method of case study approach

Method

In research on the communication activities of peer support groups in Karawang Regency, the researcher uses qualitative research methods. This qualitative study is supported by a constructionist and narrative philosophy (9). Qualitative research aims to construct a story that comes from the sources involved in it. This time's qualitative approach is a case study, a research approach that departs from the why and how questions. This study's case is a single case, namely the communication activities of peer support groups in Karawang Regency.

In the research of peer support group communication activities, researchers conducted in-depth interviews and observations to health workers and members of peer support groups and peer support group companion participants with the criteria that the group members being interviewed were those who actively carried out communication activities that aimed to provide literacy-related to lifestyle information—healthy people with HIV/AIDS and their assistance. In-depth interviews were conducted to gather as much information as possible from sources regarding communication activities and the communication strategies used in the communication approach to people living with HIV/AIDS. Interviews in qualitative research are conducted by meeting separate sources one by one to obtain the information needed in the study (10). Then the data obtained is collected and reduced so that the data is sufficient to answer the questions and research objectives,

then the researcher triangulates the data to the informants and confirms the findings in the field to the relevant health communication theory. Data triangulation or checking the validity of data can be done through sources where the research results that have been compiled are read back to the informants to ensure that the data is correct (11). Triangulation can also be done by confirming the findings to the theory (12).

Result and Discussion

Resilience has different definitions depending on the conditions at hand (13). Resilience concerns a person's psychological problems and how they survive when facing life's problems (14). HIV as a virus that is considered deadly, and the public thinks badly of those who are exposed to the virus, therefore; not all health workers can tell patients the fact that they are exposed to HIV; there is a preparatory process carried out by health workers to inform the patient's examination results when they are declared to have HIV (15). Building resilience for those affected by HIV is essential, considering that HIV not only hurts the patient's body but also destroys the patient's psychology (16).

A peer support group is a group formed based on individuals' voluntary and willingness to help HIV patients lead an everyday life like the average person. On average, peer support group members are those who are indicated by HIV and can accept the condition and live like ordinary people
(results of interview with participant 1)

A peer support group is a group that comes from a particular community concern for PLWHA. One of the peer support groups present in Karawang Regency is the Harapan Hati peer support group, the Harapan Hati peer support group was formed on 22 April 2013.

Harapan Hati peer support group always welcomes anyone who wants to join. In Karawang itself, peer support groups have been formed with various characteristics and needs, in line with the increasing presence of peer support groups and the number of cases requiring immediate assistance. Harapan Hati peer support group consists of 60 members with a closed meeting and home-visit program to help support programs for increasing support for PLWHA in preventing HIV / AIDS transmission in the City of Karawang
(Results of an interview with participants 2)

Peer support groups exist to give HIV/AIDS sufferers strength to keep their spirit to live and live well. Stigma in society sometimes becomes a scourge that aggravates the psychological condition of PLWHA itself; in some cases, related to psychology, communication and mentoring can accelerate the handling of mental health problems in patients. The

existence of peer support groups much helps the number of health workers who are smaller in number than the patients served

As an extension of health workers to advocate for HIV patients, peer support group members are first given health literacy related to how to live and how people living with HIV should live their lives in order to reduce the risk of death and the risk of transmission to the community
(Result of interview participant 1)

Peer support groups are partners of health workers to carry out literacy and surveillance of HIV patients. Peer support groups' existence is an immensely profitable alternative considering that most members of peer support groups have the same fate as HIV patients. Some group members in peer support groups are infected with HIV; these peer support group members will be easier to empathize with because they feel what the patient felt. To empathize in this case is to position yourself in the position of others

Harapan Hati's peer support group has a vision and mission to improve the quality of human resources for people with HIV/AIDS to be more independent and empowered, both individually and in groups. Through skills and involvement and collaboration between peer support groups and stakeholders.
(Results of interviews with participant 3)

A stigma in society that sees people with HIV/AIDS associated with free sex, drugs, and other immoral acts leads people with HIV/AIDS to be caused by differences in behavior towards people with HIV/AIDS. This causes people with HIV/AIDS to have limitations in accessing some of their needs, such as getting services at the hospital and obtaining drugs needed by people with HIV/AIDS, not infrequently even in some studies, the stigma comes from the health workers themselves (17). Peer support groups were formed to facilitate people with HIV/AIDS to respond to the needs and strengthen people with HIV/AIDS in the City of Karawang in the HIV / AIDS Prevention and Control Program to get full access to services and support.

The aim of the peer support group itself is to provide a forum for understanding, acceptance, and self-determination, provide free information, education, empowerment, and support for its members, be able to be a useful complement to existing treatments/treatments, and be able to be a force in influencing motivation and develop self-confidence in behavior.
(Results of interviews with participant 4)

It is not an easy thing when someone is declared sick, and sometimes it is not just about the pain that is felt by the body but psychological pain; how will people treat even those closest to them if they find out that the patient is infected with a deadly virus. The existence of peer support groups not only provides literacy about what and how to deal with the virus but also seeks meaning from life in the future.

When it was stated that I had HIV, the world seemed to collapse. I never thought that my sexual behavior would cause such a big problem in my life. If it is like this, it feels sorry to want to go back to the past, but it is impossible, said the nurse and the doctor who told me how I could live an everyday life provided I have to change my behavior and continue to take the medicine that was given
(Results of partisan interview 5)

Being infected with a virus that is dangerous but has a bad stigma in society will have an impact not only on the physical but also on the psychology of the sufferer, especially if the patient is not ready for the conditions that must be lived.

It is not easy to prepare a patient to accept that he is infected with HIV, let alone accept it; just asking for a checkup is not easy. I have a patient, the signs that he has HIV can be seen from his physical appearance, he is also a sex worker, you can say all the conditions that appear to lead to a diagnosis of being infected with the HIV, but the patient refuses to be tested even if we are health workers. If the patient has refused, then we need the help of peer support groups to literate the patient, make an approach, and provide moral support so that the patient wants to be examined.
(Results of an interview with participants 6)

A process is carried out to prepare a patient to accept the condition that he is exposed to the HIV/AIDS virus; the preparation process is carried out by trained and certified health workers issued by the Health Office. Voluntary counseling and testing are defined as voluntary HIV testing and counseling. This service aims to assist the prevention, care, and treatment of people with HIV / AIDS. Voluntary counseling and testing can be done at community health centers, hospitals, or clinics that provide voluntary counseling and testing services. Prevention of HIV transmission by conducting voluntary testing has been proven to reduce the incidence of infection by the HIV (18); by conducting tests voluntarily and with full awareness, patients without coercion will want to take further treatment and change their lifestyle. To get the willingness to do the test voluntarily, various supporting efforts are needed to convince the patient. Communities that support healthy behavior change provide

literacy and show how to live life when infected with HIV help the self-acceptance of patients infected with HIV (19).

One of the activities carried out by the leading management of the peer support group is working with nurses and doctors in charge of voluntary counseling and testing activities. Health workers maintain the privacy of patients who are going to have HIV checks. Usually, we visit the polyclinic, and we do not interfere in the voluntary counseling and testing process. The circle of those infected with HIV is very narrow, and they are exposed to the virus; some of the incidents are caused by unhealthy lifestyles or inappropriate behavior, so because some of our members are also those in that circle so mostly we know each other because some of us also have experienced how to receive news for the first time we were told we were infected so we could empathize with those who were newly diagnosed with HIV because we came with good intentions to accompany them through life. Hence, they wanted to open up to us and tell us about their conditions.

(Results of Interview with participants 3)

The communication activities carried out by peer support group members by providing time and accompanying the reading of the results of the examination of HIV-infected patients are certainly an essential period in the process of self-acceptance from HIV patients themselves. Support from a community will have a positive effect on patients (20). The communication process is expected to help patients understand their condition, make a life plan that will be lived, and the therapy that patients with HIV/AIDS should carry out. Community support can also prevent patients from the social isolation that their environment may carry out (21) so that patients infected with HIV can live everyday life with a healthy lifestyle, have an optimistic mind, and prevent transmission to others.

Some cases of people with HIV/AIDS do not understand the disease or feel hopeless with the virus in their body so that they think of transmitting the virus to others by not changing their lifestyle, free sex without protective equipment, using narcotics, even messing up their lives hoping that they are fast die and many people have the same fate as him this will undoubtedly be detrimental not only to patients but to many people. That is why peer support groups are consistent in assisting so that this does not happen and the death rate due to HIV can be reduced, maybe even eliminated on this earth. Peer support groups are also actively working with stakeholders in Karawang Regency, and we are not only collaborating with the government, but we are also trying to collaborate with private institutions such as several companies in Karawang Regency to provide guidance and training to our members so that everyone with HIV/AIDS can stay productive and working and can generate money for daily life.

(Results of an interview with participant 3)

Peer support groups' presence is significant support for people with HIV/AIDS, health literacy activities in the form of mentoring, increasing health knowledge, and being part of the self-acceptance process of these patients can make them realize that life must continue and not just stop when diagnosed with exposure. HIV/AIDS virus (22). Communicating in groups helps someone realize their position in society; communication in groups can prevent communication actors from isolating the communication freeze (23). The ability to empathize with each group member with similar experiences brings each actor of communication to share problems without the fear that they will be isolated; the convenience of communication in the activities carried out will bring each group member to effective communication to achieve the goals desired by each member of the group.

Some people with HIV AID is infected with the virus due to their behavior, such as commercial sex workers, drug users who use sharing needles, or those who have sex deviations. However, not all patients are infected in the way mentioned earlier, and there is also a wife who is infected from a husband who likes to snack behind his wife or children who are born not according to established procedures for HIV-infected mothers. Peer support groups exist to accompany patients infected with HIV to help them stop blaming themselves or others, change their lifestyle and remain productive in the right way to live long and not pass the virus on to others.

(a result of an interview with participant 3)

Health literacy is the primary key in reducing the spread of HIV; carrying out literacy means educating patients infected with HIV and the surrounding community. Self-acceptance of a condition faced by an HIV patient must be accompanied by sufficient knowledge about the disease he is suffering from, such as how to live a healthy life, change behavior and do the best therapy for diseases in his body. Health literacy is a situational factor that plays an essential role in people's lives, especially for those who suffer from certain diseases; the sophistication of communication and information technology may play an essential role in providing health information (24) but in some cases, for those affected by chronic disease, discussing with someone instead more desirable and reliable (25). Peer support groups in the necessary conditions of self-acceptance are a solution for people with HIV/AIDS.

Group communication-built inequality of communication actors is considered a sufficiently helpful factor for achieving effective communication. In activities carried out by peer support groups, by developing a sense of empathy among the actors of peer support group communication, it is hoped that each communicator will pass through a stage of real

empathy, namely when the communicator can tell himself that they had gone through such a period and want others to do attitude as desired by him when he passed the vase. Altman and Dalmas likened humans to onions (26). Human nature consists of several layers. The outer layer of skin is the layer that other humans recognize and recognize, and the outermost layer looks like what other humans want in the social sphere so that what is seen by other humans does not necessarily describe what a human look like. The innermost layer is the most honest, and sometimes a human being wants to hide. Humans' innermost layer is the most special and is kept by humans as the essential part or secret that they only want to share with certain people who can be trusted.

The innermost layer of the human being determines how close a relationship can be; in terms of dealing with the principle of profit and loss, it is also considered to build a relationship. Some communication actors calculate the advantages and disadvantages that will be caused by a relationship. If a relationship generates benefits and satisfaction from all parties, the relationship will develop in a closer direction to achieve each communicator's goals. Likewise, with the relationship process that occurs within peer support group members, each communication actor certainly has their own goals in dealing. The approach taken by peer support group members to patients infected with HIV is carried out by promoting a sense of empathy and sincerity that can be felt by patients who finally open up and join joint support group members; when the patient can open up, it will be easy to establish effective communication.

The psychological burden experienced by people with HIVAIDS will more or less be lifted if there are groups that support each other; failure to accept people with HIVAIDS in some cases hurts those around them. The lack of understanding and from people with HIVAIDS is likely to result in more and more people being infected with this vision as well as public ignorance, and the negative stigma that HIVAIDS sufferers get will become a mental burden and make them depressed so that they self-isolate and worsen with the illness they suffer. Therefore it is essential to establish effective communication with various parties so that people and people with HIVAIDS can have an understanding of the HIVAIDS virus.

Peer support groups exist to increase people's confidence with HIVAIDS to live a good life without being afraid to connect and collaborate with other people. On several occasions, volunteers who joined peer support groups helped socialize how to live healthily and avoid sexual violence, often in patients who feel insecure and intimidated by their immediate

environment. Peer support group interventions also help HIV/AIDS sufferers manage the emotions possessed by HIV/AIDS sufferers. Peer support groups are considered sufficient to reduce the incidence of HIV/AIDS deaths and the rate of HIV/AIDS transmission itself.

Advances in communication and information technology have had a significant impact on the world of traditional health, and people can quickly get information about all things on this earth, including about the HIV/AIDS virus. Unfortunately, the information obtained is sometimes not all true, and it is rare for the community to re-check the truth of the information obtained (27). It is not uncommon for social media to be used as a reference for seeking health information (28); peer support groups are present and participate in health literacy to ensure that people obtain accurate information related to HIV. Health information-seeking behavior will become a reference for everyone for decision making (29); therefore, peer support groups in the community should receive attention and obtain policy support from both local government and community governments. Policymakers must consider and make peer support groups as partners in efforts to reduce the HIV transmission rate.

Resources for the management and activities of peer support groups still depend on group members' care and active participation. This is still a challenge for the sustainability of peer support group organizations. Therefore, peer support groups' existence and sustainability are still very much needed to play an active role in AIDS prevention efforts. Strengthening peer support groups can be done by increasing resources, strengthening financial capacity, building networks or partnerships with other parties, such as the government and the private sector, and increasing access to information and resources. In general, an organization becomes weak without substantial material resources, which is critical to play a role in organizational development. To strengthen the peer support group organization, the initiator group's role is essential to encourage the formation of peer support groups and strengthen the organization to maintain the sustainability of peer support groups. Strengthening peer support groups can be done by developing technical and strategic skills for institutional strengthening of peer support groups to lead to strategic needs for sustainability purposes. Another strategy is to explore and mobilize other funding sources, both local and business diversification, by developing a funding pattern, which brings benefits to the institution.

Conclusion

One of the efforts to reduce HIV-infected patients' mortality rate can be made by conducting health literacy to those who are indicated to have been exposed to HIV, as has been done by peer support groups in Karawang District. Peer support groups with various communication activities such as mentoring patients during examinations and after being declared exposed to HIV, psychological assistance for patients, group discussion among members, and self-potency training activities are considered quite effective ways to reduce the spread of HIV. People with HIV/AIDS are invited to accept their current conditions, and then they are trained to plan for their future lives and be assisted in undergoing therapy. Peer support groups consisting of people with HIV/AIDS are considered capable of empathizing and having equality in communicating to feel every phase that other members pass. Obtaining support from the local government, from private institutions in Karawang Regency, and continuous socialization to the community is one of the significant points helping to get patients out of the social isolation that patients with HIV/AIDS imagine so far. Changes in behavior and lifestyle are more or less easy for patients with HIV/AIDS if they receive positive support from their immediate environment.

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